

Māori With Lived Experience of Disability Part I

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for Stage Two of the Wai 2575 Health Services
and Outcomes Kaupapa Inquiry

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About the author

Tēnā koutou katoa,

Ko Paula King tōku ingoa.

Ko Ngāpuhi, ko Te Rarawa, ko Ngāti Whātua, ko Waikato Tainui, ko Ngāti Maniapoto ngā iwi.

I am a vocationally registered Public Health Medicine Specialist (Fellow of the New Zealand College of Public Health Medicine), and kaupapa Māori researcher.

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My research area includes health and well-being of mokopuna Māori, and the elimination of health inequities in Aotearoa/New Zealand. My current research examines impacts of racism on health and well-being of mokopuna Māori, and the exploration of concepts of co-design in relation to health and disability services to achieve health equity for mokopuna Māori in Aotearoa/New Zealand.

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Glossary of technical terms and abbreviations

ableism	discrimination or prejudice against people with lived experience of disability
ACC	Accident Compensation Corporation
Corrections	Department of Corrections, the Department
Crown agent	a subset of Crown entities, including the Accident Compensation Corporation and district health boards, as set out in the Crown Entities Act 2004
Crown entity	a Crown organisation as set out in the Crown Entities Act 2004
Crown organisation	a Crown entity, government department, or government-related organisation. In this report it refers to the Crown entities, government departments and government related organisations that have relevant health and disability sector roles and were subject to information requests under the Official Information Act 1982.
CTOs	compulsory treatment orders
DHB	district health board
DIAS	disability information advisory service

DPO	Disabled People’s Organisation
DSS	disability support services; services to support people with lived experience of disability – and the people who care for them
EMS	equipment and modification services
government department	a government organisation as set out in section 27A of the State Sector Act 1988
habilitable	meaning ‘to make fit’
HCF	high and complex framework of supports for individuals with a learning/intellectual disability who present significant risk to themselves and/or others and have been engaged with the criminal justice system
HDC	Health and Disability Commissioner
He Korowai Oranga	Māori Health Strategy
healthcare services	a range of services including hospital and specialist care, and visiting the doctor or dentist
HPA	Health Promotion Agency
HQSC	Health, Quality & Safety Commission
HRC	Health Research Council
ID(CC&R) Act	Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003

IMM	Independent Monitoring Mechanism
impairment	signifies a problem with body function or structure. A person may have a range of barriers and impairments restricting their full and equal participation in society.
MH(CAT) Act	Mental Health (Compulsory Assessment and Treatment) Act 1992
Māori provider	Māori-owned and Māori-governed health or disability provider
MoH	Ministry of Health
MPDS	Māori provider development scheme
NGO	non-governmental organisation
NZALS	New Zealand Artificial Limb Service
NZBS	New Zealand Blood Service
ODI	Office for Disability Issues
PHARMAC	Pharmaceutical Management Agency
PHO	primary health organisation
public health	the art and science of preventing disease, prolonging life and promoting health
rehabilitation	to restore
RIDSS	regional intellectual disability secure services

the Tribunal	Waitangi Tribunal
TPK	Te Puni Kōkiri
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNDRIP	United Nations Declaration on the Rights of Indigenous Peoples
Whāia Te Ao Marama	Māori Disability Action Plan
WHO	World Health Organization

Kupu Māori

Aotearoa	Māori name for New Zealand
Hapū	kinship group, subtribe; hapū – to be pregnant
hauora	healthy, well
here taratahi	seclusion and restraint
Iwi	extended kinship group, tribe, nation, people, bone
kāwanatanga	authority, governorship
kaumātua	elders
kaupapa Māori	Māori agenda, Māori principles, Māori ideology—a philosophical doctrine, incorporating the knowledge, skills, attitudes and values of Māori society
mana	spiritually sanctioned or endorsed influence, power and authority
Māori	tāngata whenua; the Indigenous peoples of Aotearoa
mātauranga	knowledge, wisdom
mātua	parents
mokopuna	grandchild, grandchildren, descendant

ōritetanga	equality, equal opportunity
Pākeha	non-Māori; foreign
pēpē	babies
rangatahi	younger generation
rangatira	chief/chieftainess
tamariki	children
tangata	person
tāngata	people
tangata kāpō	blind person
tangata matarehu	visually impaired person
tāngata whaikaha	people with disabilities
tāngata whai ora	service users/consumers/people seeking wellness
tāngata whenua	people born of the land
taonga	treasure, anything prized
Te Ao Māori	the Māori world
Te Ao Tawhito	the ancient world
te reo Māori	the Māori language
te reo turi	sign language

tikanga Māori	customary system of values and practices that have been developed over time and are deeply embedded in the social context
tino rangatiratanga	sovereignty, self-determination, autonomy
tīpuna/tūpuna	ancestors
turi	deaf
utu	balance, reciprocity
wāhine	women
wānanga	meeting and discussion, deliberation, consideration
whaikaha	disabled
whakapapa	genealogy, ancestry, familial relationships
whakataukī	ancestral saying, proverb
whānau	to be born; extended family, family group
whānau hauā	people with disabilities
whanaungatanga	relationships
whenua	placenta; ground, land

Introduction

‘It’s a disability to have your land taken off you, it’s a disability to have your family dissolved and shifted to an urban environment, where you’ve never been before. It’s a disability to be told that you can no longer grow your own food so you have to get a job in a system that has been set up by white people for white people to try to survive. We’re a group of people who are brown living in a white system set up by white people, that is a disadvantage...people who are struggling and it’s not their fault they’re struggling. Just with life. Like being old, it’s a disability’.¹

This kaupapa Māori research report examines the historical and contemporary issues relevant to Māori with lived experience of disability, to address the research questions set out by the Waitangi Tribunal (the Tribunal) for stage two of Wai 2575 – the Health Services and Outcomes Inquiry.² It comprises Part I of two reports specifically commissioned by the Tribunal, to examine issues for Māori with lived experience of disability in Aotearoa/New Zealand.

The introduction to this report presents an overview of the structure for Part I. Māori concepts of disability are discussed, followed by the definitions of disability currently used by the Crown. Westernised models of disability, conceptualised, theorised and developed by disability scholars, advocates, and activists are then discussed. These models help describe the range of ideologies that informed approaches of broader society toward people with lived experience of disability. Māori scholars have also suggested they reflect the attitudinal, social, political, cultural, and economic factors which have, historically and in contemporary times, defined approaches by the Crown and broader society toward Māori with lived experience of disability in Aotearoa/New Zealand. This is followed by a discussion of some of the relevant statistics for

¹ Jo Kingi and Anne Bray, *Māori Concepts of Disability*. (Dunedin: Donald Beasley Institute, 2000), p.8.

² Wai 2575, #2.5.29; Wai 2575, #2.3.3.

Māori with lived experience of disability in Aotearoa/New Zealand, and a summary of key issues is presented at the end.

Structure of the report

Chapter I of this report provides an overview of the research project commissioned by the Tribunal, and the theoretical approach and research methods undertaken to address the Tribunal's research questions. Chapter II describes the historical context for Māori with lived experience of disability, chronicling the development of the health and disability system from the mid-1840s up to the 2000s, and impacts for Māori with lived experience of disability. Chapter III provides an overview of the contemporary context and relevant issues for Māori with lived experience of disability within the health and disability system from the 2000s onwards. Chapter IV presents a review of data collected from Crown organisations, providing information for Māori with lived experience of disability in health and disability services, including Māori imprisoned by the Crown, and Māori children and young people who are placed in the Ministry for Children's care and protection and youth justice residences. Chapter V provides a summary of the thematic analysis of qualitative information. This is followed by the conclusion to the report which summarises the overall findings of the research, and addresses the Tribunal's research questions.

Note that macrons have been used throughout this report. However, they have not been added to names. For example, Te Ropu Wahine Maori Toko i te Ora (the Maori Women's Welfare League), or to acts of parliament or archival publication titles (where they did not exist in the original).

Māori concepts of disability

‘...it appears that Māori in the ancient world who had impairment were people with god-like power and god-like status. They were known for the talents that they possessed, not for what they didn’t have. As time progressed, this notion appeared to change...’³

The extent of the published academic discourse and knowledge of disability within a Māori paradigm in Te Ao Tawhito is sparse, however there has been some research led by contemporary Māori scholars in this area. Kelly Tikao et al., researched archival literature, oral history including whakataukī and pūrākau, examining how Māori society perceived and treated people with impairment in the ancient Māori world, and particularly for Māori who were kāpō (or kāpo). They found that within Te Ao Māori cosmogonies and cosmologies, to be kāpō Māori was not a disability but instead,

‘...a tohu (sign) of greatness. Being kāpo was their source of power because they were not reliant on all of their senses and had high levels of ability, which were displayed in their use of the senses that they did possess. For example, Maui Tikitiki a Taranga, a well-known hero and trickster of Polynesian mythology had a blind grandparent, Murirangawhenua (Note: some readings vary in the gender of Murirangawhenua). Murirangawhenua was also known as Matakerepo (cloudy vision). Murirangawhenua gifted her jawbone to Maui so he could create a fishhook that would be used to fish up Te Ika a Maui (North Island)...Murirangawhenua was held in high esteem for her/his knowledge and wisdom and in te ao Māori these qualities reside in the jawbone. Hence, Maui knew that this was the tool that would make his mission successful’.⁴

³ Kelly Tikao, Nancy Higgins, Hazel Phillips, and Christine Cowan, “Kāpo (blind) Māori in the ancient world.” *MAI Review* 2 no. 4 (2009): 1–14. <http://review.mai.ac.nz/MR/article/download/237/237-1621-1-PB.pdf>, p.11.

⁴ Tikao et al., “Kāpo (blind) Māori in the ancient world”, p.5.

Jill Bevan Brown also found that for Māori, concepts of disability and attitudes towards disability, ‘...are intertwined with other Māori concepts, beliefs and values such as Whanaunatanga, Aroha-ki-te-tāngata, Wairua, Āwhinatanga, and Manaakitanga’.⁵

Keri Ratima and Mihi Ratima have emphasised the contrast between Māori holistic concepts of health and well-being, with individualistic Western worldviews of disability that have a tendency to focus on,

‘...physical, sensory, psychiatric/psychological, learning or intellectual impairments, and reduced functioning...[whereas] Māori concepts of health are holistic in nature, locating individuals within the whānau context and, therefore, emphasising interdependence, recognising determinants of health (including cultural and spiritual determinants), incorporating a focus on continuity between the past and the present, and viewing good health as a balance between interacting variables’.⁶

Huhana Hickey and Denise Wilson highlight that, in addition to different concepts of disability, Indigenous peoples’ lived experience of disability is starkly different to that of non-Indigenous whereby,

‘Indigenous people have additional and diverse historical and contemporary impacts of disablement arising from colonisation, societal discourses about racism, subjugation and dysfunction that are in themselves disabling’.⁷

Jo Kingi and Anne Bray also emphasise that, although concepts of disability are diverse within Te Ao Māori, all sit within the broader context of colonisation.

⁵ Jill Bevan-Brown, “Intellectual Disability: A Māori Perspective” in *Disability, Family, Whānau and Society*, ed. Keith Ballard (Auckland: Dunmore Press, 1994), p.211.

⁶ Keri Ratima and Mihi Ratima, “Māori Experience of Disability and Disability Support Services” in *Hauora: Māori Standards of Health IV. A study of the years 2000–2005*, eds. Bridget Robson and Ricci Harris, (Wellington: Te Rōpū Rangahau Hauora a Eru Pōmare, University of Otago, 2007), p.189–198.

⁷ Huhana Hickey and Denise L Wilson, “Whānau hauā: Reframing disability from an Indigenous perspective.” *MAI Journal* 6 no.1 (2017): 82–94. <https://doi.org/10.20507/MAIJournal.2017.6.1.7.>, p.85.

‘The loss of land, government policies, loss of knowledge of whakapapa and identity, and the ongoing effects and process of colonisation and assimilation have all been identified [as] having a disabling effect on...tangata whenua’.

The impact of colonisation is reinforced by Nancy Higgins, Hazel Phillips, and Christine Cowan who state that Māori experience disablement secondary to exclusion by a society that,

‘...takes no account of their culture, identity or the meanings that Māori themselves give to disability...Māori have been disabled through deficit theorising and assimilatory...practices that have marginalised and excluded Māori from their own knowledge base, language, cultural values, and practices.

Thus, being Māori and being disabled may not be discreet oppressions, but instead “interconnected” parts of a whole way of looking at the world in which difference is considered inferior and in which unequal relationships are demarcated’.⁸

Māori terms currently used to describe disability include that of ‘tāngata whaikaha’ which ‘describes two or more Māori people with a disability...whaikaha means “to have ability” or “to be enabled”’.⁹ Maaka Tibble states,

‘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’.¹⁰

⁸ Nancy Higgins, Hazel Phillips and Christine Cowan, “Eighty years of growing up kāpo (blind) Māori: what can we learn about inclusive education in New Zealand?” *International Journal of Inclusive Education* 17 no. 8 (2013): p.812–826. <https://doi.org/10.1080/13603116.2011.602519>, p.813.

⁹ Ministry of Health, *Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan*. Ministry of Health (Wellington, 2018). <https://www.health.govt.nz/publication/whaia-te-ao-marama-2018-2022-maori-disability-action-plan>, p.4.

¹⁰ Maaka Tibble, founding member of the Māori Disability Leadership Group quoted in Ministry of Health, *Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan*. Ministry of Health (Wellington, 2018). <https://www.health.govt.nz/publication/whaia-te-ao-marama-2018-2022-maori-disability-action-plan>, p.4.

Another term is ‘whānau hauā’, used as an ‘umbrella’ term for Māori with lived experience of disability and their whānau.

‘Donny Rangiahau (Tuhoe) gifted the term whānau hauā and its description...

Metaphorically, whānau hauā signifies the wind that propels whānau with member(s) who have a disability. The word “hau” means “wind”, “gale” or “breeze” while “ā” refers to the drive or urge that propels this wind. Depending upon the mood of Tāwhiri-mātea, the wind can quickly change the environment, making it unstable’.¹¹

Kingi and Bray have highlighted that, ‘...tangata whenua concepts of disability are expressed in varying and diverse ways...’.¹² Thus, for the purposes of this research, guidance was sought from claimants regarding the terms and definitions to describe disability.¹³ Following feedback received, it was decided to use the phrase, ‘Māori with lived experience of disability’ for this report, with the recognition that tāngata whenua are a collective encompassing many diverse and autonomous nations with varying cosmogonies, genealogies, histories, lived realities and experiences. The term ‘Māori’ is therefore considered a construct used to describe the Indigenous peoples of Aotearoa/New Zealand.

Crown concepts of disability

Current concepts and definitions of disability that are used by the Crown are not consistent across government, varying by Crown organisation. The *New Zealand Disability Strategy 2016–2026* provides the framework for the government’s overall direction of the disability sector in improving disability support services and is led by the Office for Disability Issues.¹⁴ Aligned with the Social and Rights-based Models of disability (described in the sections following), the *New*

¹¹ Hickey and Wilson, “Whānau hauā: Reframing disability from an Indigenous perspective”, p.86.

¹² Kingi and Bray, *Māori Concepts of Disability*. (Dunedin: Donald Beasley Institute, 2000), p.24.

¹³ This occurred during the Wai 2575 Research Hui held 30 January 2019, and from feedback received from interested claimant groups in the two weeks following the hui.

¹⁴ Office for Disability Issues, *New Zealand Disability Strategy 2016–2026*. Ministry of Social Development (Wellington, 2016).

Zealand Disability Strategy 2016–2026 stresses that, it is not the person with impairment(s) that has a disability, rather it is society itself that is disabling of the person. It states,

‘Disability is something that happens when people with impairments face barriers in society; it is society that disables us, not our impairments, this is the thing all disabled people have in common. It is something that happens when the world we live in has been designed by people who assume that everyone is the same...Every human being is a unique individual. Even if we have the same impairment as someone else, we will experience different opportunities and barriers because of where we live and how we are treated by those around us. The time and context in our lives when we may acquire our impairment(s) also informs what barriers or opportunities we may experience’.¹⁵

The *New Zealand Disability Strategy* (NZDS) uses the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) definition, which defines disability as,

‘...long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder...full and effective participation in society on an equal basis with others...’.¹⁶

The Ministry of Health states that it uses the NZDS definition of disability.¹⁷ However, within the context of setting eligibility criteria for the provision of disability support services, the Ministry of Health focuses on reduced functionality, defining disability as,

¹⁵ Office for Disability Issues, *New Zealand Disability Strategy 2016–2026.*, p.12.

¹⁶ United Nations Convention on the Rights of Persons with Disabilities, Article 1.

¹⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g MoH Response 3 main appendix.

‘...a physical, intellectual or sensory disability (or a combination of these) that is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required’.¹⁸

Similarly, Statistics New Zealand’s definition focuses on reduced functionality, rather than disablement by societal barriers. Here, disability is defined as,

‘...an impairment that has a long-term, limiting effect on a person’s 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. People [are] not considered to have a disability if an assistive device (such as glasses or crutches) [eliminate] their impairment’.¹⁹

Other definitions used in the report

The following definitions are also used in this report. Colonisation is considered to include,

‘...a range of practices, predominantly historical: war, displacement, forced labour, removal of children, relocation, ecological destruction, massacres, genocide, slavery, (un)intentional spread of deadly diseases, banning of indigenous languages, regulation of marriage, assimilation and eradication of social, cultural and spiritual practices’.²⁰

¹⁸ Ministry of Health, *Disability Support Services: Frequently Asked Questions*. (Wellington, 2015). <https://www.health.govt.nz/your-health/services-and-support/disability-services/more-information-disability-support>.

¹⁹ Statistics New Zealand, *2013 New Zealand Disability Survey*, Statistics New Zealand (Wellington, 2014). http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx, p.12.

²⁰ Yin Paradies, “Colonisation, racism and indigenous health.” *Journal of Population Research*, 33 no.1 (2016): 83– 96. <https://link-springer-com.wmezproxy.wnmeds.ac.nz/article/10.1007/s12546-016-9159-y>, p.83.

Coloniality relates to the, ‘...continuity of colonial forms of domination after the end of colonial administrations’.²¹ In which case it incorporates, ‘...an understanding of the ways in which colonial mind-sets and conditions endure beyond what is recognised as the formal colonial period’.²² Papaarangi Reid, Donna Cormack and Sarah-Jane Paine highlight that, such a definition, ‘...allows us to acknowledge the contemporary effects of marginalisation on Indigenous peoples as distinct from the historic process itself and thus understand coloniality as an ongoing process rather than solely as an isolated historic event’.²³

In alignment with international scholars on racism and impacts on health and well-being, racism is defined as,

‘...an organised social system in which the dominant racial group, based on an ideology of inferiority, categorizes and ranks people into social groups called “races” and uses its power to devalue, disempower, and differentially allocate valued societal resources and opportunities to groups regarded as inferior’.²⁴

Reid, Cormack and Paine point out that racism,

‘...is so abhorrent and life-threatening that it is possible to lose sight of its real purpose, which is to deliver and maintain unearned privilege for groups constructed as superior within racial hierarchies. This privilege is so normalised that it is invisible to those who benefit from it, so much so that even raising the possibility of unearned white privilege in discussions about racism can result in beneficiaries of white privilege exhibiting “white fragility”. This “fragility”, often expressed as hostility,

²¹ Ramón Grosfoguel, “Colonial difference, geopolitics of knowledge, and global coloniality in the modern/colonial capitalist world-system.” *Review* (Fernand Braudel Center), 25 no. 3 (2002), p.203–224. https://www.jstor.org/stable/40241548?seq=1#page_scan_tab_contents., p.205.

²² Paula King, Donna Cormack, and Mark Kōpua, “Oranga Mokopuna: A tāngata whenua rights-based approach to health and wellbeing”. *MAI Journal* 7 no. 2 (2018). http://www.journal.mai.ac.nz/sites/default/files/MAIJrnl_7_2_King_FINAL.pdf, p.187.

²³ Papaarangi Reid, Donna Cormack, and Sarah-Jane Paine, “Colonial histories, racism and health—The experience of Māori and Indigenous peoples.” *Public health* (2019). <https://doi.org/10.1016/j.puhe.2019.03.027>., p.2.

²⁴ David R. Williams, Jourdyn A. Lawrence, and Brigette A. Davis, “Racism and health: Evidence and needed research.” *Annual review of public health*. Vol. 40 (2019): 105–125. <https://doi.org/10.1146/annurev-publhealth-040218-043750>., p.14.2.

defensiveness or other emotions, derails constructive conversations to identify and name racism and privilege'.²⁵

They go on to highlight that colonisation and coloniality are,

'...made possible by a racist ideology of supposed white supremacy and Indigenous inferiority, and this ideology has been inscribed into colonial institutions, policies, practices as well as into the values, norms and beliefs of people. It shaped who was thought to be deserving and undeserving, and this ideology of racism continues to be reproduced today. Understanding racism (and white privilege) as a global system that, intertwined with colonisation, delivers resources and opportunities inequitably is necessary to make sense of Indigenous health. Further, this understanding of racism as being underpinned by racialised ideologies and supported by unequal power structures is critical for developing appropriate and effective interventions to realise health equity'.²⁶

Thus, the approach to racism in this report acknowledges its relationship to colonisation and coloniality within Aotearoa/New Zealand. The belief systems and entrenched hierarchal power structures which underlay and characterise the system of racism, in addition to the range of discriminatory processes and practices which occur at multiple levels — societal, institutional, and interpersonal, are therefore recognised in this report as inextricably linked to colonisation and coloniality.²⁷

²⁵ Reid, Cormack, and Paine, "Colonial histories, racism and health—The experience of Māori and Indigenous peoples", p.2.

²⁶ Reid, Cormack, and Paine, "Colonial histories, racism and health—The experience of Māori and Indigenous peoples", pp.2–3.

²⁷ Camara P Jones, "Invited commentary: "race," racism, and the practice of epidemiology." *American journal of epidemiology* 154, no. 4 (2001): 299–304. <https://doi.org/10.1093/aje/154.4.299>; Steve Garner, *Racisms: An Introduction*. Thousand Oaks, CA: Sage Publications; Teun A van Dijk, *Elite Discourse and Racism*. Newbury Park, CA: Sage Publications, 1993; David R. Williams, Jourdyn A. Lawrence, and Brigette A. Davis, "Racism and Health: Evidence and Needed Research." *Annual review of public health*. Vol. 40: 105–125. <https://doi.org/10.1146/annurev-publhealth-040218-043750>,p.14.2; Naomi Priest, Yin Paradies, Brigid Trenerry B, Mandy Truong, Saffron Karlsen and Yvonne Kelly, "A systematic review of studies examining the relationship between reported racism and health and wellbeing for children and young people." *Social Science and Medicine*, 95 (2013): 115–127. <https://doi.org/10.1016/j.socscimed.2012.11.031>.

This report uses the World Health Organization definition of equity which incorporates the concepts of fairness, social justice, and human rights. Equity is thus considered to be,

‘...the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically. Health inequities therefore involve more than inequality with respect to health determinants, access to the resources needed to improve and maintain health or health outcomes. They also entail a failure to avoid or overcome inequalities that infringe on fairness and human rights norms’.²⁸

Conceptual models of disability

In order to provide context for the report, the following section presents an overview of Western conceptual models of disability (predominantly originating from the United Kingdom and the United States of America). These models have been conceptualised, theorised and developed by disability scholars and activists to describe the prevailing ideologies that have informed approaches of broader society toward people with lived experience of disability. They have also been postulated by Māori scholars as reflective of the attitudinal, social, political, cultural, and economic factors which have, historically and in contemporary times, defined approaches by the Crown and broader society toward disability in Aotearoa/New Zealand,²⁹ and, as a consequence, have impacted considerably on Māori with lived experience of disability. Chronologically, the models show an evolution from those discriminatory, paternalistic, individualised and deficit-based approaches where there is a, ‘...tendency to “victim-blame” peoples...and shows superficial knowledge of the determinants of health and

²⁸ World Health Organization Health systems: Equity. <http://www.who.int/healthsystems/topics/equity/en/> Accessed 1 February 2019.

²⁹ Huhana Hickey, “The Unmet Legal, Social and Cultural Needs of Māori with Disabilities,” ((Unpublished Doctoral thesis). University of Waikato, 2008); Nikora et al., *Disabled Maori and Disability Support Options: A report prepared for the Ministry of Health*.

health inequities’,³⁰ to that of a civil rights-based approach. The conceptual models are described as follows:³¹

1. The Tragedy/Charity Model

People with lived experience of disability are viewed as tragic, pitiable victims requiring charity to survive. Because people are perceived in this way, ‘...it follows that they need care, are not

³⁰ Papaarangi Reid, Sarah-Jane Paine, Elana Curtis, Rhys Jones, Aneka Anderson, Esther Willing, and Matire Harwood, “Achieving health equity in Aotearoa: strengthening responsiveness to Māori in health research.” *The New Zealand Medical Journal* 130, 1465 (2017): 96–103. <https://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2017/vol-130-no-1465-10-november-2017/7414>., p.100.

³¹ Maya Sabatello, “A Short History of the International Disability Rights Movement.” In *Human Rights and Disability Advocacy*, eds. Maya Sabatello and Marianne Schulze, 13–24. Philadelphia: University of Pennsylvania Press, 2014; Hickey, “The Unmet Legal, Social and Cultural Needs of Māori with Disabilities.”; Nikora et al., *Disabled Maori and Disability Support Options: A report prepared for the Ministry of Health*; Andrew Moore and Margaret Tennant, “Who Is Responsible for the Provision of Support Services for People with Disabilities? A Discussion Paper.” *National Advisory Committee on Health and Disability* (Wellington: 1997); Peter Beatson, *The Disability Revolution in New Zealand: A Social Model*. Palmerston North: Massey University, 2004; Jeffrey C Kirby, “Disability and justice: A pluralistic account.” *Social theory and practice* 30 no. 2 (2013): 229–246. <https://www.jstor.org/stable/23559261>; Jenny Morris, “Impairment and disability: Constructing an ethics of care that promotes human rights.” *Hypatia* 16 no. 4 (2001): 1–16. <https://doi-org.wmezproxy.wnmeds.ac.nz/10.1111/j.1527-2001.2001.tb00750.x>; Tanya Titchkosky, *Disability, Self, and Society*. University of Toronto Press; Barbara M Altman, “Disability Definitions, Models, Classification Schemes, and Applications,” in *Handbook of Disability Studies*, ed. Gary. L. Albrecht, Katherine.D. Seelman, and Michael. Bury, Thousand Oaks, CA: Sage Publications (2001), pp. 97–122; Dimitris Anastasiou and James M. Kauffman, “The social model of disability: Dichotomy between impairment and disability” in *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*, vol. 38, no. 4 (2003), pp.441–459. Oxford University Press, 2013. <https://doi-org.wmezproxy.wnmeds.ac.nz/10.1093/jmp/jht026>; Lorella Terz, “The social model of disability: A philosophical critique.” *Journal of applied philosophy* 21, no.2 (2004): 141–157. <https://onlinelibrary-wiley-com.wmezproxy.wnmeds.ac.nz/doi/pdf/10.1111/j.0264-3758.2004.00269.x>; Tom Shakespeare, “The social model of disability” in *The Disability Studies Reader*, ed. Lennard J Davis (4th ed., 2013 pp. 214–221). New York, NY: Routledge; Carmelo Masala and Donatella Rita Petretto. 2008. “From disablement to enablement: Conceptual models of disability in the 20th century”. *Disability and Rehabilitation*, 30:17, 1233–1244. <https://doi.org/10.1080/09638280701602418>; Stewart Lawrence and Manzurul Alam, “Disability Support Services in a Liberalised Economy – a NZ Case Study.” *International Journal of Public Sector Management* 13, no. 3 (2000): 186–205. <https://doi.org/10.1108/09513550010345946>; Mike Oliver, “The social model of disability: thirty years on”. *Disability & Society*, 28 (2013):7, 1024–1026. <https://www-tandfonline-com.wmezproxy.wnmeds.ac.nz/doi/pdf/10.1080/09687599.2013.818773?needAccess=true>; Deborah Marks, “Models of disability” *Disability and Rehabilitation*, 19 (1997):3, 85–91. <https://doi.org/10.3109/09638289709166831>; Committee on Assessing Rehabilitation Science and Engineering, Institute of Medicine. “Models of Disability and Rehabilitation” in *Enabling America: Assessing the Role of Rehabilitation Science and Engineering Models of Disability and Rehabilitation*, eds. Edward N Brandt and Andrew M Pope, pp.62–80. Washington: National Academy Press, 1997; Disabled World. Definitions of The Models of Disability. <https://www.disabled-world.com/definitions/disability-models.php>. Accessed 1 February 2019.

capable of looking after themselves or managing their own affairs...From tragedy and pity stems a culture of “care”.³²

2. The Religious/Moral Model

Disability is perceived as the result of a punishment imposed upon a person and/or their family by external forces. Because disability is viewed as the result of a transgression (by a person, their family or their predecessors), people with lived experience of disability and their family may be segregated or socially excluded from their own communities. On the contrary, disability can also be perceived as a requisite ‘burden to be endured’ for spiritual restitution.

3. The Medical Model

Critiqued for being deficit-focused and ‘abnormalising’ people with lived experience of disability, yet, at the same time, dictating the course of disability policy for years, the Medical Model views disability as the result of person’s physical or mental limitations directly caused by disease, injury or other health condition/s. The focus of the Medical Model is,

‘...on individual pathology and attempts to find ways of preventing, curing or (failing these) caring for disabled people. Given that the focus is on the individual, a central concern is to make an accurate diagnosis of their “condition”. Policy-makers tend to rely on medical definitions of disablement in order to assess the prevalence of disability and provide treatments, services and benefits’.³³

The Medical Model disconnects people with lived experience of disability from any historical, socioeconomic, political and geographic environmental contexts. In which case, solutions are individual and deficit-focused, aimed at ‘finding a cure’, and approaches are paternalistic.

³² Nikora et al., *Disabled Maori and Disability Support Options: A Report Prepared for the Ministry of Health*, p.6.

³³ Deborah Marks, “Models of disability”. *Disability and Rehabilitation*, 19 no 3. (1997): 85–91. <https://doi.org/10.3109/09638289709166831>, p.86.

4. The Expert/Professional Model

An offshoot of the Medical Model, this model has informed responses to disability issues for many years, whereby experts/professionals take on the,

‘...“gatekeeping role” and follow a process of identifying impairment and its limitations (using the Medical Model), and taking the necessary action to improve the position of the disabled person. This has tended to produce a system where an authoritarian, over-active service provider can prescribe and act for a passive client, resulting in a “fixer”/“fixee” power relationship that can limit choice, dignity and self-determination’.³⁴

The provider, therefore, is the paternalistic ‘fixer’ and people with lived experience of disability positioned as the passive, acquiescent ‘fixee’.

‘Assessments based on medical models suggest that needs can be objectively identified by professionals who are well placed to decide on specific needs for certain resources...Medical diagnosis has provided a framework for arranging services around the major categories of disabilities. Consequently, organizations and professional groups, such as occupational therapists, psychiatrists, psychologists, doctors and social workers were organised to provide intervention on the lives of people with objectively diagnosed disabilities. Traditional professional boundaries provided services in a fragmented way by creating artificial boundaries for services’.³⁵

³⁴ Nikora et al., *Disabled Maori and Disability Support Options: A report prepared for the Ministry of Health*, pp.5–6.

³⁵ Stewart Lawrence and Manzurul Alam, “Disability support services in a liberalised economy – A NZ case study,” *International Journal of Public Sector Management* 13, no. 3 (2000). <https://doi.org/10.1108/09513550010345946>, pp.189–190.

5. The Rehabilitation Model

Also an offshoot of the Medical Model, the Rehabilitation Model views disability as the result of a person's functional limitations, with rehabilitation as the process by which experts/professionals/providers 'restore' and 'enable' people,

'...physical, sensory, and mental capacities...in (and for) people with disabling conditions—reversing what has been called the disabling process...This is achieved not only through functional changes in the person...but also through changes in the physical and social environments that surround them'.³⁶

6. The Economic Model

The Economic Model defines disability around whether or not a person with lived experience of disability is able to participate in the labour force, and to what level. This model drives policy that primarily focuses on the economic consequences of workforce (in)ability for the person, the employer, and the state.

7. The Social Model

Disability is perceived to be the direct result of those attitudinal, institutional, societal and environmental barriers which preclude people from fully participating in society. Disablement is thus imposed on people by society. The Social Model defines disability as, '...the product of specific social and economic structures'³⁷ and primarily aims to deconstruct and counter the,

'...individual model of disability with a perspective situated in the direct experience and understanding of disability by disabled people themselves. It also aims to address issues of marginalisation, oppression and discrimination while trying to denounce and

³⁶ Committee on Assessing Rehabilitation Science and Engineering, Institute of Medicine, "Introduction," in *Enabling America: Assessing the Role of Rehabilitation Science and Engineering Models of Disability and Rehabilitation*, eds. Edward N Brandt and Andrew M Pope (Washington: National Academy Press, 1997), pp.24–25.

³⁷ Lorella Terzi, "The social model of disability: A philosophical critique." *Journal of applied philosophy* 21, no. 2 (2004): 141–157. <https://onlinelibrary-wiley-com.wmezproxy.wnmeds.ac.nz/doi/pdf/10.1111/j.0264-3758.2004.00269.x>, p.141.

remove the disabling barriers produced by hegemonic social and cultural institutions'.³⁸

Disability is not viewed as an attribute of a person, but rather a result from society's failure to meet the aspirations and needs of people with lived experience of disability. Thus, it is the collective responsibility of society to ensure that people with lived experience of disability are able to fully participate in all areas of life through the removal of disabling barriers created by society.

8. The Social Adapted Model

The Social Adapted Model is an adaptation of the Social Model which includes features of the Medical Model. The model acknowledges the role of impairment (in terms of its potential impacts on any interactions a person has within the environments they inhabit), but the primary focus is still on the social, economic and environmental barriers that lead to disablement.

9. The Customer/Empowering Model

The Customer/Empowering Model is the counterpart to the Expert/ Professional Model, where the expert/professional provides services to the person with lived experience of disability and their whānau, who, as the 'customer, is the decision-maker regarding the services they view as appropriate to meet their needs and aspirations. Examples of implementation of this model involve situating financial resources with the customer who chooses the services they wish to purchase.

10. The Rights-based Model

Drawing on the Social Model but situated within human rights-based frameworks that oppose ableism, racism and sexism, disability is theorised as a socio-political construct. The model focuses on inclusion and emphasises independence over dependence. This model is considered the international best-practice model for disability.

³⁸ Lorella Terzi, "The social model of disability: A philosophical critique", p.143.

All of the models described frame disability within an individual context. This contrasts with the role that collectivism and the interdependence of Māori, play in health and well-being. There is a need within a collectivist society such as Te Ao Māori, for models of disability to incorporate indigenous, culturally based, and collectivist paradigms. However, although Māori models of health and well-being have existed for decades,³⁹ and could have been incorporated or integrated into established disability models – indeed, Māori frameworks of disability and identity have been theorised and developed by Māori scholars,⁴⁰ – none appear to have been applied by the Crown with regard to the use of appropriate approaches to health and well-being of Māori with lived experience of disability.

³⁹ Mason Durie, *Whaiora: Maori Health Development*. Oxford University Press 1998; Mason Durie, “An Indigenous model of health promotion”, *Health Promotion Journal of Australia*, 15 no. 3 (2004), 181–185. <http://doi.org/ct83>; Manuka Henare, “Ngā tikanga me ngā ritenga o te ao Māori: Standards and foundations of Māori society,” in *The April Report III: Report of the Royal Commission on Social Policy*, ed. I. K. M. Richardson (Wellington, New Zealand, 1988), pp. 7–41; Rose Pere, *A Celebration of Infinite Wisdom*. (Wairoa, New Zealand: Ao Ako Global Learning New Zealand, 1997).

⁴⁰ Mihi M Ratima, Mason H Durie, GR Allan, PS Morrison, A Gillies, and John A Waldon, *He Anga Whakamana: A Framework for the Delivery of Disability Support Services for Māori*. Te Pūmanawa Hauora, Massey University (Palmerston North, 1995). <http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/37D7A973746694CF4C2565D700185D8B?opendocument>; Huhana Hickey, “The Unmet Legal, Social and Cultural Needs of Māori with Disabilities”; Huhana Hickey, “Replacing medical and social models of disability by a communities-based model of equal access for people of differing abilities: A Māori perspective,” *He Puna Korero: Journal of Maori and Pacific Development* 7 no. 1 (2006): 35–47. <https://search.informit.com.au/documentSummary;dn=285940984141502;res=IELNZC>.

Disability statistics for Māori

‘The health of Māori, the Indigenous peoples of Aotearoa, New Zealand, like that of almost all Indigenous peoples worldwide, is characterised by systematic inequities in health outcomes, differential exposure to the determinants of health, inequitable access to and through health and social systems, disproportionate marginalisation and inadequate representation in the health workforce...While health commentators acknowledge the unequal health outcomes of Indigenous people, and an increasing number also link these inequities to Indigenous marginalisation resulting from historic events, very few go further and expose the deep relationship between racism and coloniality and how these continue to be the basic determinants of Indigenous health today’.⁴¹

The relationship between colonisation and health inequities for Indigenous peoples is well described both internationally,⁴² and in Aotearoa/New Zealand,^{43,44} as is the association between racism and health in Aotearoa/New Zealand.⁴⁵ The significant and pervasive health inequities experienced by Māori compared with non-Māori in Aotearoa/New Zealand arise from inequitable access to the determinants of health and well-being, inequitable access to and

⁴¹ Reid, Cormack, and Paine, “Colonial histories, racism and health—The experience of Māori and Indigenous peoples”, p.1.

⁴² Karina Czyzewski, “Colonialism as a Broader Social Determinant of Health” *The International Indigenous Policy Journal*, 2 no. 1 (2011).
<https://ir.lib.uwo.ca/cgi/viewcontent.cgi?referer=https://www.google.co.nz/&httpsredir=1&article=1016&context=iipj>; Yin Paradies, “Colonisation, racism and indigenous health” *Journal of Population Research*, 33 no. 1 (2016), 83–96.

⁴³ Reid, Cormack, and Paine, “Colonial histories, racism and health—The experience of Māori and Indigenous peoples.”

⁴⁴ Papaarangi Reid and Bridget Robson, “Understanding Health Inequities” in *Hauora Māori Standards of Health IV: A study of the years 2000-2005*, eds. Bridget Robson and Ricci Harris (Wellington: Te Rōpū Rangahau Hauora A Eru Pōmare, University of Otago, 2007), pp.3–10.

⁴⁵ Ricci B Harris, James Stanley, and Donna M Cormack, “Racism and health in New Zealand: Prevalence over time and associations between recent experience of racism and health and wellbeing measures using national survey data,” *PLOS ONE* 2018; 13 (5): e0196476. <https://doi.org/10.1371/journal.pone.0196476>.

through health and disability care, and from the differential quality of care received.^{46,47} At the same time this (mal)distribution is the manifestation of colonisation,^{48,49} coloniality,^{50,51} and racism,⁵² where the structural determinants of health and well-being continue to be differentially distributed in Aotearoa/New Zealand by ethnicity, and in particular, by indigeneity.^{53,54}

Thus, the inequities that impact on Māori with lived experience of disability presented in the following sections, rather than viewed from a deficit and 'victim-blaming' lens, are instead considered the symptomatology of the socio-political and economic environments that drive poor health and well-being outcomes in Aotearoa/New Zealand.

⁴⁶ Reid, Cormack, and Paine, "Colonial histories, racism and health—The experience of Māori and Indigenous peoples."

⁴⁷ Camara P Jones, "Systems of power, axes of inequity: parallels, intersections, braiding the strands," *Med Care* 2014 Oct; 52(10 Suppl 3): S71-5. <https://oae-ovid-com.wmezproxy.wnmeds.ac.nz/article/00005650-201410001-00012/HTML>.

⁴⁸ Reid, Cormack, and Paine, "Colonial histories, racism and health—The experience of Māori and Indigenous peoples."

⁴⁹ Reid and Robson, "Understanding Health Inequities" in *Hauora Māori Standards of Health IV: A study of the years 2000-2005*.

⁵⁰ Reid, Cormack, and Paine, "Colonial histories, racism and health—The experience of Māori and Indigenous peoples."

⁵¹ Ramón Grosfoguel, "Decolonizing post-colonial studies and paradigms of political-economy: Transmodernity, decolonial thinking, and global coloniality."

⁵² Harris, Stanley, and Cormack, "Racism and health in New Zealand: Prevalence over time and associations between recent experience of racism and health and wellbeing measures using national survey data."

⁵³ Reid, Cormack, and Paine, "Colonial histories, racism and health—The experience of Māori and Indigenous peoples."

⁵⁴ Papaarangi Reid and Bridget Robson, "Understanding Health Inequities" in *Hauora Māori Standards of Health IV: A study of the years 2000-2005*, pp.3–10.

Prevalence

According to Crown data submitted to the Tribunal,⁵⁵ there are 176,000 Māori with lived experience of disability compared with 885,000 non-Māori in Aotearoa/New Zealand. Additionally, the prevalence of disability is higher for Māori than non-Māori.⁵⁶ The proportion of Māori with lived experience of disability in 2013 was 23.9 per cent compared with 15.6 per cent for non-Māori.⁵⁷ For Māori males it was 25.7 per cent compared with 16 per cent for non-Māori, and for Māori females it was 22.1 per cent compared with 15 per cent for non-Māori.⁵⁸

Māori have higher proportions of disability across all age groups. For Māori children aged 0–14 years, the proportion was 14.9 per cent compared with 9.2 per cent for non-Māori. For Māori aged 15–24 years, the proportion was 20.9 per cent compared with 13.9 per cent for non-Māori. For Māori aged 25–44 years, the proportion was 23.3 per cent compared with 14.7 per cent for non-Māori. For Māori aged 45–64 years, the proportion was 43.6 per cent compared with 26.1 per cent for non-Māori, and for Māori aged 65 years and over, the proportion was 62.2 per cent compared 55.9 per cent for non-Māori.⁵⁹

Māori were also more likely to experience disability 12 months after an injury than non-Māori (21 per cent compared with 13 per cent). Predictors of disability for Māori who had been injured were: two or more chronic conditions; trouble accessing healthcare services; hospitalisation due to injury; and inadequate household income. Māori hospitalised for injury were found to be 1.8 times more likely to experience disability 24 months post-injury

⁵⁵ The statistics presented are from the Crown brief which provides data from the 1996, 2001, 2006 and 2013 Statistics New Zealand Disability Surveys. There was minimal change in the content of the 1996, 2001 and 2006 surveys. However, the 2013 survey was redeveloped. In which case time series analysis across the 1996, 2001, 2006, and 2013 disability surveys is not possible. Refer to Wai 2575, #B19.

⁵⁶ Wai 2575, #3.2.89; Wai 2575, #B19.

⁵⁷ The proportions have been age-standardised to the 2001 Census Māori population. Refer to Wai 2575, #B19.

⁵⁸ The proportions have been age-standardised to the 2001 Census Māori population. Refer to Wai 2575, #B19.

⁵⁹ Ministry of Health, *Tatau Kahukura: Māori Health Chart Book 2015* (3rd edition). Ministry of Health. (Wellington: 2015). <https://www.health.govt.nz/publication/tatau-kahukura-maori-health-chart-book-2015-3rd-edition>.

compared with non-Māori. Forty per cent of Māori with lived experience of disability at 24 months post-injury had had trouble accessing healthcare services.⁶⁰

Impairment

For both Māori and non-Māori, more than 50 per cent of children, young people and young adults (aged under 44 years) had a single impairment, but more than 60 per cent of adults who were aged 45 years and over had multiple impairment.

In the *2013 New Zealand Disability Survey*, 53 per cent (just over a half) of all people reported living with limitations arising from multiple impairment. Forty-eight per cent of all children (0–14 years) had multiple impairment. For adults, multiple impairment increases with age. Forty-two per cent of all people aged 15–44 years reported multiple impairment, compared with 63 per cent of older adults (65 years and over). Māori adults with lived experience of disability were more likely to have multiple impairment compared with non-Māori adults across all age groups.⁶¹

⁶⁰ Georgia K McCarty, Emma H Wyeth, Helen Harcombe, Gabrielle Davie, and Sarah Derrett, “Māori Injury and Disability Information Sheet”, (Ngāi Tahu Māori Health Research Unit: Dunedin, New Zealand, 2018). https://blogs.otago.ac.nz/ipru/files/2018/11/Māori-injury-and-disability-poster_FINAL.pdf.

⁶¹ Office for Disability Issues and Statistics New Zealand, *Disability and Māori in New Zealand in 2006: Results from the New Zealand Disability Survey*. (Wellington: Statistics New Zealand, 2010). http://archive.stats.govt.nz/browse_for_stats/health/disabilities/disability-and-maori.aspx, p.12.

TYPES OF IMPAIRMENT

The top three types of impairment for Māori were: 1) mobility impairment (12 per cent),⁶² 2) hearing impairment (8 per cent),⁶³ and 3) agility impairment⁶⁴ or difficulty with learning,⁶⁵ or psychiatric/psychological impairment⁶⁶ (7 per cent each).⁶⁷

⁶² According to the definition used by Statistics New Zealand, adults with mobility impairment have difficulty with or couldn't do one or more of the following: walk about 350 metres without resting; walk up or down a flight of stairs; carry an object as heavy as five kilograms over a distance; move from room to room within the home; stand for period of 20 minutes; bend down without support; and get in and out of bed independently. Children with mobility impairment have difficulty with or cannot do one or more of the following: stand without assistive devices such as braces or crutches; walk on a flat footpath; move from room to room within the home; and bend down without support. Refer to *Statistics New Zealand, 2013 New Zealand Disability Survey*, Statistics New Zealand (Wellington, 2014).

http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx.

⁶³ According to the definition used by Statistics New Zealand, adults with hearing impairments cannot hear, or have difficulty hearing, what is said in a conversation with one other person and/or what is said in a group conversation with three or more people, even when using an assistive hearing device such as a hearing aid. Children with hearing impairments cannot hear or have difficulty hearing, even when using assistive hearing devices such as a hearing aid, grommets, or a cochlear implant. Refer to *Statistics New Zealand, 2013 New Zealand Disability Survey*, Statistics New Zealand (Wellington, 2014).

http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx.

⁶⁴ According to the definition used by Statistics New Zealand, adults with an agility impairment have difficulty with or cannot do one or more of the following: dress and undress independently; cut their own toe- or fingernails; use fingers to grasp or handle things like scissors or pliers; use arms to reach in any direction; and cut their own food. Children with an agility impairment have difficulty with or cannot do one or more of the following: use hands to grasp an object such as a spoon or a pencil/crayon (2–14 years old), and raise arms to take off a t-shirt (5–14 years old). Refer to *Statistics New Zealand, 2013 New Zealand Disability Survey*, Statistics New Zealand (Wellington, 2014).

http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx.

⁶⁵ According to the definition used by Statistics New Zealand, a learning impairment is a long-term condition or health problem that makes it hard in general for someone to learn. This question was only asked of/about respondents aged five years and older. Refer to *Statistics New Zealand, 2013 New Zealand Disability Survey*, Statistics New Zealand (Wellington, 2014).

http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx.

⁶⁶ According to the definition used by Statistics New Zealand, adults with psychological/psychiatric impairment have a long-term emotional, psychological, or psychiatric condition that causes: difficulty with everyday activities, or difficulty communicating, mixing with others, or socialising. Children with psychological/psychiatric impairment have one or more of the following: occasional emotional, nervous, or behavioural problems that limit the type or amount of activity a child can do a long-term psychological or mental health condition that causes difficulty with everyday activities. Refer to *Statistics New Zealand, 2013 New Zealand Disability Survey*, Statistics New Zealand (Wellington, 2014).

http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx.

⁶⁷ Statistics New Zealand, *He Hauā Māori: Findings from the 2013 Disability Survey*, Statistics New Zealand (Wellington: 2015). http://archive.stats.govt.nz/browse_for_stats/health/disabilities/He-haua-maori-findings-from-2013-disability-survey.aspx.

Four impairment types were significantly more likely to be experienced by Māori than non-Māori. These were: 1) difficulty with learning, 2) psychological/psychiatric impairment, 3) difficulty with speaking,⁶⁸ and 4) intellectual disability.⁶⁹ Māori compared with non-Māori also had a slightly higher proportion of vision impairment⁷⁰ compared with non-Māori.⁷¹

The prevalence of physical and sensory impairments⁷² increases as people get older whilst the prevalence of intellectual, psychiatric/psychological, speaking, and learning impairments shows relatively less variation by age. For Māori aged 65 and over, 52 per cent had mobility impairment, 32 per cent had hearing impairment, and 31 per cent had agility impairment.⁷³

CAUSES OF IMPAIRMENT

The most common causes of impairment for Māori with lived experience of disability was disease or illness (40 per cent), then accident or injury (28 per cent), followed by conditions existing since birth (24 per cent), and ageing (18 per cent).⁷⁴ For children, 51 per cent of

⁶⁸ According to the definition used by Statistics New Zealand, people with a speaking impairment have difficulty speaking or being understood (aged two years and older). Refer to *Statistics New Zealand, 2013 New Zealand Disability Survey*, Statistics New Zealand (Wellington, 2014).
http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx.

⁶⁹ According to the definition used by Statistics New Zealand, adults with an intellectual disability need support or help from people or organisations, have been to a special school, or receive special education because of an intellectual disability. For children, the parent or caregiver was asked whether a child (5–14 years old) has ‘a recognised intellectual disability’. Refer to *Statistics New Zealand, 2013 New Zealand Disability Survey*, Statistics New Zealand (Wellington, 2014).
http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx.

⁷⁰ According to the definition used by Statistics New Zealand, adults with vision impairment have difficulty seeing, or cannot see, ordinary newsprint, and/or the face of someone from across a room, even when wearing corrective lenses. Children with vision impairment cannot see, or have difficulty seeing, even when wearing glasses or contact lenses. Refer to *Statistics New Zealand, 2013 New Zealand Disability Survey*, Statistics New Zealand (Wellington, 2014).
http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx.

⁷¹ *Statistics New Zealand, 2013 New Zealand Disability Survey*, Statistics New Zealand (Wellington, 2014).
http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx.

⁷² According to the definition used by Statistics New Zealand, physical impairment includes mobility and/or agility impairments. Sensory impairment includes a hearing and/or vision impairment. Refer to *Statistics New Zealand, 2013 New Zealand Disability Survey*, Statistics New Zealand (Wellington, 2014),
http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx.

⁷³ Statistics New Zealand, *He Hauā Māori: Findings from the 2013 Disability Survey*.

⁷⁴ Individuals may have more than one impairment; thus the causes add up to more than 100 percent. Refer to Statistics New Zealand, *He Hauā Māori: Findings from the 2013 Disability Survey*.

impairment was caused by conditions that existed at birth. However, this became less common with age, with disease and illness becoming more common as a cause of impairment. For example, among Māori aged 65 and over, 63 per cent of impairment was caused by disease or illness, and 46 per cent was due to ageing for Māori aged 65 years and over. Māori females were more likely than males to have impairment caused by disease or illness, or ageing, whilst Māori males were more likely to have impairment since birth, or caused by accident or injury.⁷⁵

Socioeconomic indicators

The Ministry of Health reports in *Tatau Kahukura Māori Health Chartbook 2015*, that Māori experience less privilege than non-Māori across all socioeconomic indicators examined.

‘Māori adults had lower rates of school completion and much higher rates of unemployment. More Māori adults had personal income less than \$10,000, and more Māori adults received income support. Māori were more likely to live in households without any telecommunications (including internet access) and without motor vehicle access. More Māori lived in rented accommodation and lived in crowded households’.⁷⁶

Within the Māori population, however, there are inequities apparent for Māori with lived experience of disability compared with Māori. These are an expression of the impacts that further occur for Māori with lived experience of disability secondary to colonisation, coloniality, racism and further discrimination and marginalisation from the intersection of indigeneity with disability.

LABOUR FORCE PARTICIPATION

Within the Māori population, Māori with lived experience of disability are less likely to be in the labour force (53 per cent compared with 76 per cent), while those who are in the labour force have higher rates of unemployment (17 per cent compared with 11 per cent). Overall, this

⁷⁵ Statistics New Zealand, *He Hauā Māori: Findings from the 2013 Disability Survey*.

⁷⁶ Ministry of Health, *Tatau Kahukura: Māori Health Chart Book 2015*, p.13.

means the proportion of employed working age people within the Māori population is much lower for Māori with lived experience of disability (44 per cent compared with 68 per cent).

INCOME

Māori with lived experience of disability were more likely to have lower incomes than Māori without lived experience of disability. In 2013, 68 per cent of had incomes of \$30,000 or less, while 14 per cent had incomes over \$50,000. Māori adults with lived experience of disability were more likely to report they did not have enough money for everyday needs such as accommodation, food, clothing and other necessities compared with Māori without lived experience of disability (25 per cent compared with eight per cent).⁷⁷

HOUSING TENURE

In 2013, four in 10 Māori with lived experience of disability lived in homes owned by the occupants or held in a family trust. However, four in 10 Māori with lived experience of disability were also more likely to report problems with the houses they lived in, including coldness. A third reported they lived in damp houses. Twelve per cent reported that their house was not large enough, and 16 per cent reported other problems with their houses.⁷⁸

HIGHEST EDUCATION QUALIFICATION

Within the Māori population, 41 per cent of Māori with lived experience of disability had no formal educational qualifications compared with 24 per cent of Māori without lived experience of disability. Seven per cent of Māori with lived experience of disability were less likely to have degrees (seven per cent compared with 15 per cent).⁷⁹

⁷⁷ Statistics New Zealand, *He Hauā Māori: Findings from the 2013 Disability Survey*, p.14.

⁷⁸ Statistics New Zealand, *He Hauā Māori: Findings from the 2013 Disability Survey*.

⁷⁹ Statistics New Zealand, *He Hauā Māori: Findings from the 2013 Disability Survey*.

Experience of crime

Sixteen per cent of Māori adults with lived experience of disability reported they had been victims of crime in the previous 12 months, and were more likely to have been victims of violent crime than Māori adults without lived experience of disability (eight per cent compared with three per cent). For Māori with lived experience of disability, there were no significant differences in age and sex regarding the proportions of those who had experienced crime.⁸⁰

Experience of discrimination

The *Tatau Kahukura Māori Health Chartbook 2015* reports prevalence of self-reported experience of racial discrimination 'ever' in a person's lifetime for Māori. In the report, 'racial discrimination' refers to any experience of ethnically motivated personal attack (physical or verbal) or unfair treatment on the basis of ethnicity in any of three situations: healthcare, housing or work.⁸¹ The report states that, overall, 'Māori adults were almost twice as likely as non-Māori adults to have experienced any type of racial discrimination' (27.5 per cent compared with 14.7 per cent).⁸²

The *New Zealand Disability Survey 2013* reports the experience of discrimination in the past 12 months but not specifically self-reported racism. The experience of discrimination in the past 12 months was more common among Māori with lived experience of disability than Māori. Twenty-three per cent of Māori adults with lived experience of disability reported having experienced discrimination in the past 12 months, compared with 13 per cent of Māori without lived experience of disability. Thirteen per cent also reported having experienced discrimination more than three times during the previous 12 months, compared with six per cent of Māori without lived experience of disability.⁸³

⁸⁰ Statistics New Zealand, *He Hauā Māori: Findings from the 2013 Disability Survey*.

⁸¹ Ministry of Health, *Tatau Kahukura: Māori Health Chart Book 2015*.

⁸² Ministry of Health, *Tatau Kahukura: Māori Health Chart Book 2015*, p.14.

⁸³ Statistics New Zealand, *He Hauā Māori: Findings from the 2013 Disability Survey*.

Feelings of loneliness

Feelings of loneliness were more common among Māori with lived experience of disability. Four in 10 Māori with lived experience of disability reported feeling lonely at least occasionally in the past four weeks, compared with three in 10 of Māori without lived experience of disability. Feeling lonely often was more common among Māori with lived experience of disability (eight per cent compared with two per cent).⁸⁴

Overall life satisfaction

On a scale of zero to 10, where zero is the lowest and 10 is the highest level of satisfaction, 48 per cent of Māori adults with lived experience of disability rated their life satisfaction as eight or higher, whilst nine per cent rated their life satisfaction as below five. However, Māori with lived experience of disability were less likely to report high levels of satisfaction.⁸⁵

Self-assessed health status

Māori with lived experience of disability were much less likely to report 'very good' or 'excellent' (self-rated) health. Within the Māori population, 11 per cent of Māori with lived experience of disability reported their health as excellent (compared with 35 per cent), and 24 per cent reported their health as very good (compared with 37 per cent). Almost a third of Māori with lived experience of disability self-rated their health as 'fair' or 'poor', compared with six per cent of Māori without lived experience of disability.⁸⁶

Unmet need

Despite having higher prevalence of disability and higher proportions of disability across all age groups, Māori with lived experience of disability compared with non-Māori have higher proportions of unmet need for access to health professionals, and special equipment. Māori

⁸⁴ Statistics New Zealand, *He Hauā Māori: Findings from the 2013 Disability Survey*.

⁸⁵ Statistics New Zealand, *He Hauā Māori: Findings from the 2013 Disability Survey*.

⁸⁶ Statistics New Zealand, *He Hauā Māori: Findings from the 2013 Disability Survey*.

with lived experience of disability also appear to have disproportionate access to disability support services according to need.

ACCESS TO A HEALTH PROFESSIONAL

It is estimated that 36,000 Māori and 96,000 non-Māori with lived experience of disability have unmet need with regard to accessing a health professional. Māori however, have a higher proportion of unmet need than non-Māori (21.9 per cent compared with 15.5 per cent).⁸⁷ Māori males have a higher proportion of unmet need than non-Māori males (17.8 per cent compared with 13.5 per cent), and Māori females have a higher proportion of unmet need than non-Māori females (25.5 per cent compared with 16.8 per cent).⁸⁸

For Māori, unmet need with regard to accessing a health professional was highest for those aged 25 to 44 years (31.0 per cent), and lowest for those aged 65 years and older (4.2 per cent). Similarly for non-Māori, unmet need was highest for those aged 25 to 44 years (21.1 per cent), and lowest for those aged 65 years and older (4.3 per cent).⁸⁹

SPECIAL EQUIPMENT

On estimate, 33,000 Māori and 128,000 non-Māori with lived experience of disability have unmet need for special equipment.⁹⁰ Māori have a higher proportion of unmet need for special equipment than non-Māori (16.1 per cent compared with 12.2 per cent).⁹¹

Māori males have a higher proportion of unmet need than non-Māori males (16.3 per cent compared with 12.4 per cent), and Māori females have a higher proportion of unmet need

⁸⁷ The proportions have been age-standardised to the 2001 Census Māori population. Refer to Wai 2575, #B19.

⁸⁸ The proportions have been age-standardised to the 2001 Census Māori population. Refer to Wai 2575, #B19.

⁸⁹ Wai 2575, #B19.

⁹⁰ Wai 2575, #B19.

⁹¹ The proportions have been age-standardised to the 2001 Census Māori population. Refer to Wai 2575, #B19.

than non-Māori females (18.1 per cent compared with 11.3 per cent).⁹² For Māori, unmet need for special equipment was highest for those aged 65 years and older (29.2 per cent), and lowest for those aged 15 to 24 years (12.5 per cent). Similarly, for non-Māori, unmet need was highest for those aged 65 years and older (17.1 per cent), and lowest for those aged 15 to 24 years (seven per cent).⁹³

DISABILITY SUPPORT SERVICES

The Ministry of Health report, *Demographic Report on Clients Allocated the Ministry of Health's Disability Support Services: As at September 2016*, shows that 17.5 per cent of Māori with lived experience of disability compared with 78.5 per cent of non-Māori made up the client base for disability support services (DSS) in 2016.⁹⁴ The proportion for Māori with lived experience of disability had increased from 16.5 per cent in 2013. For both Māori and non-Māori, carer support was the most widely used Ministry of Health-funded DSS, followed by home and community supports as the second most commonly used.⁹⁵

The report observes that, 'Māori are somewhat over-represented in the [Disability Support Services] Client group. This may be because the age-adjusted disability rate among Māori is higher than for the total population'.⁹⁶ However, as the *2013 New Zealand Disability Survey*⁹⁷ shows that the proportion of Māori with lived experience of disability is 23.9 per cent,⁹⁸ it is

⁹² The proportions have been age-standardised to the 2001 Census Māori population. Refer to Wai 2575, #B19.

⁹³ Wai 2575, #B19.

⁹⁴ This excludes the category of 'unknown ethnicity' which comprised four percent of the total.

⁹⁵ Ministry of Health, *Demographic Report on Clients Allocated the Ministry of Health's Disability Support Services: As at September 2016*. Ministry of Health (Wellington, 2017). <https://www.health.govt.nz/publication/demographic-report-clients-allocated-ministry-healths-disability-support-services-september-2016>.

⁹⁶ Ministry of Health, *Demographic Report on Clients Allocated the Ministry of Health's Disability Support Services: As at September 2016*, p.6.

⁹⁷ The statistics presented are from the Crown brief which provides data from the 1996, 2001, 2006 and 2013 *Statistics New Zealand Disability Surveys*. There was minimal change in the content of the 1996, 2001 and 2006 surveys. However, the 2013 survey was redeveloped. In which case time series analysis across the 1996, 2001, 2006, and 2013 disability surveys is not possible. Refer to Wai 2575, #B19.

⁹⁸ The proportions have been age-standardised to the 2001 Census Māori population. Refer to Wai 2575, #B19.

just as likely that Māori are under-represented in the DSS client group, as their access to DSS (17.5 per cent) is disproportionate to need according to the higher prevalence of disability for Māori.

BARRIERS TO HEALTH AND DISABILITY SERVICES

Research into Māori experiences of health and disability services provides further context for why Māori with lived experience of disability have higher proportions of unmet need, despite having higher prevalence of disability. Peter Jansen, Kira Bacal and Sue Crengle report a number of barriers to healthcare for Māori but highlight such barriers are greatest for Māori with lived experience of disability. For example,

‘Organisational barriers included: the distance to travel for care, the availability of appointments at suitable times, waiting times, the (lack of) choice of provider, inflexibility of healthcare systems, and poor experiences (e.g., lack of response to complaints, lengthy resolution times).

Cost barriers included: direct costs (e.g., consultation costs, prescription charges), and indirect costs (e.g., loss of wages due to time off work while obtaining care, expenses relating to travel or childcare). Participants also questioned whether a general practitioner visit was “value for money”.⁹⁹

Nikora et al., also report that,

‘...the majority of disability support services, particularly specialist services are concentrated in major urban centres like Hamilton, Tauranga, and Rotorua. People in major urban centres are also more likely than those in minor urban centres like Gisborne, Whakatane, and Opotiki and rural communities like Murupara, Tirau, Ruatoki, Whatawhata, and Waimana to have a diversity of disability support services

⁹⁹ Peter Jansen, Kira Bacal, and Sue Crengle, *He Ritenga Whakaaro: Māori Experiences of Health Services*. (Auckland: Mauri Ora Associates, 2008).
[http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/2A6CAF401ABBEFB9CC2575F4000B6D0C/\\$file/He-Ritenga-Whakaaro.pdf](http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/2A6CAF401ABBEFB9CC2575F4000B6D0C/$file/He-Ritenga-Whakaaro.pdf), p.9.

available to them, particularly community based services focused on specific disabilities like stroke, blindness, deafness, epilepsy, and on specific types of service delivery [for example,] Kaupapa Maori. However, in rural areas, tasks like visiting a medical practitioner, having blood tests completed, or accessing day care facilities, or specialists are complicated by the need for and expense of transport'.¹⁰⁰

Leigh Hale et al., found that access to funding for transport for Māori with lived experience of disability is '...problematic, especially in the rural areas'.¹⁰¹ They also highlight the issue of funding for the, '...many rurally located services surveyed [which] prevented services from being offered optimally...inadequate timing and availability of services and appointment systems was a common theme...'.¹⁰²

Adelaide Collins and Greg Wilson report that, for Māori with lived experience of disability,

'...the availability of free or subsidised transport to hospitals is sporadic, especially in rural areas. The majority of disabled Māori use their own vehicles and do not access public transport subsidies. There is no nationwide data on availability of transport enabling access to healthcare. The cost of transport is a key issue for Māori with a disability or chronic conditions'.¹⁰³

They also highlight that these '...costs tend to be borne by whānau caregivers. While subsidies and grants are available to Māori with disabilities to buy vehicles, there is no support for

¹⁰⁰ Nikora et al., *Disabled Maori and Disability Support Options: A report prepared for the Ministry of Health*, p.14.

¹⁰¹ The Centre for Health, Activity, and Rehabilitation Research. *Hauā Mana Māori: Living Unique and Enriched Lives - a Report for the Health Research Council and the Ministry of Health*. (Dunedin: University of Otago, 2014). <https://www.otago.ac.nz/physio/otago066906.pdf>, p.77.

¹⁰² Leigh Hale, Katrina Potiki Bryant, Aimee L Ward, Amy Falloon, Aroha Montgomery, Brigit Mirfin-Veitch, Kelly Tikao, and Stephan Milosavljevic, "Organisational Views on Health Care Access for Hauā (Disabled) Māori in Murihiku (Southland), Aotearoa New Zealand: A Mixed Methods Approach ". *New Zealand Journal of Physiotherapy* 46, no. 2 (2018): 51-66., p.63.

¹⁰³ Adelaide Collins and Greg Wilson, *Māori and Informal Caregiving: A Background Paper Prepared for the National Health Committee*. Ministry of Health (Wellington: 2008). [http://www.moh.govt.nz/notebook/nbbooks.nsf/0/933A5FFFCE411AFECC2579A5006B42E3/\\$file/maori-informal-caregiving-apr08.pdf](http://www.moh.govt.nz/notebook/nbbooks.nsf/0/933A5FFFCE411AFECC2579A5006B42E3/$file/maori-informal-caregiving-apr08.pdf), p.34.

ongoing transport costs for whānau using the vehicle for the benefit of a disabled whānau member'.¹⁰⁴

Andrea Corbett's research describes the challenges for whānau carers of Māori with lived experience of disability living in rural areas. For example, living,

'...42 kilometres from the main hospital and rehabilitation service where the main outpatient day clinic services were provided [meant that, although there] was a small limited functioning outpatient rehabilitation clinic service offering primarily physiotherapy available in their country town and a small service further south...unless one has their own motor vehicle that access is denied them. This raises not only the issue of transport but also the issue of the lack of domiciliary rehabilitation physical service and supervision in the whanau member's own home'.¹⁰⁵

Research by Nancy Higgins et al., examining access to paediatric ophthalmology services for Kāpō Māori found that,

'For some whānau, who do not live in, or near, the main centers, access to full specialist care was limited. In these instances, whānau may have had to travel to a base hospital. This may be costly and disruptive for whānau especially those with other young children or babies.

A few whānau, who participated in this study, lived just outside the cut off distance for eligibility for a travel allowance, while others, who were eligible, did not apply for

¹⁰⁴ Collins and Wilson, *Māori and Informal Caregiving: A Background Paper Prepared for the National Health Committee*, p.34.

¹⁰⁵ Andrea M Corbett, "The Experience of Whānau Caring for Members Disabled from the Effects of Stroke." (Unpublished Masters thesis). Massey University, 2003., p.108.

it because of the bureaucratic process to access it and the delays in being reimbursed'.¹⁰⁶

A stocktake and needs analysis of low vision services in Aotearoa/New Zealand also reports that,

'Based on the number of and location of low vision clinics and private optometrists providing low vision consultations identified in the stocktake, when compared to the prevalence of people who currently and in the future will experience low vision, there is a significant unmet need and services are inadequate...People in need of low vision services who identify as Māori...and/or who live in provincial and rural areas are not receiving adequate services currently. Low vision services in New Zealand are therefore inequitable and inadequate to meet the needs of people with low vision'.¹⁰⁷

Higgins et al., highlight however, that even when Kāpo Māori lived in cities where services were available, they didn't always find them easily accessible,

'...because of the cost and availability of transport. When talking about the cost of access to services, one parent reflected on the inequalities in the health system, which arose out of the cost of receiving services, because those who "had money" seemed to easily receive more attention'.¹⁰⁸

¹⁰⁶ Nancy Higgins, Hazel Phillips, Karen Stobbs, Graham Wilson, and Hannah Pascoe, *Summary of the Findings - Growing up Kāpō Māori: Accessing Paediatric Ophthalmology Services*. (Hastings: Ngāti Kāpo O Aotearoa Inc., 2012), p.12.

¹⁰⁷ Litmus Limited, *Stocktake and Needs Analysis of Low Vision Services in New Zealand*. (Wellington: Litmus Limited, 2015). <https://www.health.govt.nz/publication/stocktake-and-needs-analysis-low-vision-services-new-zealand>., p.6.

¹⁰⁸ Higgins et al., *Summary of the Findings - Growing up Kāpō Māori: Accessing Paediatric Ophthalmology Services*, p.12.

Summary

Historically, perceptions and treatment of Māori with lived experience of disability were based on valuing their abilities and strengths they possessed. In Te Ao Tawhito, Māori concepts of disability were diverse, and continue to be so in contemporary times.

The Crown definitions of disability across policy, implementation and monitoring are not consistent. For example, the *New Zealand Disability Strategy* emphasises that it is not the person with impairment(s) that has a disability, rather it is society that is disabling of the person. However, definitions of disability used by the Ministry of Health and Statistics New Zealand are based primarily upon reduced functionality of an individual, secondary to their impairment(s).

Western conceptual models of disability demonstrate an evolution from deficit-based to civil-rights based approaches. The Rights-based Model is considered the international best-practice model for disability. However, Western models are individualistic, and do not incorporate interdependence and collectivism of Māori within Te Ao Māori. Although, Māori frameworks of disability and identity have been theorised and developed by Māori scholars over the decades, none appear to have been recognised and/or incorporated by the Crown.

There are 176,000 Māori with lived experience of disability in Aotearoa/New Zealand (23 per cent Māori compared with 15.6 per cent for non-Māori). Māori have a higher prevalence of disability, as well as a higher proportion of disability across all age groups compared with non-Māori. Compared with non-Māori, Māori experience less privilege across almost all socioeconomic indicators. Within the Māori population however, the intersection of indigeneity and disability is demonstrated by the significant inequities for Māori with lived experience of disability compared to Māori without lived experience of disability, that occur across a number of socioeconomic indicators.

Despite a higher prevalence of disability, Māori have higher proportions of unmet need for access to health professionals and special equipment compared with non-Māori, and are likely to have disproportionate access to disability support services. There are number of barriers to healthcare for Māori, for example, organisational and appointment/transport costs. However, such barriers are reported as greatest for Māori with lived experience of disability, and particularly so for those who live in rural areas.

Significant inequities exist for Māori with lived experience of disability compared with non-Māori in health outcomes – in terms of exposure to the determinants of health and well-being, access to health and disability services, and the quality of health and disability care received. There is clear evidence of multiple systemic and structural barriers affecting these health outcomes for Māori with lived experience of disability, secondary to racism, colonisation, and coloniality.

Chapter I – Theoretical approach and research methods

Introduction

This chapter outlines the theoretical approach, purpose of this research, research objectives, and the methods used. Underpinned by kaupapa Māori theory, this research utilises a mixed-methods approach (quantitative and qualitative) of data collection and analyses. Methods include an environmental scan, strategic literature review, and a data review (quantitative and thematic analysis) of information provided by a selection of Crown organisations under the Official Information Act 1982. Ultimately this research is intended to contribute positively to the health and well-being of Māori with lived experience of disability, their whānau, and communities.

Theoretical approach

The underlying epistemological perspective informing the approach to systematic inquiry for this research is that of kaupapa Māori theory. Leonie Pihama describes kaupapa Māori theory as, ‘...a theory that is underpinned by Māori philosophies of the world, that has Māori foundations, that has Māori understandings. It is a theory that is about working for our people’.¹⁰⁹

¹⁰⁹ Leonie Pihama, “Keynote: A conversation about kaupapa Māori theory and research” (paper presented at the Kei Tua o Te Pae hui proceedings: The challenges of kaupapa Māori research in the 21st century, Wellington, New Zealand, 2011), p.39.

In the context of research, Elana Curtis articulates kaupapa Māori theory as challenging to the ‘...privileging of non-Māori ways of knowing (that often lead to Māori being held accountable for our current health...positioning)’.¹¹⁰ Instead, Māori ‘...ways of knowing, derived from both traditional and contemporary experiences [are] taken as valid and legitimate’.¹¹¹ Inherent in this approach is the requirement to recognise, acknowledge and critique the ‘...historical, social, cultural, economic, and political relations of inequality, privilege, and colonialism and...how these relations are produced and reproduced’.¹¹² Critically, Māori scholars highlight that,

‘Kaupapa Māori is for all Māori not for select groups or individuals. Kaupapa Māori is not owned by any grouping nor can it be defined in such ways that deny Māori people access to its articulation. What this means is that Kaupapa Māori must of necessity be diverse and recognise the diversity within our people; women, men, tamariki, kuia, koroua, rangatahi, whānau, hapū, iwi, urban Māori, these are some examples of the diversity within our people and therefore Kaupapa Māori needs to be accessible and available to all. It must also ensure analysis that is able to take into account, both in principles and practice, the diversity of Māori communities’.¹¹³

Additionally, Ani Mikaere aptly points out, ‘...if one of the driving imperatives of Kaupapa Māori research is the empowerment of Māori people then, as a bare minimum, its findings should be accessible – which means that they should be readily understood’.¹¹⁴

¹¹⁰ Elana Curtis, “Indigenous Positioning in Health Research: The importance of Kaupapa Māori theory-informed practice,” *Alternative* 12, no. 4 (2016), <https://doi.org/10.20507/AlterNative.2016.12.4.5.>, p.398.

¹¹¹ Curtis, “Indigenous Positioning in Health Research: The importance of Kaupapa Māori theory-informed practice.”, p.398.

¹¹² Graham Hingangaroa Smith and Linda Tuhiwai Smith, “Doing Indigenous Work: Decolonizing and Transforming the Academy,” in *Handbook of Indigenous Education*, ed. Elizabeth Ann McKinley and Linda Tuhiwai Smith (Singapore: Springer, 2018)., p.22.

¹¹³ University of Auckland International Research Institute for Māori and Indigenous Education, with Te Rōpū Rangahau Hauora a Eru Pōmare, Wellington School of Medicine, University of Otago, *Māori Research Development - Kaupapa Māori Principles and Practices: A Literature Review*, Te Puni Kōkiri (Wellington, 2000), [http://www.rangahau.co.nz/assets/SmithL/Maori_research.pdf.](http://www.rangahau.co.nz/assets/SmithL/Maori_research.pdf), p.14.

¹¹⁴ Ani Mikaere, “From kaupapa Māori research to re-searching kaupapa Māori: Making our contribution to Māori survival” (paper presented at the Kei Tua o Te Pae hui proceedings: The challenges of kaupapa Māori research in the 21st century, Wellington, New Zealand, 2011)., p.30.

Curtis describes a number of key principles and considerations underpinning effective kaupapa Māori research. That is, effective kaupapa Māori research is ¹¹⁵: transformative; beneficial to Māori; under Māori control; informed by mātauranga Māori; aligned with a ‘structural determinants’ approach to critique issues of power, privilege and racism and promote social justice; non-victim-blaming and rejecting of cultural-deficit theories; emancipatory and supportive of decolonisation; accepting of diverse Māori realities and rejecting of cultural essentialism; an exemplar of excellence; and free to dream, whereby, ‘Kaupapa Māori and mātauranga Māori should retain the right to develop unrestrained by conventional limitations and restrictions – it must always have a future’.¹¹⁶

If effective kaupapa Māori research is to be transformative, determining what transformation looks like, and how to get there, can be challenging. Pihama points out there are ‘...different ways in which transformation is an outcome of something. But a transformative approach to theory and research goes all the way through the process’.¹¹⁷ Two foundational publications in kaupapa Māori research convey kaupapa Māori as both theory and transformative practice.¹¹⁸ The authors of these texts, Graham Hingangaroa Smith and Linda Tuhiwai Smith, reiterate the necessity to ‘...move beyond the reproduction of the status quo and develop meaningful transformative outcomes’,¹¹⁹ and describe a framework supporting critical, continual self-reflexive practice in the evaluation of effective transformative practice for Indigenous peoples. The five components of this framework include: positionality; criticality; structuralist and culturalist considerations; praxicality; and transformability.¹²⁰

¹¹⁵ Curtis, “Indigenous Positioning in Health Research: The importance of Kaupapa Māori theory-informed practice.”

¹¹⁶ Curtis, “Indigenous Positioning in Health Research: The importance of Kaupapa Māori theory-informed practice.”, p.403.

¹¹⁷ Pihama, “Keynote: A conversation about kaupapa Māori theory and research.”, p.55.

¹¹⁸ Graham Hingangaroa Smith, “Kaupapa Māori: Theory and praxis,” ((Unpublished Doctoral thesis), The University of Auckland, 1997); Linda Tuhiwai Smith, *Decolonizing methodologies: Research and indigenous peoples* (London: Zed Books, 1999); Linda Tuhiwai Smith, *Decolonizing methodologies: Research and indigenous peoples*, 2nd ed. (London and New York: Zed Books, 2012).

¹¹⁹ Smith and Smith, “Doing Indigenous Work: Decolonizing and Transforming the Academy.”, p.24.

¹²⁰ Smith and Smith, “Doing Indigenous Work: Decolonizing and Transforming the Academy.”

Underpinned by kaupapa Māori theory, this research is intended to contribute positively to the health and well-being of Māori with lived experience of disability, their whānau, and communities. It centralises and prioritises Māori, viewing Māori worldviews, knowledge and experiences as ‘the norm’. The qualitative research methods and descriptive statistics undertaken use an equity-analytical framework investigating Māori versus non-Māori health inequities. This analysis occurs within the broader context of a Māori reality within Aotearoa/New Zealand’s structural society, and the subsequent societal determinants of Māori health and well-being. As Smith and Smith point out, ‘...a fundamental understanding here relates to how power is exercised and manipulated by dominant interest groups to maintain power and control over other minority groups and colonized populations’.¹²¹

Purpose of the research

The purpose of this research is to examine the historical and contemporary issues relevant to Māori with lived experience of disability, in order to address the research questions set out by the Waitangi Tribunal (the Tribunal) for stage two of Wai 2575 – the Health Services and Outcomes Inquiry.¹²²

Research objectives

A kaupapa Māori theoretical approach to systematic inquiry informed the researcher’s interpretation of the Tribunal’s research questions for Māori with lived experience of disability (refer to Appendices 1–2 for the Tribunal’s research questions). The following seven research objectives were developed from this approach:

¹²¹ Smith and Smith, “Doing Indigenous Work: Decolonizing and Transforming the Academy.”,p.22.

¹²² Wai 2575, #2.5.29; Wai 2575, #2.3.3.

1. To describe the key historical developments that have contributed to the development of the current system of government health and disability services for Māori with lived experience of disability, and to Māori historical and contemporary experiences of, and views toward health and disability services, examining how these may have contributed to barriers to service.
2. To provide an outline of contemporary health and disability services relevant to Māori with lived experience of disability, including how these are implemented, impacts and outcomes for Māori and Māori responses, examining how legislation, policies and practices recognise and provide for the needs of Māori with lived experience of disability, and the extent to which, if any, implementation and outcomes diverge from policy objectives.
3. To identify the extent to which Māori with lived experience of disability have had opportunities to participate in relevant policy and legislative developments, and health and disability governance.
4. To examine the extent to which health and disability policies and practices provide culturally appropriate health and disability services for Māori with lived experience of disability, or provide for Māori led and developed systems and methods of health and disability care.
5. To identify the extent to which, if any, Crown action, inaction or omissions have contributed to inequities in services and outcomes for Māori with lived experience of disability compared with non-Māori, and how these have been recognised and addressed.
6. To identify any barriers to the accessibility of, responsiveness to, and effectiveness of, services for Māori with lived experience of disability, and existing Crown policies and practices for recognising and addressing any such barriers.

7. To examine how effective, the current monitoring and data collection is, for identifying, and addressing, inequities in services and outcomes for Māori with lived experience of disability.

Scope of the research

This research report comprises Part I of two reports specifically commissioned by the Tribunal,¹²³ to examine issues for Māori with lived experience of disability. The scope of the Part I research is the examination and analysis of primary and secondary data sources. This research does not draw directly upon qualitative interviews/thematic analyses of interviews with Māori with lived experience of disability as that is covered in the Part II report (commissioned by the Tribunal). The following are also outside of the scope of this report:

- description of the historical developments in Māori health as that is already being covered by the Crown-commissioned *Historical Health Overview Report 1840-1992*,¹²⁴
- provision of statistical data for Māori with lived experience of disability that has already covered been by the Crown-commissioned *Māori Health Trends 1990-2015 Report* and *Māori Disability Statistical Status Report*,¹²⁵
- inclusion of issues relevant to mental health and addictions as these are already being covered in other research reports commissioned by the Tribunal for Wai 2575 stage two.¹²⁶ However, issues that are relevant to Māori with lived experience of disability are still covered in this report.¹²⁷

¹²³ Wai 2575, #2.3.3.

¹²⁴ Wai 2575, #2.5.31(b).

¹²⁵ Wai 2575, #2.5.31(b).

¹²⁶ Wai 2575, #2.5.29.

¹²⁷ For example, Māori with lived experience of learning/intellectual disability and mental health conditions.

Methods

This research utilises a mixed-methods approach (quantitative and qualitative) of data collection and analyses. Methods include an environmental scan, strategic literature review (of archival and contemporary sources), and a data review (quantitative and thematic analysis) of information provided by a selection of Crown organisations under the Official Information Act 1982.

Environmental scan

An environmental scan¹²⁸ was undertaken to inform both the scope for the literature search, and that of the information requests from Crown organisations relevant to Māori with lived experience of disability and their whānau. It ran from 28 November 2018 to 28 February 2019. Information was sourced from media releases, published documents, and relevant websites (for example, the Waitangi Tribunal, the Ministry of Health, the Office for Disability Issues, the National Archives Catalog, and Papers Past) using Google, and Google Scholar.

The environmental scan also included a review of the *Waitangi Tribunal Wai 2575 – The Health Services and Outcomes Kaupapa Inquiry Part 1: Record of Proceedings* and relevant documents in order to note any issues relevant for Māori with lived experience of disability. In addition, the environmental scan included: feedback from the Ministry of Health¹²⁹; presentation to and feedback received from, claimant and Crown participants at the Wai 2575 Research Hui held on

¹²⁸ Lauren Baba, *Cultural safety in First Nations, Inuit and Métis public health: Environmental scan of cultural competency and safety in education, training and health services*, National Collaborating Centre for Aboriginal Health (Prince George, British Columbia, Canada, 2013), https://aned.sd61.bc.ca/edsrvs/ANED/educationalResources/Miscellaneous/Cultural_Safety_in_Public_Health.pdf; National Collaborating Centre for Aboriginal Health, *Landscapes of First Nations, Inuit, and Métis Health: An Environmental Scan of Organizations, Literature, and Research, 3rd Edition*, National Collaborating Centre for Aboriginal Health (Prince George, British Columbia, Canada, 2014), <https://www.ccsa-nccah.ca/docs/context/RPT-LandscapesofHealth2014-EN.pdf>.

¹²⁹ A meeting was held with Ministry of Health representatives on 3 December 2018 to obtain clarification regarding the contents of the Crown-commissioned *Māori Health Trends 1990-2015 Report* and *Māori Disability Statistical Status Report*.

30 January 2019; and feedback received from interested claimant groups in the two weeks following the Wai 2575 Research Hui.¹³⁰

Literature search

A literature search was undertaken between 28 November 2018 to 28 February 2019 to inform the strategic literature review. The purpose of the strategic literature review was to provide an overview of:

1. The significant historical developments relevant to the development of the current health and disability system for Māori with lived experience of disability, including historical experiences of Crown health and disability services up to the year 2000.
2. The contemporary issues relevant to Māori with lived experience of disability from the 2000s onwards. These include (but are not limited to): implementation of Crown legislation, policies and practices and the impacts and outcomes for Māori with lived experience of disability; participation of Māori with lived experience of disability in legislation, governance and policy developments; and a summary of the available evidence into factors impacting on the health and well-being of Māori with lived experience of disability.

LITERATURE SEARCH STRATEGY

The following (archival and contemporary) databases were searched using a detailed search strategy from the earliest time when record keeping commenced to 28 February 2019. These included: Appendices to the Journals of the House of Representatives, Archives New Zealand, ARCHWAY, CINAHL (via Ebsco), Cochrane Library, Google Scholar, Informit Health Collection, INNZ, MEDLINE, National Library of New Zealand Catalogue, NZ Research, Papers Past, Proquest, PsychInfo, Scopus, Te Puna, The Hub, and Web of Science. Other relevant documents

¹³⁰ Following the Wai 2575 Research Hui held on 30 January 2019, meetings were held separately with two interested claimant groups on 7 and 11 February 2019 respectively.

and published studies were also sourced using Google and relevant websites. Finally, a systemic hand-search of reference lists for selected full texts was undertaken.

An example of a search strategy is provided in Appendix 3. Titles and abstracts were screened for eligibility based on whether they met the inclusion and exclusion criteria to inform the strategic literature review. Where inclusion was in doubt, full texts were retrieved for the documents and published studies, and these were reviewed in order to determine inclusion.

Conceptual framework based on ‘Treaty of Waitangi principles’

To inform the development of questions for the information requests from Crown organisations, and to support the thematic analyses of the data review component, the following framework based on the ‘principles of the Treaty of Waitangi’ was used (Table 1). Specifically, the framework includes a number of ‘Treaty principles’ that have come to light from various Tribunal reports over the years, and are published by the Tribunal.^{131,132} A further principle of ‘participation’ was included in the conceptual framework as, although ‘participation’ has not occurred to date in Treaty jurisprudence,¹³³ it is recognised within the health and disability sector.¹³⁴

Not without their limitations,¹³⁵ the ‘Treaty principles’ were used in order to provide a conceptual framework within which a vast amount of information from primary and secondary sources could be pragmatically collected, organised, and presented for the report.

¹³¹The Waitangi Tribunal, “Principles of the Treaty: The Waitangi Tribunal and Treaty principles,” 2016, <https://www.waitangitribunal.govt.nz/treaty-of-waitangi/principles-of-the-treaty/>. Accessed 1 February 2019.

¹³² The Treaty principles (and their interpretation as set out by the Tribunal) currently published by the Tribunal are derived from the Tribunal inquiry into the historical claims of Te Tau Ihu district.

¹³³ Te Puni Kōkiri, *He Tirohanga o Kawa ki te Tiriti o Waitangi*, Te Puni Kōkiri (Wellington, 2001), <https://www.tpk.govt.nz/en/a-matou-mohiotanga/crownmaori-relations/he-tirohanga-o-kawa-ki-te-tiriti-o-waitangi>; Waitangi Tribunal, “Principles of the Treaty: The Waitangi Tribunal and Treaty principles.”

¹³⁴ New Zealand Public Health and Disability Act 2000; The Royal Commission on Social Policy, *April Report Volume II*, Royal Commission (Wellington, 1988); Ministry of Health, *He Korowai Oranga: Māori Health Strategy*, (Wellington: Ministry of Health, 2014).

¹³⁵ The researcher acknowledges that the growing body of predominantly Crown legislative discourse surrounding te Tiriti o Waitangi (te Tiriti) contributes to conflicting reinterpretations. For this reason, the three articles of te Tiriti and the intention of te Tiriti based upon its specific phrasing and words, and of the text

Table 1: Principles of the Treaty of Waitangi

Principles	Waitangi Tribunal interpretation
Partnership	The Court of Appeal has referred to the Treaty as a partnership, with each partner having to act towards the other with the utmost good faith. The obligations of partnership include the duty to consult Māori and to obtain full, free, and informed consent.
Reciprocity	Above all, the partnership is a reciprocal one, involving fundamental exchanges for mutual advantage and benefits.
Autonomy	As part of the mutual recognition of kāwanatanga and tino rangatiratanga, the Crown guarantees to protect Māori autonomy. Inherent in Māori autonomy and tino rangatiratanga is the right to retain their own customary law and institutions and the right to determine their own decision makers and land entitlements.
Active protection	The Crown’s duty to protect Māori rights and interests arises from the plain meaning of the Treaty, the promises that were made at the time (and since) to secure the Treaty’s acceptance, and the principles of partnership and reciprocity. Active protection requires honourable conduct by, and fair processes from, the Crown, and full consultation with – and, where appropriate, decision-making by – those whose interests are to be protected.
Options	Inherent in the Treaty relationship was that Māori, whose laws and autonomy were guaranteed and protected, would have options when settlement and the new society developed. They could choose to continue their tikanga and way of life largely as it was, to assimilate to the new society and economy, or to combine elements of both and walk in two worlds. Their choices were to be free and unconstrained.
Mutual benefit	When the Treaty was signed, both settlers and Māori were expected to obtain or retain the resources necessary for them to develop and prosper in the new, shared nation state. The colonisation of New Zealand was thus to be for the mutual benefit of both Māori and settlers.
Equity	The obligations arising from kāwanatanga, partnership, reciprocity, and active protection required the Crown to act fairly to both settlers and Māori – the interests of settlers could not be prioritised to the disadvantage of Māori. Where Māori have been disadvantaged, the principle of equity – in conjunction with the principles of active protection and redress – requires that active measures be taken to restore the balance.
Equal treatment	The principles of partnership, reciprocity, autonomy, and active protection required the Crown to act fairly as between Māori groups – it could not unfairly advantage one group over another if their circumstances, rights, and interests were broadly the same.

collectively must be considered. For example, refer to King, Cormack, and Kōpua. 2018. “Oranga Mokopuna: A tāngata whenua rights-based approach to health and wellbeing.”

Principles	Waitangi Tribunal interpretation
Redress	Where the Crown has acted in breach of the principles of the Treaty, and Māori have suffered prejudice as a result, the Crown has a clear duty to set matters right. This is the principle of redress, where the Crown is required to act so as to ‘restore the honour and integrity of the Crown and the mana and status of Māori’. It will involve compromise on both sides, and, should not create fresh injustices.

Principles	Ministry of Health interpretation
Participation	The principle of participation requires Māori to be involved at all levels of the health and disability sector, including in decision-making, planning, development and delivery of health and disability services.

Source: Adapted from the Waitangi Tribunal,¹³⁶ and the Ministry of Health.¹³⁷

Table 2 presents the seven research objectives mapped to the framework and the research methods. A pragmatic approach was also taken in this mapping – so that the most relevant principles, based on the descriptions in Table 1, were aligned with each of the research objectives. It is important to note that because the principles are interconnected and overlapping, the mapping is not intended to be exhaustive.

¹³⁶ The Waitangi Tribunal, “Principles of the Treaty: The Waitangi Tribunal and Treaty principles,” 2016, <https://www.waitangitribunal.govt.nz/treaty-of-waitangi/principles-of-the-treaty/>. Accessed 1 February 2019.

¹³⁷ Ministry of Health, *He Korowai Oranga: Māori Health Strategy*.

Table 2: Mapping research objectives to principles framework and research methods

Research objectives	Analytical frame: principles of the Treaty of Waitangi	Methods
<p>Objective 1</p> <p>To describe the key historical developments that have contributed to the development of the current system of government health and disability services for Māori with lived experience of disability, and to Māori historical and contemporary experiences of, and views toward health and disability services, examining how these may have contributed to barriers to service.</p>	<p>Partnership</p> <p>Reciprocity</p> <p>Autonomy</p> <p>Active protection</p> <p>Options</p> <p>Equity</p> <p>Equal treatment</p> <p>Redress</p> <p>Participation</p> <p>Mutual benefit</p>	<p>Environmental scan</p> <p>Strategic literature review</p>
<p>Objective 2</p> <p>To provide an outline of contemporary health and disability services relevant to Māori with lived experience of disability, including how these are implemented, impacts and outcomes for Māori, and Māori responses, examining how legislation, policies and practices, recognise and provide for the needs of Māori with lived experience of disability, and the extent to which, if any, implementation and outcomes diverge from policy objectives.</p>	<p>Partnership</p> <p>Autonomy</p> <p>Active protection</p> <p>Options</p> <p>Equity</p> <p>Participation</p>	<p>Environmental scan</p> <p>Strategic literature review</p> <p>Information request/data review</p> <p>Thematic analysis</p>
<p>Objective 3</p> <p>To identify the extent to which Māori with lived experience of disability have had opportunities to participate in relevant policy and legislative developments, and health and disability governance.</p>	<p>Partnership</p> <p>Participation</p>	<p>Environmental scan</p> <p>Strategic literature review</p> <p>Information request/data review</p> <p>Thematic analysis</p>

Research objectives	Analytical frame: principles of the Treaty of Waitangi	Methods
<p>Objective 4</p> <p>To examine the extent to which health and disability policies and practices provide culturally appropriate health and disability services for Māori with lived experience of disability, or provide for Māori led and developed systems and methods of health and disability care.</p>	<p>Active protection</p> <p>Options</p> <p>Equity</p>	<p>Environmental scan</p> <p>Strategic literature review</p> <p>Information request/data review</p> <p>Thematic analysis</p>
<p>Objective 5</p> <p>To identify the extent to which, if any, Crown action, inaction or omissions have contributed to inequities in services and outcomes for Māori with lived experience of disability compared with non-Māori, and how these have been recognised and addressed.</p>	<p>Active protection</p> <p>Equity</p>	<p>Environmental scan</p> <p>Strategic literature review</p> <p>Information request/data review</p> <p>Thematic analysis</p>
<p>Objective 6</p> <p>To identify any barriers to the accessibility of, responsiveness to, and effectiveness of, services for Māori with lived experience of disability, and existing Crown policies and practices for recognising and addressing any such barriers.</p>	<p>Active protection</p> <p>Options</p> <p>Equity</p>	<p>Environmental scan</p> <p>Strategic literature review</p> <p>Information request/data review</p> <p>Thematic analysis</p>
<p>Objective 7</p> <p>To examine how effective, the current monitoring and data collection is, for identifying, and addressing, inequities in services and outcomes for Māori with lived experience of disability.</p>	<p>Active protection</p> <p>Equity</p> <p>Redress</p>	<p>Environmental scan</p> <p>Strategic literature review</p> <p>Information request/data review</p> <p>Thematic analysis</p>

Information-gathering from Crown organisations

To achieve the research objectives informed by the Tribunal's seven research questions, further primary sources of information were required from a number of Crown organisations relevant to Māori with lived experience of disability. Requests for information were sent to Crown organisations over two stages between December 2018 and March 2019. These were made under the Official Information Act 1982 (the OIA). Given the short time-frame for the research (a little over five months), the OIA was considered particularly appropriate as it was assumed Crown organisations would have existing processes in place to ensure swift release of information. Additionally, a precedent for use of the OIA in accessing official information for a Tribunal judiciary process had previously been set by Crown organisations (and Crown Law) during the course of research undertaken by Tribunal-commissioned researchers for *The Napier Hospital and Health Services Report*.¹³⁸ The Waitangi Tribunal Research Unit was informed of the researcher's decision on the approach with the OIA in December 2018 (as part of the research project plan).

STAGE ONE (DECEMBER 2018)

During stage one, information requests were made to a total of 30 Crown organisations. These included: the Ministry of Health; all 20 district health boards; the Pharmaceutical Management Agency (PHARMAC); the Accident Compensation Corporation (ACC); the Health and Disability Commissioner; the Health Promotion Agency; the Health, Quality and Safety Commission; the Health Research Council; the New Zealand Artificial Limb Service; the New Zealand Blood Service; and the Office for Disability Issues.

The first stage of OIA requests was sent on 19 December 2018. Using the Office of the Ombudsman guidelines, 20 working days for responses was calculated to end on

¹³⁸ Waitangi Tribunal, *The Napier Hospital and Health Services Report*, Legislation Direct (Wellington, 2001).

8 February 2019 (as the three weeks between Christmas Day and 15 January 2019 did not count as working days for government agencies).^{139,140}

STAGE TWO (FEBRUARY TO MARCH 2019)

During stage two, further information requests were sent to a number of the Crown organisations from stage one, as well as to the Ministry for Children; the Department of Corrections; and Te Puni Kōkiri. The information requests for stage two were informed by feedback received from claimant and Crown participants at the Wai 2575 Research Hui held on 30 January 2019; and feedback received from interested claimant groups in the two weeks following the Wai 2575 Research Hui.

The second stage of OIA requests were sent between 13 February and 18 February 2019 (with an expected due return date of no later than 18 March 2019).¹⁴¹ Between 1 March and 23 March 2019, a small number of Crown organisations were sent follow-up requests, seeking clarification on their earlier responses.

INFORMATION REQUESTS TO CROWN ORGANISATIONS

The content of the information requests sent to the Crown organisations were primarily informed by the environmental scan and the Treaty principles framework. Five further considerations were taken into account:

1. The Crown organisations' objectives and functions as set out in relevant legislation. For example, district health boards, PHARMAC, the Health Quality and Safety Commission, the Health Promotion Agency, and the New Zealand Blood Service were asked questions informed by the New Zealand Public Health and Disability Act 2000. Whereas,

¹³⁹ Office of the Ombudsman, *Making Official Information Requests: A guide for requesters* (2016), http://www.ombudsman.parliament.nz/system/paperclip/document_files/document_files/2465/original/making_o_i_requests_-_guide_for_requesters.pdf?1516146924.

¹⁴⁰ One agency (the Health Promotion Agency) was sent the request on 20 December 2019 because the original email request was delayed by its server.

¹⁴¹ One additional request was made on 27 February 2019 to Te Puni Kōkiri.

the Health and Disability Commissioner was asked questions informed by the Health and Disability Commissioner Act 1994.

2. The Crown organisations' responsibilities for health and disability services. For example, the request for information to the Department of Corrections was informed by its responsibilities as set out in the memorandum of understanding (MOU) with the Ministry of Health.¹⁴²
3. The Crown organisations' policies, work programmes and other activities, as set out in publicly available documents including annual reports, annual plans or statements of intent. For example, the requests made to ACC were informed by its most recent statement of intent.¹⁴³
4. Publicly available Ministerial or Cabinet decisions relevant to Crown organisations. For example, requests made to the Ministry of Health were informed by recent Cabinet decisions on disability support service transformation,¹⁴⁴ and requests made to district health boards were informed by the Minister of Health's *Letter of Expectations for district health boards and subsidiary entities for 2019/20*.¹⁴⁵
5. Government strategy documents. For example, requests made to the Office for Disability Issues were informed by the *New Zealand Disability Strategy*.¹⁴⁶

¹⁴² Ministry of Health and the Department of Corrections, *Memorandum of Understanding between the Ministry of Health and the Department of Corrections*. (Wellington: Ministry of Health and the Department of Corrections, 2012).

¹⁴³ Accident Compensation Corporation, *Statement of Intent 2018-2022*, Accident Compensation Corporation (Wellington, 2018), <https://www.acc.co.nz/assets/corporate-documents/acc7849-statement-of-intent-2018-2022.pdf>.

¹⁴⁴ Office of the Minister for Disability Issues and Associate Minister of Health, *Disability Support System Transformation: Overall Approach* (2017), <https://www.odi.govt.nz/assets/New-Zealand-Disability-Strategy-files/Disability-Support-System-Transformation-Overall-Approach.pdf>.

¹⁴⁵ Hon Dr David Clark, *Letter of Expectations for district health boards and subsidiary entities for 2019/20*, (Wellington: Minister of Health, 2018).

¹⁴⁶ Office for Disability Issues, *New Zealand Disability Strategy 2016-2026*. (Wellington: Ministry of Social Development, 2016).

Broadly, the questions in the information requests sent to Crown organisations covered: information on how Māori with lived experience of disability are involved in decision-making, for example, boards and committees; mechanisms used to ensure Māori with lived experience of disability are involved in strategy, policy, implementation, service design, delivery, evaluation and monitoring; information on organisational workforce make-up; organisational spend on services by, and for Māori with lived experience of disability; and how Crown organisations ensured services are appropriate for, and meet the needs of Māori with lived experience of disability. For most Crown organisations, information covering the past five financial years was sought.¹⁴⁷

All information requests made by the researcher under the OIA, and the OIA responses from the Crown organisations have been provided to the Waitangi Tribunal Research Unit to be recorded as part of the Record of Inquiry. However, they can also be found at the following link:

<https://www.dropbox.com/sh/gli0jjiodbk5mte/AABp3Uve91WvZMd6Tjggu7uSa?dl=0>

Table 3 provides an overview of the types of information requested mapped by the Treaty of Waitangi principles. Table 4 shows the information requests to Crown organisations mapped by the Treaty of Waitangi principles. As with the mapping of principles to the research objectives, the mapping of types of information requested to the principles is based upon a pragmatic application of the principles. It is not intended to imply the principles are clearly delineated. It is also not intended as a legal analysis of the principles.

¹⁴⁷ The exception was the Health Promotion Agency and the Health Quality and Safety Commission, where information covering the years since their establishment was sought as they were only established in 2012 and 2010 respectively and it was assumed information would be available since their establishment.

Table 3: Types of information requested from Crown organisations by Treaty principles

Principle	Types of information requested
Partnership	Organisation decision making and consultation including identifying priorities for Māori with lived experience of disability.
Reciprocity	Organisational decision making and working with Māori with lived experience of disability for mutual advantage and benefit. Linked to partnership principle.
Autonomy	The role of Māori institutions, including Māori-run, -centred health and/ or disability services. Linked to options principle.
Active protection	Responsiveness to Māori with lived experience of disability, including workforce training and development. Refer to equity principle also.
Options	Allowance and support for Māori-run, -centred health and/or disability support services.
Mutual benefit	Evidence of investment to support the role of Māori institutions, including Māori-run, -centred health and/ or disability services. Refer to partnership and options principles also.
Equity	Organisation monitoring and performance, and key results/data broken down by Māori, non-Māori, Māori with lived experience of disability, non-Māori with lived experience of disability, and evidence of active measures to ‘restore the balance’.
Equal treatment	Relative support provided to similar Māori groups or Māori disability organisations. Refer to equity principle also.
Redress	Service complaints for Māori with lived experience of disability. Refer also to strategic literature review.
Participation	Involvement of Māori with lived experience of disability in formal decision making (for example, boards, statutory committees), advisory groups, workforce (for example, staff levels), service delivery and system/ service design.

Table 4: Information requests to Crown organisations mapped to the Treaty principles framework,¹⁴⁸

Principle	Agency data request: relevant question(s)* * = Applies to more than one principle.
Partnership	District Health Boards request: 4*, 5*, 21*, 22* Ministry of Health request I: 1*, 4*, 11*, 17* Ministry of Health request II: 4* PHARMAC request: 4* ACC request: 3*, 6* Health and Disability Commissioner request: 1*, 6* Health Promotion Agency request: 3* Health Quality and Safety Commission request: 3* Health Research Council request: 1*, 4* NZ Artificial Limb Service request: 1* NZ Blood Service request: 1* Office for Disability Issues request I: 5*
Reciprocity	Refer to partnership principle.
Autonomy	Refer to options principle.
Active protection	District Health Board request: 2*, 3, 4*, 5*, 7*, 8*, 9*, 10*, 13*, 18*, 19*, 20*, 24*, 26* Ministry of Health request I: 3, 11*, 13*, 14*, 15*, 16* Ministry of Health request II: 5*, 6, 7* Ministry of Health request III: 1* PHARMAC request: 2, 4*, 5, 6, 8*, 10* ACC request: 3*, 5, 7, 9, 10 Health and Disability Commissioner request: 2*, 5*, 6* Health Research Council request: 1* Health Promotion Agency request: 2, 3*, 5, 7, 8, 9* Health Quality and Safety Commission request: 2, 3*, 6, 7 NZ Artificial Limb Service request: 1* NZ Blood Service request: 1* Ministry for Children request: 2* Department of Corrections request: 2, 3* Office for Disability Issues request I: 4*, 5*, 6, 8, 9

¹⁴⁸ Two requests (Department of Corrections request: 1, Ministry for Children request: 1) are not included in this table as they pertain to seeking Memoranda of Understanding between Crown organisations).

Principle	Agency data request: relevant question(s)* * = Applies to more than one principle.
	Office for Disability Issues request II: 1, 2, 3*
Options	District Health Boards request: 5*, 9*, 12, 16* Ministry of Health request I: 11* Ministry of Health request II: 1*, 2, 3* ACC request: 6* Health Research Council request: 4*
Mutual benefit	Refer to partnership principle.
Equity	District Health Boards request: 5*, 6, 7*, 8*, 9*, 10*, 11*, 18*, 19*, 20*, 21*, 22, 24*, 25 Ministry of Health request I: 4*, 11*, 12, 13*, 14*, 15*, 16*, 17*, 18, 19, 20, 21 Ministry of Health request II: 1*, 5*, 8 Ministry of Health request III: 1*, 2, 3, 4 PHARMAC request: 8*, 9, 10* ACC request: 11, 12* Health and Disability Commissioner request: 2*, 5*, 6* Health Promotion Agency request: 3*, 4 Health Quality and Safety Commission request: 3*, 8, 9 Health Research Council request: 1* NZ Artificial Limb Service request: 1* NZ Blood Service: 1*, 2 Ministry for Children request: 2*, 3, 4 Department of Corrections request: 3*, 4, 5, 6, 7, 8 Office for Disability Issues request I: 4* Office for Disability Issues request II: 3*
Equal treatment	Ministry of Health request II: 1* Refer to equity principle also.
Redress	No specific requests – Refer to literature search and strategic literature review.

Principle	Agency data request: relevant question(s)* * = Applies to more than one principle.
Participation	District Health Boards request: 1 (a, b, c, d*, e), 2*, 4*, 7*, 11*, 14, 15, 16*, 21*, 26* Ministry of Health request I: 1*, 2, 4*, 5, 6, 7, 8, 9, 10, 11*, 13*, 17* Ministry of Health request II: 4*, 7* PHARMAC request: 1, 3, 4*, 7, 8* ACC request: 1, 2, 3*, 4, 6*, 8 Health and Disability Commissioner request: 1*, 3, 4, 6* Health Promotion Agency request: 1, 3*, 6, 9* Health Quality and Safety Commission request: 1, 3*, 4, 5 Health Research Council request: 1*, 2, 4* NZ Artificial Limb Service request: 1* NZ Blood Service request: 1* Office for Disability Issues request I: 1, 2, 3, 5*, 7 Te Puni Kōkiri request: 1

Limitations of the research

The limitations of this research are identified and discussed in two parts. Firstly, are the limitations pertaining to the strategic literature review. Secondly are the limitations pertaining to incompleteness of information secondary to Crown organisations' responses to requests for provision of official information relevant to Māori with lived experience of disability. These are further outlined below.

Limitations pertaining to the strategic literature review

Although archival records were extensively searched, there was very limited information to be found about Māori with lived experience of disability in Te Ao Tawhito. The findings around the considerable lack of information within archival sources¹⁴⁹ relating to Māori with lived

¹⁴⁹ It is noted by the researcher that whakapapa knowledge and whānau oral traditions are likely to be a source of relevant information for Māori with lived experience of disability. However, as Tikao et al., have pointed out, '[...]finding literature evidence about an oral culture is not always easy...', p.1. They highlight the

experience of disability is not dissimilar to those findings already reported by Māori and non-Māori scholars in this area.¹⁵⁰ In any case, Tikao et al., warns that researchers,

‘...need to be aware that all of the literature from this period (before 1840) was written by non-Māori historians or missionaries who carried their own cultural bias. They would often write their own interpretation of what had been told to them by their informants, and thus placed a particular lens on their knowledge and writings. This will have an impact on how the reader sees and interprets the material’.^{151,152}

From a kaupapa Māori perspective, the researcher questioned the ‘value add’ of extending any platform to the Eurocentric perceptions of Māori within primary sources of archival information containing the reports of the early ethnographer/travellers’, if it did not extend the knowledge base for Māori with lived experience of disability.^{153,154} However, it was clear following the review of the evidence in archival sources relating to Māori with lived experience of disability, that such sources had already been analysed, and reported comprehensively on in the literature by Māori disability scholars.¹⁵⁵

Andrew Moore and Margaret Tennant surmise that the dearth of information in the archival sources pertaining to disability issues for Māori is likely secondary to the fact that such issues

need to prioritise, ‘...further research...to gather this oral information and to search historical collections of relevant documents throughout New Zealand’, p.11. This was outside of the scope of the research due to the short timeframe.

¹⁵⁰ Refer to Tikao et al., “Kāpo (blind) Māori in the ancient world”; Andrew Moore, and Margaret Tennant, *Who Is Responsible for the Provision of Support Services for People with Disabilities? A Discussion Paper*, (Wellington: National Advisory Committee on Health and Disability, 1997).

¹⁵¹ Tikao et al., “Kāpo (blind) Māori in the ancient world”, p.11.

¹⁵² For example, Elsdon Best, and James Herries Beattie.

¹⁵³ Linda Tuhiwai Smith, *Decolonizing Methodologies: Research and Indigenous Peoples*, (London: Zed Books, 1999); Linda Tuhiwai Smith, *Decolonizing Methodologies: Research and Indigenous Peoples*. 2nd ed., (London and New York: Zed Books, 2012).

¹⁵⁴ On a similar note, it was also not considered appropriate by the researcher to insert portraits or photographs of tūpuna from various archival sources into this report without first seeking the express permission of their own mokopuna and whānau.

¹⁵⁵ For example, refer to Tikao et al., “Kāpo (blind) Māori in the ancient world”. Also refer to the works of Huhana Hickey.

were not considered a priority at the time. They point out that, as definitions of disability have historically been,

‘...measured against expectations of health...where these were low, disability was probably less distinguishable than it has since become. The need to reduce the incidence of typhoid, tuberculosis and infant mortality among Māori sometimes took precedence over concerns about disability...and the living conditions which produced [infectious diseases] were the focus of public health effort’.^{156, 157}

There were however, a number of archival sources that broadly discussed Māori health (but made no mention of disability). For example, one archival source from 1860 describes population statistics for Māori, and postulates a number of (non-evidenced based) reasons as to why ‘native’ Māori numbers were decreasing.¹⁵⁸ However inclusion of such archival sources were considered to be outside of the scope of this research.¹⁵⁹ Other archival sources mentioned disability in the context of Māori health (usually in the title or key words), but on review of the full text, were outside the scope of the research as were found to pertain to ‘psychiatric disability’.¹⁶⁰

Other limitations of the strategic literature review relate to bias. Although the search strategy was broad enough to incorporate a wide range of literature relevant to the historical and contemporary issues for Māori with lived experience of disability, and every effort made to locate unpublished studies and reports, findings may still be susceptible to selective reporting. The inclusion of discussion papers, dissertations and theses, sought to reduce the impact of

¹⁵⁶ Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*, p.25.

¹⁵⁷ Unpublished official records from the the Health and Native Departments provide some information on what was considered to be Māori health issues at the time. For example, refer to H41/13 Smallpox Epidemic, 1913; H 156 Influenza (Auckland province), 1918–20; MA 21/22 Rawhiti Epidemic, 1906 (N.165A); Health Department, *Maori Maternal and Infant Welfare*, (Wellington: Health Department, 1934).

¹⁵⁸ For example, F.D Fenton, “Observations on the State of the Aboriginal Maori Inhabitants of New Zealand”, *Journal of the Statistical Society of London* 1860, 23(4), pp.508–541.

¹⁵⁹ A report on the historical developments in Māori health has been commissioned by the Crown. Refer to the section within this chapter on the research scope.

¹⁶⁰ A report on issues relating to Māori mental health has been commissioned by the Waitangi Tribunal. Refer to the section within this chapter on the research scope.

publication bias. The search strategy also included only electronic databases that mainly contained English language publications. Thus, as the strategic literature review is dependent upon publications written in the English language (as opposed to publications written in te reo Māori), this can be considered a source of bias.

Limitations pertaining to incomplete information from the Crown

organisations

The following provides a summary of issues that was identified in the request for provision of information from Crown organisations:

RESISTANCE FROM AGENCIES TO THE PROVISION OF INFORMATION

From the outset, there was resistance from some Crown organisations with respect to providing the information requested. Central Region Technical Advisory Services Limited (TAS), a professional services organisation for district health boards (DHBs), expressed their view that the majority (20 out of the initial 25) of the questions were ‘subjective’ and therefore outside the scope of the OIA. In which case, TAS indicated that their advice to DHBs was to not provide answers to the information request (and in doing so, fail to provide the information sought by the researcher for the Tribunal’s judiciary process). However, TAS did not provide any rationale for this advice to DHBs. Clarification was thus sought from TAS as to their rationale. For example, TAS was asked as to why a question pertaining to the number of Māori board members on a DHB would be ‘subjective’. However, TAS did not respond and made no further contact with the researcher. Despite the lack of clarification and follow-up from TAS regarding their rationale for why questions were ‘subjective’, a number of DHBs indicated in their OIA responses that TAS had, in fact, sent such advice to the DHBs, indicating that they should only answer a subset of five (out of the original 25) questions within the information request. A copy of the email from TAS to DHBs was not provided to the researcher.

A meeting was held with Ministry of Health representatives on 17 January 2019 to discuss the process for information-gathering from Crown organisations under the OIA. Following the meeting, the Ministry of Health sent an email to a selection of Crown organisations which

provided more context to the information requests, encouraging them to: 1) respond in a timely way for the Tribunal judiciary process, and 2) contact the researcher if they needed more information on specific questions, or required more time to respond.

Following the helpful email from the Ministry of Health, four Crown organisations sought clarification from the researcher on specific questions. However, only 14 (out of 30) Crown organisations provided a substantive response to the December 2018 requests within the 20 working days as specified under the legislation.

Ten Crown organisations responded on time and to all aspects of the information request made of them. A further four Crown organisations responded to the initial request on time, but with incomplete information. Information was deemed to be incomplete if any of the following factors occurred:

- a. Information was withheld by Crown organisations without sufficient rationale (as specified by the OIA's provisions),
- b. Responses by Crown organisations were notably too general to answer the questions asked of them, or
- c. Rationale provided by Crown organisations for withholding information appeared to contradict other information they had already released publicly, for example, in a previous OIA response published online.

CROWN ORGANISATIONS WERE GENEROUS IN DETERMINING A 'REASONABLE PERIOD OF TIME' FOR AN EXTENSION

Twelve Crown organisations sought extensions ranging from a few days through to an additional 25 working days. One Crown organisation did not acknowledge the request for a full 30 working days following the request being made, despite multiple reminder emails. At the time of writing that organisation had not fully responded, more than 50 working days after the request was made.

The OIA states that, in setting a time frame for an extension, the time frame ‘...shall be for a reasonable period of time having regard to the circumstances’.¹⁶¹ The Ombudsman guidance, *The OIA for Ministers and Agencies: A Guide to Processing Official Information Requests for Ministers* elaborates on this, stating that a ‘reasonable period of time’ is not defined in the OIA – what amounts to a reasonable period of time for an extension will depend on the circumstances of the particular case’.¹⁶² Despite the guidance provided, some Crown organisations appeared to seek extended time frames disproportionate to the size or nature of the request. For example, one Crown organisation sought an extension for 20 working days to answer a single question.

CROWN ORGANISATIONS WITH SIMILAR ROLES APPROACHED THE SAME QUESTIONS IN VASTLY DIFFERENT WAYS

All DHBs were sent the same information request on the same day. One DHB stated a number of the questions were out of the scope of the OIA, while most DHBs attempted to answer all of the questions contained in the information request, even if the answer was that the DHB did not hold the information.

- a. Thirteen indicated that they did not hold information whether board members were disabled, but provided a partial response by providing information on board member ethnicity.
- b. Eight DHBs provided responses to the request for information on DHB spending for the past five years on Māori with lived experience of disability (compared with non-Māori with lived experience of disability). The rest either provided a partial response (such as total funding), or stated that the DHB did not hold the information.
- c. One DHB stated that its limited ability to provide information on funding related questions was ‘due in no small measure to the DHB having no direct responsibility for

¹⁶¹ Official Information Act 1982, s15A(2).

¹⁶² Office of the Ombudsman. 2019. “The OIA for Ministers and Agencies: A Guide to Processing Official Information Requests.” <http://www.ombudsman.parliament.nz/resources-and-publications/guides/official-information-legislation-guides>.

provision or contracting of disability services for under 65's'.¹⁶³ However, this rationale was used by the DHB to explain its non-response to an information request that applied to health service provision (not just disability support services for people under 65 years). Other DHBs attempted to answer this question more fully.

SOME CROWN ORGANISATIONS PROVIDED SPECIFIC AND HELPFUL RESPONSES TO THE INFORMATION REQUESTS, OTHERS DID NOT

While a small number of Crown organisations took particular care to make sure they provided full answers (as evidenced by their responding on time, and seeking clarification during the process (five out of 30 organisations), other Crown organisations provided answers that were either very generalised or provided a large number of additional documents that were not specifically related to the information request.

Other features of responses included:

- a. Information was provided by Crown organisations that was not sought by the researcher, for example, information provided pertaining to Pacific health, whilst failing to answer the question for Māori.
- b. Responses were not always fit for purpose. For example, when asked what strategies and policies were in place to ensure compliance with accessibility of DHB buildings and facilities under NZS4121:2001, one DHB responded, 'Accessibility of DHB buildings and facilities under NZHS4121:2001'.¹⁶⁴ For DHBs specifically, there was also considerable inconsistency regarding whether they were providing responses from the point of view of their provider arm (relating to hospital services delivered by the DHB and its staff), or their funder arm (covering services purchased by the DHB and delivered in the

¹⁶³ Index of supplementary information provided to the researcher under the OIA – Responses from district health boards.

¹⁶⁴ Index of supplementary information provided to the researcher under the OIA – Responses from district health boards.

community), or both. Sometimes it was clearly labelled but predominantly it was left for the reader to determine, based on context.

Table 5 presents a summary of the grounds for refusal, or withholding of information under the OIA by the Crown organisations.

Table 5: Ground for refusal withholding information under OIA

Agency	Request	Ground for refusal/ withholding information under the OIA
Ministry of Health	<p>For each of the Ministerial committees administered by the Ministry of Health:</p> <ul style="list-style-type: none"> - How many members are disabled Māori? - How many members are disabled non-Māori? 	<p>Refused</p> <p>Section 18(e) – information does not exist</p>
	<p>How does the Ministry of Health monitor DHB compliance with the following requirements?</p> <p>Accessibility of DHB buildings and facilities under NZS4121:2001.</p> <p>Accurate ethnicity data recording and reporting under the Ministry of Health HISO 10001:2017 Ethnicity Data Protocols.</p> <p>Accessibility of public consultation for disabled Māori (for example, Ministry of Health Guide to Community Engagement with People with Disabilities 2017).</p> <p>Implementation of NZ Web accessibility standard 1.0.</p> <p>Implementation of NZ Web usability standard 1.2.</p> <p>Compliance with the Code of Health and Disability Services Consumers' Rights, particularly, Right 4 and Right 5.</p>	<p>Refused</p> <p>Section 18(e) – Ministry of Health does not monitor DHB compliance against these requirements; information does not exist</p>
	<p>What proportion of staff (by profession) have undergone 1) cultural safety / competence training, 2) disability responsiveness training, and 3) both cultural safety / competence and disability responsiveness training?</p>	<p>Refused</p> <p>Section 18(f) – requires substantial collation or research</p>
	<p>How many providers were contracted to provide health or disability support services to disabled Māori for each of the past five years, and how much were they funded, broken down by Māori owned and governed providers, and other providers?</p>	<p>Refused</p> <p>Section 18(e) – information does not exist</p> <p>(Note that the Ministry of Health later provided some</p>

Agency	Request	Ground for refusal/ withholding information under the OIA
		of the information in a follow-up request on Māori owned and Māori governed providers)
	Please provide lists of the Māori owned and Māori governed providers contracted with the Ministry of Health for disability support services over each of the past five years, and a description of the services they were contracted to provide, including whether they were national or district/regional level services and the targeted or eligible population for their services.	Refused Section 18(e) – information does not exist
	For each of the past five years how many audits have been conducted of disability support service providers broken down by Māori owned and governed providers, and other providers?	Refused Section 18(e) – information does not exist for Māori providers
	What proportion of Vote Health is targeted for health care and disability supports for disabled Māori each year, for the past five years? How does the Ministry ensure funding targeted for services and supports for disabled Māori is spent appropriately?	Refused Section 18(e) – information does not exist
	Over the 10-year period from 2008 to 2017, please provide the following information for people defined as care recipients or special care recipients under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003: a Number of Māori and non-Māori secluded. b People secluded per 100,000 population for Māori and non-Māori. Please also provide Māori/non-Māori rate ratios with 95% confidence intervals. c Seclusion events per 100,000 population for Māori and non-Māori. Please also provide Māori/non-Māori rate ratios with 95% confidence intervals.	Refused Section 18(e) – information does not exist
	Over the 10-year period from 2008 to 2017, please provide the following information for people defined as care recipients or special care recipients under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003: a Number of Māori and non-Māori deaths in care	Refused Section 18(e) – information does not exist (Note that the Ministry of Health stated the request was refused under s18(e) but its rationale is that it would require substantial analysis of individual records that could

Agency	Request	Ground for refusal/ withholding information under the OIA
	<p>b Mortality rate per 100,000 population for Māori and non-Māori. Please also provide Māori/non-Māori rate ratios with 95% confidence intervals.</p>	<p>not be completed within the timeframe of the request – similar to s18(f) ‘the information requested cannot be made available without substantial collation or research’)</p>
<p>Health Quality and Safety Commission</p>	<p>Are you able to please now provide how much has been spent by the commission on the Atlas of Healthcare variation each year since it began and how much was spent on other intelligence tools over the same period?</p>	<p>Refused Section 18(g) – information not held (Note that the Health Quality & Safety Commission provides 18(g) as the rationale but states it is difficult to calculate rather than it is not held ‘[f]or the Atlas, the information requested is literally impossible as it is largely related to the proportion of staff time allocated’)</p>
<p>Office for Disability Issues</p>	<p>Please provide the number of ODI employees who are:</p> <ul style="list-style-type: none"> a Māori. b Non-Māori. c Disabled Māori. d Disabled non-Māori. 	<p>Withheld Section 9(2)(a) – protect the privacy of natural persons (Note that although the information was withheld, the Office for Disability Issues states, ‘...two staff in ODI are proud to acknowledge their Māori whakapapa and are willing to declare within this OIA their Māori heritage’)</p>
<p>Ministry for Children</p>	<p>Please provide copies of all Memorandum of Understandings with the Ministry of Health and or District Health Boards.</p> <hr/> <p>Over the 10-year period from 2008 to 2017, please provide the following information per year broken down by two groups: 1) total care and protection residences 2) total youth justice residences:</p> <ul style="list-style-type: none"> • Number of disabled Māori and disabled non-Māori children and young people. 	<p>Withheld (some of the information) Section 9(2)(a) – protect the privacy of natural persons</p> <hr/> <p>Refused Section 18(f) – requires substantial collation or research</p>

Agency	Request	Ground for refusal/ withholding information under the OIA
	<p>Over the five-year period from 2013 to 2017, please provide the following information per year pertaining to health care and disability support services utilisation, broken down by two groups 1) total care and protection residences 2) total youth justice residences:</p> <ul style="list-style-type: none"> • Number of disabled Māori and disabled non-Māori children and young people who accessed primary health care services • Number of disabled Māori and disabled non-Māori children and young people who accessed dental care services • Number of disabled Māori and disabled non-Māori children and young people referred to secondary mental health services • Number of disabled Māori and disabled non-Māori children and young people referred to disability support services • For both the disabled Māori and disabled non-Māori categories, please break down by the following: <ul style="list-style-type: none"> ○ intellectual disability ○ physical disability ○ other disability. 	<p>Refused</p> <p>Section 18(f) – requires substantial collation or research</p>
	<p>Over the five-year period from 2013 to 2017, please provide the following information per year broken down by 2 groups: 1) total care and protection residences 2) total youth justice residences:</p> <ul style="list-style-type: none"> • Number of Secure Care Unit stays for Māori and non-Māori • Number of Secure Care Unit stays for disabled Māori and disabled non-Māori • For both the disabled Māori and disabled non-Māori categories, please break down by the following: <ul style="list-style-type: none"> ○ intellectual disability ○ physical disability ○ other disability. 	<p>Refused</p> <p>Section 18(f) – requires substantial collation or research</p>
<p>Department of Corrections</p>	<p>What training does the Department of Corrections offer staff to build their skills and expertise to provide appropriate health services to disabled Māori in prison,</p>	<p>Withheld (information in appendices)</p>

Agency	Request	Ground for refusal/ withholding information under the OIA
	for example, cultural safety/ competence training and disability responsiveness training? Please provide evidence.	Section 9(2)(a) – protect the privacy of natural persons
	<p>Over the 10-year period from 2008 to 2017, please provide the following information per year (broken down into two groups: 1) total of the 15 men’s prisons, and 2) total of the three women’s prisons):</p> <p>c For both the disabled Māori and disabled non-Māori categories, please break down by the following: intellectual disability; physical disability; and other disability.</p>	<p>Refused</p> <p>Section 18(f) – requires substantial collation or research</p>
	<p>Over the five-year period from 2013 to 2017, please provide the following information per year (broken down into two groups: 1) total of the 15 men’s prisons and 2) total of the three women’s prisons):</p> <p>a Number of disabled Māori and disabled non-Māori in prison who have been referred to Disability Support Services.</p> <p>b Number of disabled Māori and disabled non-Māori in prison who have been referred to regional forensic mental health services.</p> <p>c Number of disabled Māori and disabled non-Māori in prison who have been referred to secondary and/or tertiary health care services.</p> <p>d Number of disabled Māori and disabled non-Māori in prison who have been referred to dental care services</p>	<p>Refused</p> <p>Section 18(f) – requires substantial collation or research</p>
	<p>Over the five-year period from 2013 to 2017, please provide the following information per year (broken down into two groups: 1) total of the 15 men’s prisons, and 2) total of the three women’s prisons):</p> <p>a Number of mechanical restraint incidents for Māori and non-Māori.</p> <p>b Number of mechanical restraint incidents for disabled Māori and disabled non-Māori.</p> <p>c For both the disabled Māori and disabled non-Māori categories, please break down by the following: intellectual disability; physical disability; and other disability.</p>	<p>Refused</p> <p>Section 18(f) – requires substantial collation or research</p> <p>(Note that, initially the Department of Corrections refused this request under s18(g). When the researcher sought clarification, the Department of Corrections amended its ground for refusal)</p>
	Over the five-year period from 2013 to 2017, please provide the following information per year (broken	Refused

Agency	Request	Ground for refusal/ withholding information under the OIA
	<p>down into two groups: 1) total of the 15 men's prisons, and 2) total of the three women's prisons):</p> <ul style="list-style-type: none"> a [Not applicable] b Number of directed segregation events for disabled Māori and disabled non-Māori. c For both the disabled Māori and disabled non-Māori categories, please break down by the following: intellectual disability; physical disability; and other disability. 	<p>Section 18(f) – requires substantial collation or research</p>
	<p>Over the five-year period from 2013 to 2017, please provide the following information per year (broken down into two groups: 1) total of the 15 men's prisons, and 2) total of the three women's prisons):</p> <ul style="list-style-type: none"> a [Not applicable] b Number of periods started in an ARU for disabled Māori and disabled non-Māori. <p>For both the disabled Māori and disabled non-Māori categories, please break down by the following: intellectual disability; physical disability; and other disability.</p>	<p>Refused</p> <p>Section 18(f) – requires substantial collation or research</p>
	<p>Over the five-year period from 2013 to 2017, please provide the following information per year pertaining to the transport of people detained in a Regional Forensic Mental Health Service or a Care Facility for people with Intellectual Disability to and from court appointments or medical appointments (set out in Schedule 1 'Transports destinations and Patient and Care Recipient groups covered by this agreement' of the Memorandum of Understanding between the Ministry of Health and Department of Corrections 2011):</p> <ul style="list-style-type: none"> a Number of restraint incidents for Māori and non-Māori. b Number of restraint incidents for disabled Māori and disabled non-Māori. c For both the disabled Māori and disabled non-Māori categories, please provide the reason for restraint and relevant legislative provision. <p>For both the disabled Māori and disabled non-Māori categories, please break down by the following: intellectual disability; physical disability; and other disability.</p>	<p>Refused</p> <p>Section 18(f) – requires substantial collation or research</p>

One of the reasons the OIA was chosen as a method of information collection was that there are set processes used by Crown organisations to ensure compliance with the Act. Despite this, the researcher notes that some Crown organisations did not calculate the '20 working day' time frame accurately, some did not acknowledge the request, and there were instances where the OIA request was not logged (in one case causing a delay in the response). Additionally, one Crown organisation asked the researcher to keep the response confidential, despite releasing it under the OIA (and without redactions).

Chapter II – The Historical Context

Introduction

This chapter outlines the Crown’s historical response to the health and well-being of Māori with lived experience of disability in Aotearoa/New Zealand. A chronological overview of major developments in the Crown’s health and disability system that occurred in Aotearoa/New Zealand, from the mid-1800s onwards up to the 2000s is presented. It does not provide an exhaustive historical account. Rather, it describes those key events which have determined the funding, planning and delivery of health and disability services over time for Māori with lived experience of disability.

The models of disability outlined in the introduction to this report,¹⁶⁵ in addition to the Crown’s health and disability reforms, provide the context for key events that have occurred in the evolution of Crown’s approaches to Māori experience of disability over time. It also provides the context for within which Māori with lived experience of disability in Aotearoa/New Zealand have responded to the challenges faced. A summary of key issues is presented at the end of the chapter.

¹⁶⁵ Refer to Introduction for discussion of conceptual models of disability.

The Crown's health and disability system reforms

The pivotal work *Whaiora: Māori Health Development*, documents Māori health and development over the nineteenth and twentieth centuries. Its author, Mason Durie, highlights the advancement of Māori health encompasses not only consideration of, '...diverse Māori realities [but also] the reconciliation of the past with the future'.¹⁶⁶ However, what is most fundamental to Māori health development, is that Māori autonomy and control.¹⁶⁷ Māori have, for thousands of years, provided for the health and well-being of their communities.¹⁶⁸ As Durie points out,

'Well before 1800, Māori in Aotearoa recognised the importance of healthy communities, and a public health system evolved which was based on a set of values that reflected the close and intimate relationship between people and the natural environment...Māori public health systems were necessary for the well-being of the communities they served. Their effectiveness depended on an unwritten regulatory system enforced by a shared belief in communal safety and the integrity of a collective entity'.¹⁶⁹

Moore and Tennant highlight that the numerous activities driven by Māori in the advancement of Māori health and well-being over the nineteenth and twentieth centuries, although not specifically directed towards disability (or at least recorded in the literature as such), will likely have had positive impacts for Māori with lived experience of disability. This is particularly so with regard to the, '...incidence of disability among Māori and Māori access to health services'.¹⁷⁰

¹⁶⁶ Mason Durie, *Whaiora: Māori Health Development*, p.1.

¹⁶⁷ Durie, *Whaiora: Māori Health Development*.

¹⁶⁸ Durie, *Whaiora: Māori Health Development*.

¹⁶⁹ Durie, *Whaiora: Māori Health Development*, p.7.

¹⁷⁰ Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*, p.25.

Despite the presence of voluntary organisations in colonial society, it was the Crown that, for the most part, provided for disability services, through the subsidising of such organisations.

‘Right from the early years of Pākehā settlement, governments subsidised voluntary effort. In return, voluntary organisations have often acted as conduits between government and welfare recipients of various kinds, carrying out officially-sanctioned tasks that involved an element of personal support and community mobilisation. De facto agreements between the state and voluntary organisations often encouraged a situation where one provider...gained a monopoly on services, to the detriment of consumer choice’.¹⁷¹

It was the Hospital and Charitable Aid Boards, acting both as funders (including the dispensing of charitable aid), and as service-providers that provided for, ‘...income maintenance support as well as hospital and...asylum care’.¹⁷² These were the Crown organisations that engaged with the majority of people with lived experience of disability. For Māori however, evidence of their use of disability services during that time is limited. Moore and Tennant state that Māori utilisation of, ‘Pākehā-dominated disability services, voluntary and public, can certainly be found as far back as the nineteenth century, but numbers were small’.¹⁷³ There was, ‘...scarcely any mention of a Māori presence at the [Auckland Institute for the Blind] in annual reports or the [Auckland Institute for the Blind’s] official history prior to the 1940s...and it is likely that those Māori admitted did so at a price to their cultural identity’.¹⁷⁴

Thus, the evidence is unclear regarding whether Māori had access to disability services or not, at least prior to World War II. Moore and Tennant surmise that service utilisation by Māori at

¹⁷¹ Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*, p.12.

¹⁷² Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*, p.14.

¹⁷³ Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*, p.23.

¹⁷⁴ Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*, p.23.

this time was minimal as Māori were actually dissuaded by the Crown from accessing services. For example,

‘...prior to the introduction of hospital benefits under the Social Security Act 1938, hospital boards frequently claimed that Māori did not pay the fees charged to them, failed to contribute their share of the local rates, and should therefore not be eligible for treatment in public hospitals. Staff were often unsympathetic to Māori patients...’¹⁷⁵

Charlotte Williams notes that,

‘...Māori use of hospital services, which remained low, depended on their circumstances, including ability to afford both travel and treatment – promises of free hospital services where Māori had provided land or income from native reserves were not consistently kept...It would be something of an exaggeration to describe such patchy arrangements as a system of healthcare for Māori – so much depended on the interest of local MPs, individual doctors (and others less qualified) and local bodies...’¹⁷⁶

Other reasons for Māori not accessing disability services was that the use of such services,

‘...usually indicated, and even necessitated, estrangement from whānau and other traditional supports. This was especially true where institutional services were provided...[these] tended to be based in urban centres and, at a time when the Māori population was predominantly rural, treatment and other forms of assistance involved travel and time spent apart from whānau...Māori understandably resisted this. Most services, public and non-public were monocultural in emphasis, and those

¹⁷⁵ Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*, p.24.

¹⁷⁶ Charlotte Williams, *More power to do the work: Māori and the health system in the twentieth century*. (Wellington: Treaty of Waitangi Research Unit, Stout Research Centre for New Zealand Studies, Victoria University of Wellington, 2007), p.7.

limited numbers of Māori who used such services probably did so at a cost to their cultural identity and whānau links'.¹⁷⁷

In addition, Māori likely had differing interpretations of, '...what was (and is) a "disability" from those of Pākehā health professionals'.¹⁷⁸ Moore and Tennant also surmise that, as Westernised services had become, '...medicalised and technical, focusing on the physical dimensions...'¹⁷⁹ they conflicted with Māori worldviews of health and well-being. Although likely in conflict with a Māori worldview, it is also quite apparent however that, with regard to the 'medical technologies' introduced by the colonial medical practitioners, Māori were perhaps not so easily impressed. Toeolesulusulu Damon Salesa recounts the following,

'One surgeon who had visited New Zealand was asked: "What was [the Māori] opinion of your profession; did they consider that you had a supernatural power of healing diseases...?". The surgeon's answer was honest and humbling. "They consider it now to be the consequence of study...and they consider themselves fully equal to it if put into the way of it"'.^{180,181}

From the mid-1840s onwards

Since the early colonisation of Aotearoa/New Zealand, the Crown had established a rudimentary and ad hoc structure for the funding, planning and delivery of health and disability services. These included an assortment of government, voluntary, and privatised services whereby independent medical practitioners charged fees-for-services. However, Derek Dow

¹⁷⁷ Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*, p.24.

¹⁷⁸ Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*, p.25.

¹⁷⁹ Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*, p.24.

¹⁸⁰ Toeolesulusulu Damon Salesa, "The Power of the Physician': Doctors and the 'Dying Maori' in Early Colonial New Zealand." *Health and History* 3, no. 1 (2001): 13–40. <https://www-jstor-org.wmezproxy.wnmeds.ac.nz/stable/pdf/40111391.pdf>, p.21–22.

¹⁸¹ Also, refer to John Watkins, evidence before the "Report from the Select Committee of the House of Lords to inquire into the present State of the Islands of New Zealand", GBPP, 1838, XXI (680).

points out that the, ‘...provision of western medical services for Māori prior to 1846 was haphazard’.¹⁸² Raeburn Lange is less generous, stating that,

‘[a]t no stage before 1900 did the government see a need for concerted official action against low standards of Māori health. The Native Department was preoccupied with political matters and later...with the administration of land-purchasing operations; social welfare activities were merely an unimportant and haphazard addendum. Of course this was the age of laissez-faire in social welfare, and in regard to Māori welfare also the era in which the future was thought to hold no place for the Māori – or at least for the Māori who refused to heed the example and instruction of their tutors in civilisation and cease to be a special problem’.¹⁸³

‘The Waitangi Tribunal’s *Napier Hospital and Health Services* report published in 2001 describes how, from 1841 onwards, supplementary Crown colony instructions had directed that 15 to 20 per cent of Crown land sale proceeds be set up in an endowment fund for Māori, which included promotion of Māori health.¹⁸⁴ Following this, in 1847, the Governor of New Zealand – George Grey, established a public hospital programme in four of the settler towns. Its purpose was to provide services for Māori. This was supported by a subsidised native medical officer programme. Dow highlights Grey’s intent to, ‘...establish hospitals upon a “European” model as a means to civilise the Māori’.¹⁸⁵ To begin with,

‘...Māori willingness to utilise the hospitals was evident from the outset. In Wellington, 23 of the 31 inpatients admitted by January 1848 were Māori...Almost all the patients at New Plymouth during 1848 were Māori...However, there appears not

¹⁸² Derek A Dow, *Māori Health and Government Policy 1840–1940*. (Wellington: Victoria University Press, 1999), p.15.

¹⁸³ Raeburn Lange, *May the People Live: A history of Maori health development 1900–1920*, (Auckland: Auckland University Press, 1999), p.68.

¹⁸⁴ Waitangi Tribunal, *The Napier Hospital and Health Services Report*, (Wellington: Legislation Direct, 2001).

¹⁸⁵ Derek A Dow, *Māori Health and Government Policy 1840–1940*, p.27.

to have been the same predominance of Māori patients at Auckland Hospital...By 1850, Pākehā inpatients in Auckland out-numbered Māori by 2:1'.¹⁸⁶

Five years later however, the New Zealand Constitution Act 1852 supplanted the endowment fund. Under the New Zealand Constitution Act, the country had been split into six provinces each with its own self-government comprising a Superintendent and Provincial Council, and its own legislature.¹⁸⁷ The proceeds from Crown land sales was now replaced with a fixed £7000 per annum from the 'Civil List' budget, intended to be used for Māori medical care, pensions and rations.^{188,189}

'The figure remained unchanged for almost a century and was from time to time the focus of spirited debate, accompanied by allegations of parsimony or misappropriation...The potential for conflict in the handling of the Native Civil List was recognised almost from its inception. In 1854 William Fitzherbert, Provincial Secretary for Wellington, drew attention to the "inadequacy of existing machinery for native medical treatment"...he commented on the lack of any clear division of responsibility between the central and provincial authorities'.¹⁹⁰

In 1854, the public hospitals were reassigned to the control of the provinces. Hospital subsidies for Māori patients, in addition to the native medical officer programme, also became financed from the Civil List. The Waitangi Tribunal highlights that by this point in time, '...efforts to respect tikanga Māori were short-lived'.¹⁹¹ For example, the *Napier Hospital and Health Services* report states, '...the reported experiences at the Government hospitals at Wanganui and New Plymouth during the 1850s made colonial officials aware of the importance of consulting local Māori on respecting tikanga Māori in order to provide them with an effective

¹⁸⁶ Derek A Dow, *Māori Health and Government Policy 1840–1940*, pp.28–29.

¹⁸⁷ The provinces were abolished by the enactment of the Abolition of Provinces Act 1875.

¹⁸⁸ Derek A Dow, *Māori Health and Government Policy 1840–1940*.

¹⁸⁹ Lange, *May the People Live: A history of Maori health development 1900–1920*.

¹⁹⁰ Derek A Dow, *Māori Health and Government Policy 1840–1940*, p.16.

¹⁹¹ Waitangi Tribunal, *The Napier Hospital and Health Services Report*, p.394.

hospital service'.¹⁹² However, the '...bicultural accommodations that some early hospital superintendents made with tikanga Māori disappeared as hospitals became Pākehā community institutions'.¹⁹³ Also, not all native medical officers were actually qualified. For example, '...George Topp had become [native medical officer] NMO at Waiuku in July 1858 despite having no formal medical qualifications...'.¹⁹⁴ Following the Crown's 'cap' on funding for Māori via the Civil List, the hospital subsidies ended (in the 1860s). As a result, 'Māori patients [were] placed on same footing as Pākehā [with] native medical officer posts reduced'.¹⁹⁵

In 1872, the Public Health Act set up a Central Board of Health within each province. These were augmented by Local Boards of Health within each local authority. However, in 1875, following the abolition of the provinces (to provincial districts) under the Abolition of Provinces Act 1875, hospitals were transferred to local authority control under the Hospitals and Charitable Institutions Act 1885. Financial sources included government subsidies, with all, '...patients, including Māori, means-tested for payment of hospital fees'.¹⁹⁶ However, the Hospitals and Charitable Institutions Act did not apply to the 'lunatic' asylums, in which case the Crown still covered some costs of institutionalisation.¹⁹⁷

The Hospital and Charitable Institutions Act 1885 had established 28 hospital districts across the country led by the appointed Hospital and Charitable Aid Boards (also known as District Boards). Funding came from the state, local authorities, charity and user-pays fees. In 1876, the Public Health Act 1900 replaced the Central Boards of Health in the provinces with one Central Board of Health, though the Local Boards of Health persisted. The Public Health Act 1900 also instituted a Department of Public Health, Minister of Public Health, six public health districts, a Chief Health Officer and District Health Officers – these were appointed medical practitioners.¹⁹⁸ From 1906 onwards, the Department of Public Health was responsible for

¹⁹² Waitangi Tribunal, *The Napier Hospital and Health Services Report*, p.207.

¹⁹³ Waitangi Tribunal, *The Napier Hospital and Health Services Report*, p.184.

¹⁹⁴ Derek A Dow, *Māori Health and Government Policy 1840–1940*, p.40.

¹⁹⁵ Waitangi Tribunal, *The Napier Hospital and Health Services Report*, p.394.

¹⁹⁶ Waitangi Tribunal, *The Napier Hospital and Health Services Report*, p.394.

¹⁹⁷ Hospitals and Charitable Institutions Act 1885.

¹⁹⁸ Public Health Act 1900.

Māori health and a Native Health Officer role was established. The first Native Health Officer was Māui Pōmare who later became the Minister of Health in 1925.¹⁹⁹

This activity had occurred around a similar time as that of the enactment of the Maori Councils Act 1900. The Waitangi Tribunal reports the Maori Councils Act had, ‘...led to limited Māori empowerment to mount community public health schemes under district councils and komiti marae’.²⁰⁰ The Maori Councils Act itself, states its purpose is to, ‘...confer a Limited Measure of Local Self-government upon Her Majesty’s Subjects of the Maori Race in the Colony’.²⁰¹ Richard Hill also highlights that the legislation,

‘...provided for elected, self-governing bodies in the rural areas where most Māori lived. In particular, the Maori Councils were authorised to control the “health and welfare and moral well-being” of Māori. They would operate at regional level, laying down rules of social control through bylaws valid within their own boundaries, which were designed to reflect meaningful tribal clusters. Beneath them, elected village committees/komiti marae would supervise and enforce their rules in the small communities in which most Māori lived. These worked with non-official flax-roots organisations such as Kotahitanga’s Komiti Wahine, which became commonly known as “Ladies Committees”. On the surface, the legislation provided for devolved local government powers which approached those of boroughs and town boards. The operation of the Maori Councils (nineteen were initially established) was to be heavily constrained and guided by the state...’²⁰²

Thus, early Māori health development such as the work of the Maori Councils and Māori health inspectors in public health regulation enforcement, occurred within the context of legislation that supported the Crown’s agenda for assimilation of Māori (through the dissolution of the Kingitanga, but more specifically, the Kotahitanga movement). Hill notes that,

¹⁹⁹ Lange, *May the People Live: A history of Maori health development 1900–1920*.

²⁰⁰ Waitangi Tribunal, *The Napier Hospital and Health Services Report*, p.394.

²⁰¹ Maori Councils Act 1900.

²⁰² Hill, *Indigenous Autonomy: Crown-Māori Relations in New Zealand/Aotearoa 1900–1950*, p.50.

‘...for its part, the Crown’s short-term aim was to indicate that nationwide tribal unity of organisation and action was unnecessary. More generally, it sought to appropriate tribally based vitality and steer it in a “safe” direction that would ultimately contribute to assimilation’.²⁰³

From the outset, however, there were,

‘...suspicions of the Crown’s intentions from Kingitanga, which (correctly) believed that the state’s primary aim with the new institutions was to head off kotahitanga. From the beginning, the government had explored various ways of gaining sufficiently widespread acceptance of the Maori Council system to supersede Kotahitanga and Kingitanga. It had decided that a colony-wide pan-tribal body placed above the local and district structures was necessary. But this could not be allowed to be too powerful. Thus the shapers of the system found a relatively anodyne solution, with the [Maori Councils] Act allowing for general conferences of Maori Council representatives’.²⁰⁴

Within the year the Kingitanga had moved to form its own local committees. Regardless, Hill points out the Crown had been successful with regard to the dissolution of the Kotahitanga, whereby in 1902,

‘...it was decided to disband Te Kotahitanga o Te Tiriti o Waitangi and merge it with Maori Council general conferences...The main perceived threat to indivisible Crown sovereignty, an authentic major Maori political movement, had quickly been subsumed and then removed’.²⁰⁵

²⁰³ Hill, *Indigenous Autonomy: Crown-Māori Relations in New Zealand/Aotearoa 1900–1950*, p.50.

²⁰⁴ Hill, *Indigenous Autonomy: Crown-Māori Relations in New Zealand/Aotearoa 1900–1950*, p.52.

²⁰⁵ Hill, *Indigenous Autonomy: Crown-Māori Relations in New Zealand/Aotearoa 1900–1950*, p.53.

Over the early 1900s, other assimilation strategies were carried out by the Crown.²⁰⁶ For example, the prohibition of tohunga practice under the Tohunga Suppression Act 1907²⁰⁷ which had considerable impacts on Māori health and well-being through the oppression and loss of mātauranga Māori.²⁰⁸ Between the years 1901 to 1911, the Māori Health Nursing Scheme (a Māori initiative) was also assimilated into the Public Health Department, and, 'Instead of Māori nurses, Pākehā were appointed to the service...and "the scheme was to be another tool of assimilation"'.²⁰⁹

Williams notes more generally that the, '...fragmented, locally elected and funded and often unhelpful hospital system, along with the sparsely located and not always competent services...created formidable barriers to an effective and coordinated response to Māori health needs...'.²¹⁰ However, Williams also highlights the political challenges apparent for Māori from the start. For example,

'...[a]t different times [Māui] Pōmare and Herbert Edgar, who was Under Secretary of the re-established Native Department from 1906 to 1907, produced plans for a coherent response to Māori health needs. These included separate institutions to care for Māori suffering from [tuberculosis] and hostels for those attending hospitals, cottage hospitals in the remoter areas, the appointment of Māori graduates as local officers of health, training in infant care for Māori women, local hospital training for Māori nurses, replacing the [native medical officer] services with medical cooperative societies, subsidies for hospital outpatient treatment and assistance to the Maori Councils with additional native health officers. Such recommendations went nowhere...

²⁰⁶ Alexandra McKegg, "The Māori Health Nursing Scheme: an experiment in autonomous health care." *New Zealand Journal of History* 26, no. 2 (1992).

²⁰⁷ Tohunga Suppression Act 1907.

²⁰⁸ Patricia Laing and Eru Pōmare, "Māori health and the health care reforms." *Health Policy* 29 (1994), [https://doi.org/10.1016/0168-8510\(94\)90012-4](https://doi.org/10.1016/0168-8510(94)90012-4).

²⁰⁹ Patricia Laing and Eru Pōmare, "Māori health and the health care reforms.", p.146.

²¹⁰ Williams, *More Power to Do the Work: Maori and the Health System in the Twentieth Century*, p.9.

More unhelpful still was government failure to fund Māori health adequately or consistently, or to provide the [Maori] Councils with administrative support, although Māori parliamentarians and other leaders made many representations on needed improvements'.²¹¹

In 1919, the Maori Councils were directed to work closely with the Department of Public Health, and in 1920 they became known as Maori Health Councils. These councils were accountable to the Department of Public Health, and held authority to enforce health and sanitation by-laws. The Health Act 1920 created a Board of Health and transformed the Department of Public Health into a new Department of Health led by a Director-General of Health (previously the Chief Health Officer). The new Department of Health consisted of seven divisions. These included the: Division of Public Hygiene; Division of Hospitals; Division of Nursing; Division of School Hygiene; Division of Child Welfare; and the Division of Māori Hygiene. Te Rangi Hīroa (Peter Henry Buck) was appointed as the first Director of the Division of Māori Hygiene.²¹²

From mid-1840s onwards, Crown legislation and policies specifically around disability had primarily focused on exclusion. For example, groups of people were excluded from settling in Aotearoa/New Zealand as they were not perceived by the Crown as contributing to the 'ideal society'. For example, the racist and ableist Acts of parliament on immigration,

'...restricted the entry of Chinese in the late 19th century also banned "cripples, idiots, lunatics, infirm, blind, deaf and dumb"...The 1882 Imbecile Passengers Act required a bond from the person in charge of the ship before one of these "undesirables" was discharged from the ship, and the 1899 Immigration Restriction Act went further banning the "idiot", the "insane" and the "contagious"'.²¹³

Any supports for people with lived experience of disability were expected to be met by their families with small amounts of financial support provided by charitable aid. As outlined in the

²¹¹ Williams, *More Power to Do the Work: Maori and the Health System in the Twentieth Century*, pp.9–10.

²¹² Durie, *Whaiora: Māori Health Development*.

²¹³ Hilary Stace, "Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy," ((Unpublished Doctoral thesis). Victoria University of Wellington, 2011)., p.104.

Tragedy/Charitable Model of disability, this approach was associated with that of a 'pity ethos', and the notion of the 'deserving poor', but only for particular groups of people. For example,

'...disabled persons (and especially those with an obvious physical or sensory disability) have tended to be placed among the "deserving poor". They were least likely to be expected to show self-help and initiative...Those with a psychiatric disability elicited least sympathy, and in this area, community support and voluntary effort were, historically, little apparent'.²¹⁴

The Crown's aim was to keep financial support to a minimum, and only for those who were more likely to meet the criteria for the 'deserving poor'.²¹⁵ However, the Lunatics Ordinance 1846 provided for the custody and prevention of offences by those considered 'dangerously insane' in addition to the care of people of 'unsound mind'. People were at first housed in jails, and then from 1854 onwards, in the large established asylums funded by the Crown which housed numerous people of all ages and backgrounds.²¹⁶ What they did have in common, however, was experience of marginalisation by the Crown.

'Lunatic asylums were established primarily to care and to treat insane people, especially those who posed a danger to themselves or to others, but they gradually acquired a catch-all role in the light of changing social, medical and legal perceptions of insanity. Most psychiatric hospitals eventually accommodated some, if not many, persons who suffered from intellectual handicap/disability or its older names of mental defect or mental subnormality. The generic title "mental hospital" included both New Zealand's psychiatric hospitals and specialist residential institutions for intellectually disabled people. These were known at different times as farm colonies,

²¹⁴ Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*, p.32.

²¹⁵ Stace, "Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy."

²¹⁶ Warwick Brunton, "The Origins of Deinstitutionalisation in New Zealand." *Health and History* 2003, 5(2): 75–103. <https://www.jstor.org/stable/40111454>.

psychopaedic hospitals, hospitals and training schools, or intellectual handicap hospitals. Most patients faced little prospect of recovery and discharge'.²¹⁷

Lorelle Barry and Catharine Coleborne note that Māori admission rates to the asylums,

'...were relatively low compared with that of non-Māori. Māori comprised less than 4 per cent of the entire patient population at [Auckland Mental Hospital] AMH in 1880. In the same year, Māori were present in just one other mental hospital, at Seacliff in Dunedin, meaning that the number of Māori was 1 per cent of the total asylum population throughout the whole country'.²¹⁸

They also highlight that Māori were less likely to be committed by their whānau. Rather confinement for Māori occurred whenever and wherever,

'...Māori and European lives intersected...in the majority of cases Māori were admitted as a result of contact with legal officials such as the police, or where Māori were married to Europeans, or where Māori lived in or around European towns and settlements, such as Auckland...'.²¹⁹

On studying the files of Māori in the Auckland Mental Hospital, Barry and Coleborne also made the discovery that the Crown had, in fact, been recording the land interests of institutionalised Māori as well as that of their whānau.

'In the pages of the Record of Maintenance Investigations book the payment details of 18 Māori patients are recorded, the largest part of which makes reference to the level of interest that the patient and their relatives had in land...This European

²¹⁷ Brunton, "The Origins of Deinstitutionalisation in New Zealand.", p.87. Also, refer to Appendix to the Journal of the House of Representatives, 1881, H-13; Appendix to the Journals of the House of Representatives, 1883, H-3; Appendix to the Journals of the House of Representatives, 1891, H-2; Appendix to the Journals of the House of Representatives, 1903, H-07a; Appendix to the Journals of the House of Representatives, 1910, H-7.

²¹⁸ Lorelle Barry and Catharine Coleborne, "Insanity and Ethnicity in New Zealand: Māori Encounters with the Auckland Mental Hospital, 1860–1900." *History of Psychiatry* 22, no. 3 (2011): 285–301. <https://doi.org/10.1177/0957154X10390435>, p.287.

²¹⁹ Barry and Coleborne, "Insanity and Ethnicity in New Zealand: Māori Encounters with the Auckland Mental Hospital, 1860–1900.", p.288–289.

interest in land arguably signalled the growing impact for Māori of land confiscation'.²²⁰

THE EUGENICS MOVEMENT

During this time, 'social Darwinism' and the eugenics movement had become popular overseas, and in Aotearoa/New Zealand.

'The term eugenics was coined in 1883 and was described by its founder, Sir Francis Galton, as "the study of agencies under social control that may improve the racial qualities of future generations, either physically or mentally". By the early twentieth century, eugenics had developed in Scandinavia, Mexico, Japan, France, Russia, Australia, South Africa, Canada and the United States. In all these countries eugenics involved the social engineering of a selected population by direct intervention through sterilization, segregation, marriage certificates, immigration restrictions and the eugenic use of birth control'.²²¹

One of the main reasons postulated for the rise of the eugenics movement in Aotearoa/New Zealand were concerns around decreasing white birth rates. This subsequently led to fears that the colonial society was about to lose its (self-perceived) racial and moral superiority.

'...officials were highly anxious about the future of the white "race". During this period health and welfare professionals, along with politicians, officials and social commentators in New Zealand, feared the consequences of racial degeneration and proposed ideological, practical and legislative solutions that fell under the broad goal of "race improvement"...

Negative eugenics, the branch of the theory that focused on restricting the reproduction of the "unfit", variously included single mothers, sexual offenders,

²²⁰ Barry and Coleborne, "Insanity and Ethnicity in New Zealand: Māori Encounters with the Auckland Mental Hospital, 1860–1900.", p.295.

²²¹ Angela Wanhalla, "To 'Better the Breed of Men': women and eugenics in New Zealand, 1900–1935." *Women's History Review*, 16 (2007):2, 163–182, <https://doi.org/10.1080/09612020601048779>, p.165.

juvenile delinquents, the “feeble-minded”, “subnormal” children and those considered social deviants. The threat that these groups posed was believed to be present at the national and imperial levels. Through sterilization, immigration restriction, segregation and restrictive marriage laws it was proposed that the country could maintain its image as a social progressive. If not, the “healthy country” image, identified as significant to New Zealand’s national identity, it was feared, would be undermined’.²²²

It was within this specific context that Frederick Truby King, the Medical Superintendent of Seacliff Lunatic Asylum, founded the Society for the Promotion of the Health of Women and Children (later the Royal New Zealand Plunket Society)²²³ in 1907.

‘Plunket was started in 1907 to train mothers to grow healthy little citizens and soldiers for the empire. Founder Truby King...believed that teaching mothers the strict rules of scientific mothering would increase the fitness of the race. Committees of wealthy middle class women then took the ideology to the breeding populace’.²²⁴

Frederick Truby King, in a 1914 speech where he attributes the plunge in infant mortality (for white babies) to the work of Plunket, states,

‘[The] object was the care of the infant before birth and during the period of infancy; in other words, practical eugenics. It was really an attempt to rear a strong and healthy race by constructive, and not by restrictive means. The object was not primarily to eliminate the unfit but to prevent their production by aiding in the full development of the healthy, for the sake of women and children, for the advancement of the Dominion, and for the honour of the Empire’.²²⁵

²²² Wanhalla, “To ‘Better the Breed of Men’: women and eugenics in New Zealand, 1900–1935”, p.166.

²²³ The Royal New Zealand Plunket Society became the Royal New Zealand Plunket Trust in 2018.

²²⁴ Stace, “Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy”, p.106.

²²⁵ Frederick Truby King. *A plea for the drawing up and circulation throughout the whole community of simple reliable consistent standards for guidance in the rearing of normal infants. With discussion.* Reprint from the

Specific Crown-defined categories of disability were linked to ‘immorality’, in which case, people were targeted by eugenicists with the aim of segregating and institutionalising them. This was in order to both ‘prevent reproduction’ and to remove them from society. This led to the Crown institutionalising both young children and adults in segregated residential schools. The Education Amendment Act 1907 had introduced compulsory education for ‘defective or epileptic’ children between the ages of 6–21 years. In 1908, a ‘special school’ for ‘mentally retarded’ boys opened in Otago, with another school opening in Nelson in 1916 – these schools were run by the Department of Education. The other two schools, Levin Farm and Mental Deficiency Colony (which later became Kimberley Hospital)²²⁶ and Templeton, came under the Mental Hospitals Department.²²⁷ This occurred secondary to Crown-defined, ‘...classifications of “defect” [which then] determined which government department was responsible for each individual’.²²⁸

The Mental Defectives Act 1911 was the first piece of legislation that classified groups of people into specific ‘medicalised’ categories.^{229,230} The education system was key to the consolidation of this structure. The Education Act, in 1914, reinforced the Mental Defectives Act’s provisions and instituted compulsory reporting by parents, teachers and police of ‘mentally defective’ children to the Department of Education.²³¹ In addition to this, a school medical service was established ostensibly to, ‘...identify “defective” children so they could be

Report of Proceedings of the Victoria League Imperial Health Conference, held at the Imperial Institute, London, 18–21 May 1914, 10–11.

²²⁶ Earlier in 1905, it was the Werarora Boys Training Farm, an institution for ‘juvenile delinquents’.

²²⁷ Established in 1908, the Mental Hospital Department became the Mental Hygiene Division of the Department of Health in 1947.

²²⁸ Stace, “Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy”, p.107.

²²⁹ Adrienne Hoult, “Institutional responses to mental deficiency in New Zealand, 1911–1935: Tokanui Mental Hospital,” ((Unpublished Masters thesis). The University of Waikato, 2007), p.21.

²³⁰ The census also classified people with lived experience of disability into categories. This was until 1916, thereafter there was no information collected with regard to disability until 1996. Stace surmises this was due to a reluctance of people to self-identify. Refer to Stace, “Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy.”

²³¹ Education Act 1914.

sent to the appropriate institutions'.²³² However, within a short period of time, the Mental Defectives Act was perceived as lacking by the Crown, in that there was no section within to cover the more,

'...“troublesome individuals” in society...Parliamentarians raised questions about the British category of “moral imbecile” and the possibility of introducing a similar classification in New Zealand as an amendment...'.²³³

Public anxiety at the underlying reasons as to why the large numbers of 'defective' people in the care of the state were still growing, led to the establishment by the Crown of the Committee of Inquiry into Mental Defectives and Sexual Offenders in 1924 (the Committee of Inquiry).²³⁴ The Committee of Inquiry was appointed by the then Minister of Health, Hon Māui Pōmare, and consisted of representatives from across Crown organisations. These were the: Director-General of Medical Services of the Defence Department; Director of the Division of Child Welfare of the Department of Health;²³⁵ Chairman of the Council of the New Zealand Branch of the British Medical Association of New Zealand; Director Division of School Hygiene of the Department of Health; Under-Secretary for Justice and Controller-General of Prisons; and the Officer in Charge of the Special Schools Branch of the Education Department.

'The 1924 Inquiry differed little from the style of eugenics prevalent in Britain, the United States, Canada and Australia of the same period. Following international trends, the testimony before the Inquiry displayed common eugenic anxieties, which centred on a fear of being “swamped” by what was believed to be a large population of “mental defectives” in the country; conveyed displeasure and concern over the differential birth rate between the middle and working classes; that sexual offences were on the rise; and the belief that crime and mental defect were intimately

²³² Stace, “Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy”, p.107.

²³³ Hoult, “Institutional responses to mental deficiency in New Zealand, 1911–1935: Tokanui Mental Hospital”, p.25.

²³⁴ Hoult, “Institutional responses to mental deficiency in New Zealand, 1911–1935: Tokanui Mental Hospital.”

²³⁵ The founder of the Plunket Society, Frederick Truby King, was the Director of the Division of Child Welfare, Department of Health at the time.

connected. The issue of reproduction was the central feature of eugenic fears and propaganda. Throughout the interwar period eugenic anxieties about the deterioration of the “white race”’.²³⁶

The report itself states, ‘...this young Dominion...[is] already reproducing some of the saddest problems of civilization which perplex the people of the Old World’.²³⁷ It goes on to bemoan the pressing issue of people (considered ‘feeble-minded’ by the Committee of Inquiry) as contributing to, ‘...the sum of human misery, an ever-increasing burden on the State, and the serious deterioration of the race’.²³⁸ During 1924, the Committee of Inquiry had,

‘...heard testimony from a range of medical experts and social welfare organizations on the threat of the “unfit” woman to the health of the nation and to the betterment of the white race...the National Council of Women...and the Women’s Christian Temperance Union...the two largest and well-known women’s organizations in the country, stated in evidence that: “Women from the very fact of their maternal functions may either themselves become the resuscitating and repairing element in the race, or else may provide many of the elements of deterioration which are so greatly to be dreaded” ...In short, women’s groups...were complicit in the construction of female deviancy....’^{239,240}

Hamish Spencer highlights that a majority of the, ‘...evidence focused on issues of sterilization and desexualisation (castration), with several medics arguing in favour of such surgical

²³⁶ Wanhalla, “To ‘Better the Breed of Men’: women and eugenics in New Zealand, 1900–1935”, p.169.

²³⁷ Committee of Inquiry into Mental Defectives and Sexual Offenders, *Report of the Committee of Inquiry Appointed by the Hon. Sir Maui Pomare, K.B.E., C.M.G., Minister of Health*, Department of Health, (Wellington: Govt. Printer, 1925). Also refer to Appendix to the Journals of the House of Representatives, 1925, H-31A.

²³⁸ Committee of Inquiry into Mental Defectives and Sexual Offenders, *Report of the Committee of Inquiry Appointed by the Hon. Sir Maui Pomare, K.B.E., C.M.G., Minister of Health*.

²³⁹ Wanhalla, “To ‘Better the Breed of Men’: women and eugenics in New Zealand, 1900–1935”, pp.163–164.

²⁴⁰ Also, refer to evidence of Isabel Howlett before the “Committee of Inquiry into Mental Defectives and Sexual Offenders in New Zealand 1924”, Transcript of Evidence, H 3/13, p. 629 (Archives New Zealand, Wellington, ANZ-W);

solutions; Elizabeth Gunn, the health-camp founder, even advocated a “lethal chamber” for “imbecile children”.²⁴¹²⁴²

Angela Wanhalla points out thus,

‘...the problem was not just that the birth rate was declining but that the quality of those producing future citizens was not considered to be up to the required standards set by the pioneer stock of the country. Most threatening to the nation and empire was the differential birth rate. The [Committee of Inquiry] was of the opinion that the multiplication of the unfit and the restriction of the birth rate among the more “intellectual classes” constituted a menace to the future welfare of New Zealand.

Such statements were common amongst eugenicists and were liberally scattered throughout the report...and contributed to, and reinforced, a perception that the white “race” was under threat of “degeneration”. Describing the falling birth rate as “slaughter”, “wastage of life”, and “ante-natal suicide”, the differential birth rate became a catch cry of eugenicist alarmists’.²⁴³

Having conducted little in the way of robust research to inform their decision making – the research methodology of the Committee of Inquiry was reliant on the study of family trees of a number of people imprisoned and in the asylums,²⁴⁴ the report recommendations also relied heavily on research conducted in Britain and the United States of America.²⁴⁵ The Committee of Inquiry made a number of recommendations which included: a register of ‘afflicted’ people;

²⁴¹ Hamish G Spencer, “Eugenic Sterilization in New Zealand: The Story of the Mental Defectives Amendment Act of 1928.” in *Eugenics at the Edges of Empire: New Zealand, Australia, Canada and South Africa*, eds. Diane B Paul, John Stenhouse and Hamish G Spencer, 85–106. (Switzerland: Palgrave Macmillan, 2018)., p.88.

²⁴² Also refer to Committee of Inquiry into Mental Defectives and Sexual Offenders (transcript of evidence) (R22300642), Archives New Zealand.

²⁴³ Wanhalla, “To ‘Better the Breed of Men’: women and eugenics in New Zealand, 1900–1935”, p.170.

²⁴⁴ Committee of Inquiry into Mental Defectives and Sexual Offenders, *Report of the Committee of Inquiry Appointed by the Hon. Sir Maui Pomare, K.B.E., C.M.G., Minister of Health*.

²⁴⁵ Hoult, “Institutional responses to mental deficiency in New Zealand, 1911–1935: Tokanui Mental Hospital.”

the formation of a Eugenics Board; forced sterilisations at the Eugenics Board's discretion;²⁴⁶ segregation; marriage restriction (through illegalising marriage with anyone on the Eugenics Board's register); and strict immigration regulation. Regarding the forced sterilisation of people, the Committee of Inquiry rationalised this was an 'appropriate action',

'...under proper safeguards and the right of appeal. Sterilization in suitable cases is not a high price to pay for liberty...Sterilization gives the patient liberty to do useful work in the community, is less drastic than segregation for life, and on the whole a much slighter interference with the rights of the individual, which are surely subordinate in such cases to the rights of the State. There are, of course, numbers of mental defectives who can never be allowed their liberty, and in the case of these the question of sterilization need not be considered'.²⁴⁷

The report provides for grim reading with regards to the Crown's ideologies and approaches to maintenance of the colonial 'stock' as the, '...highest type obtainable by human effort'.²⁴⁸ The Committee of Inquiry, stating,

'It has rightly been decided that this should be not only a "white man's country," but as completely British as possible. We ought to make every effort to keep the stock sturdy and strong, as well as racially pure'.²⁴⁹

The Committee of Inquiry also warns the Crown of the potential misfortunes that will befall society if urgent action is not taken, concluding,

'New Zealand is a young country already exhibiting some of the weaknesses of much older nations, but it is now at the stage where, if its people are wise, they may escape

²⁴⁶ Parents or guardians were required to give consent, but consent was not required from the actual person who was to be sterilised by the Crown.

²⁴⁷ Committee of Inquiry into Mental Defectives and Sexual Offenders, *Report of the Committee of Inquiry Appointed by the Hon. Sir Maui Pomare, K.B.E., C.M.G., Minister of Health.*

²⁴⁸ Committee of Inquiry into Mental Defectives and Sexual Offenders, *Report of the Committee of Inquiry Appointed by the Hon. Sir Maui Pomare, K.B.E., C.M.G., Minister of Health.*

²⁴⁹ Committee of Inquiry into Mental Defectives and Sexual Offenders, *Report of the Committee of Inquiry Appointed by the Hon. Sir Maui Pomare, K.B.E., C.M.G., Minister of Health.*

the worst evils of the Old World...Surely our aim should be...to increase the elements of the mental, moral, and physical strength of the nation'.²⁵⁰

Despite the Committee of Inquiry's advocacy for the forced sterilisation of people, the Crown chose segregation as the primary course of action.

'Publication of the report was soon followed by public lobbying for action...Legislative action could be delayed no longer and the Mental Defectives Amendment Bill was soon drawn up...The more contentious clauses included Clause 7, which extended the definition of a "mentally defective person" to include "social defectives"; Clause 11, which established a Eugenics Board; and Clause 15, which compelled the Director of Education to furnish the names of mentally defective children to the Chair of the Eugenics Board. But most of the controversy surrounded Clause 21, which prohibited the marriage of persons registered with the Board, and, especially, Clause 25, which allowed for the Board to authorize sterilization—but not castration—of those registered'.²⁵¹

The eugenics aspects of the Mental Defectives Amendment Bill however, were opposed by Labour, and in particular, by Peter Fraser, who then went on to become the Minister of Health in the first Labour government.²⁵²

'The Labour victory in the 1935 election made [Michael Joseph] Savage Prime Minister and gave [Peter] Fraser the post of Minister of Health. By the time Labour lost government in 1949, eugenics had become politically unpopular. Thus at no time after 1928 did eugenic sterilization ever again have the support of the prime

²⁵⁰ Committee of Inquiry into Mental Defectives and Sexual Offenders, *Report of the Committee of Inquiry Appointed by the Hon. Sir Maui Pomare, K.B.E., C.M.G., Minister of Health*.

²⁵¹ Spencer, "Eugenic Sterilization in New Zealand: The Story of the Mental Defectives Amendment Act of 1928", p.89.

²⁵² Spencer, "Eugenic Sterilization in New Zealand: The Story of the Mental Defectives Amendment Act of 1928".

minister...New Zealand only just failed to pass a eugenic sterilization law. Certainly, the country came much closer to enacting such a law than is generally recognized'.²⁵³

With regards to the eugenics movement, the, '...revelation of the extent of eugenic policies in Nazi Germany (including the death of many thousands of disabled people) dampened overt policy enthusiasm'.²⁵⁴ However, although the movement lost favour, there is little doubt that it heavily influenced Crown approaches taken with regard to the mass institutionalisation of children and adults with lived experience of disability in the decades that followed.

HABILITATE, REHABILITATE, AND THE PRODUCTIVITY OF THE WORKER

The role of industrialisation in the 1800s is highlighted as the contributing factor to both the increasing prevalence of disability and the increasing focus on the productivity and ability of workers. The Economic Model of disability reflects the Crown's approach during this time.²⁵⁵ Certain legislation resulted from this, such as the Workers' Compensation for Accidents Act 1900 enacting pensions for disability with a 'no-fault' principle. The War Pensions Act 1915 can be considered to have evolved from the Workers' Compensation for Accidents Act. Additionally, the,

'...Old Age Pensions Act (1898)...legislated prior to the [Workers' Compensation for Accidents Act]...was an early example of a disability pension if one considers age as an impairment. It was designed to provide for those who, through age-related disabilities, were unable to continue work and is the forerunner to the superannuation pension that exists today'.²⁵⁶

The progression of the nineteenth century saw some groups of people with lived experience of disability, particularly those with visual or hearing impairments, considered to be 'habilitable' (a

²⁵³ Spencer, "Eugenic Sterilization in New Zealand: The Story of the Mental Defectives Amendment Act of 1928", p.97.

²⁵⁴ Stace, "Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy", p.108.

²⁵⁵ Refer to Introduction for discussion of conceptual models of disability.

²⁵⁶ Hickey, "The Unmet Legal, Social and Cultural Needs of Māori with Disabilities.", p.145.

Latin derivative, meaning ‘to make fit’). The Crown viewed such groups as having the potential to be trained as fit, working, and ‘productive’ citizens. This led to the establishment of residential schools. The first of these residential schools for children opened in 1880 (now the Van Asch Deaf Education Centre in Christchurch). Other residential schools included the Jubilee Institute for the Blind (later the Blind Foundation).²⁵⁷

Ivan Prentus Te Momo has discussed the history of the Blind Foundation, and what is known about the experiences of Kāpō Māori within this context.

‘After 1840, when Aotearoa/New Zealand become a British colony, institutions for the disabled (and the sick and insane) were established in Aotearoa/New Zealand which followed British patterns...originally these institutions began with high moral intentions, based on strong Christian beliefs about caring for the disabled. However, many of the institutions eventually fell under the control of authorities who imposed a strict regime, and institutions became prisons for many disabled...Many disabled people who experienced institutional conditions recorded that they were discriminated against and suffered dehumanising treatment...’²⁵⁸

The Association of the Friends of the Blind was established in 1889, followed by the Jubilee Institute for the Blind in 1890. A residential school (the Jubilee Institute) was then set up in Parnell, Auckland and a board of trustees was appointed in 1892.

‘The board of trustees were all male, fully-sighted and Pākehā/European. They were selected because they held influential status in the local community, and their position gave social advantages, which enabled the [Jubilee Institute] to procure funds from government. The trustees were detached from the [Jubilee Institute]: many of them never set foot on its premises or had any contact with its members.

²⁵⁷ Earlier names for the Blind Foundation were the Jubilee Institute for the Blind, the New Zealand Institute for the Blind, the New Zealand Foundation for the Blind, and the Royal New Zealand Foundation for the Blind (the legal entity for the Blind Foundation).

²⁵⁸ Ivan P Te Momo, “From Darkness to Dawn? A Forum for Kāpō Māori.” ((Unpublished Masters thesis). University of Waikato, 2007)., p.28–29.

Astonishingly, some had never known any blind person personally...The board often acted without consulting the [Jubilee Institute's] members...'.²⁵⁹

The authority of these Pākehā male, fully-sighted board members also,

'...extended into the personal lives of the Sight impaired and Blind, so that they had to seek board approval on who they could meet, who they could visit, and who could visit them. At the discretion of the director, the board monitored their relationships, and if they desired to court and get married, the board had to approve. The board of trustees did not look too fondly on those with vision marrying the sight impaired and blind'.²⁶⁰

The reports by Te Momo regarding the scarcity of records of Kāpō Māori experiences prior to the establishment of the Jubilee Institute, aligns with the findings of Tikao et al., regarding the gaps in literature pertaining to the experiences of Kāpō Māori in Te Ao Tawhito.²⁶¹ However, both highlight that Māori with visual impairment were likely to have been embraced within their whānau, and most if not all lived within their communities on marae.

It was John Tigie, the director of the Jubilee Institute for the Blind that, '...negotiated with Māori communities to remove Kāpō Māori from the marae environment. It was also the case that for every Māori...he had admitted...Tigie received funding...'²⁶² having, '...extracted a promise from Sir James Carroll to have £25 per annum paid to the [Jubilee Institute for the Blind] from the Native Department's vote for each Māori admitted...'.²⁶³ Te Momo notes however, that, '...it is possible that people were admitted into institutions simply to increase institution numbers and therefore qualify for additional government funding'.²⁶⁴

²⁵⁹ Te Momo, "From Darkness to Dawn? A Forum for Kāpō Māori", pp.31–32.

²⁶⁰ Te Momo, "From Darkness to Dawn? A Forum for Kāpō Māori", p.32.

²⁶¹ Tikao et al., "Kāpō (blind) Māori in the ancient world."

²⁶² Te Momo, "From Darkness to Dawn? A Forum for Kāpō Māori", p.48.

²⁶³ Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*, p.23.

²⁶⁴ Te Momo, "From Darkness to Dawn? A Forum for Kāpō Māori", p.28–29.

Additionally, the School Attendance Act 1901 and the Education Amendment Act of 1910 meant that education was compulsory for children with visual impairment. Thus, for those, ‘...parents of Kāpō Māori, choice was limited, and the Blind Foundation was the only institution that offered services for Sight Impaired and Blind’.²⁶⁵ Te Momo questions whether the removal of Kāpō Māori from their whānau and communities, even if, ‘...done with the best intentions...was in fact a positive step’,²⁶⁶ stating,

‘...the lives of Kāpō Māori who were removed from the marae were interrupted, and henceforth they would be subject to the rules of the [Jubilee Institute for the Blind], rules based on those which operated at the British School for the Blind. Lifestyle and education of Māori members...thereafter followed a European structure. Kāpō Māori students attended school in the institution, and lived there, totally detached from their families’.²⁶⁷

The formation of Ngāti Kāpō Aotearoa was thus in response to Kāpō Māori experiences of,

‘...marginalisation and discrimination, and they endured a loss of their cultural environment, including language, when they were removed from their homes...Māori heritage was not supported during the early years of the Blind Foundation, and Kāpō Māori endured the same injustices as the general population of Sight Impaired and Blind’.²⁶⁸

In the 1940s, Māori members had proposed the integration of te reo Māori me ona tikanga into school lessons, however their proposal was turned down secondary to the Crown’s focus on the assimilation of Kāpō Māori. Te Momo points to the establishment of Ngāti Kāpō o Aotearoa²⁶⁹ as an autonomous community in 1983 as occurring within the context of the,

²⁶⁵ Te Momo, “From Darkness to Dawn? A Forum for Kāpō Māori”, p.48.

²⁶⁶ Te Momo, “From Darkness to Dawn? A Forum for Kāpō Māori”, p.48.

²⁶⁷ Te Momo, “From Darkness to Dawn? A Forum for Kāpō Māori”, pp.48–49.

²⁶⁸ Te Momo, “From Darkness to Dawn? A Forum for Kāpō Māori”, p.54.

²⁶⁹ In 1991, Ngāti Kāpō became Ngāti Kāpō Aotearoa Incorporation under the Incorporated Societies Act 1908.

‘...final decades of the twentieth century, with the establishment of Kōhanga Reo, Kura Kaupapa schools, the preparation of the Te Reo Māori language [Waitangi Tribunal] claim, and increased Māori national awareness of language and other cultural and political issues, Kāpō Māori themselves acted to form Ngāti Kāpō’.²⁷⁰

From the 1930s onwards

In the early 1930s the Division of Māori Hygiene was disestablished, with responsibility for Māori health incorporated into the core business of the Department of Health. In 1935, the first Labour Government (1935–1949) undertook a substantial reform of the social welfare and health system resulting in the enactment of the Social Security Act 1938. The Labour Government had introduced the ‘invalids’ pension in 1936, and the Social Security Act 1938, ‘...which established a comprehensive modern welfare state funded by general taxation’.²⁷¹ The stated purpose of the Social Security Act was to,

‘...provide for the Payment of Superannuation Benefits and of other Benefits designed to safeguard the People of New Zealand from Disabilities arising from Age, Sickness, Widowhood, Orphanhood, Unemployment, or other Exceptional Conditions; to provide a System whereby Medical and Hospital Treatment will be made available to Persons requiring such Treatment; and, further, to provide such other Benefits as may be necessary to maintain and promote the General Health and Welfare of the Community’.²⁷²

Although considered the foundation of the welfare state,²⁷³ the Social Security Act categorised a number of medical conditions and introduced the terminology of ‘sickness’ as a descriptor for disability. Hickey points out this further emphasised , ‘...medicalisation and the ‘object’ status

²⁷⁰ Te Momo, “From Darkness to Dawn? A Forum for Kāpō Māori”, p.49.

²⁷¹ Jo Barnes and Paul Harris, “Still Kicking? The Royal Commission on Social Policy, 20 Years On.” *Social Policy Journal of New Zealand* (1999): 136-136., no. 37 (2011), <https://www.msd.govt.nz/about-msd-and-our-work/publications-resources/journals-and-magazines/social-policy-journal/spj37/37-still-kicking-the-royal-commission-on-social-policy-20-years-on.html>., p.1

²⁷² Social Security Act 1938.

²⁷³ Stace, “Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy.”

of persons with disabilities in law'.²⁷⁴ Also, despite the intentions of the Social Security Act, a fully-funded universal health and disability system was not achieved because of the independent medical practitioners, the majority of them general practitioners, led by the British Medical Association of New Zealand (now the New Zealand Medical Association)²⁷⁵ who continued to lobby to remain as business owners within the private sector. These independent medical practitioners favoured a user-pays system for patients, with a fee-for-service subsidy from the government. The end result of this was a dual health and disability system with a predominantly public secondary care system, and, a predominantly private primary care system.

The return of large numbers of war veterans from the First World War²⁷⁶ with physical impairments resulting from having fought for the empire, had undermined, to some degree, the eugenics narrative around disability. Their lived experience of disability resulting from having sustained injuries in warfare couldn't be attributed to 'immorality' or 'weak genes' under the eugenics narrative.

'The war had created a new class of disabled people: adult men who were often well educated and who had previously been able-bodied. They had not grown up with disability and with the assumptions of childlike dependency attached to those disabled from birth. The situation in which their disability occurred rendered them the responsibility of the nation. Their wounds were honourable scars signifying sacrifice for the nation, not signs of racial inferiority'.²⁷⁷

This led to the notion of 'rehabilitation' (a Latin derivative meaning 'to restore') and described by the Rehabilitation Model of disability.²⁷⁸ As a consequence, medical rehabilitation for war

²⁷⁴ Hickey, "The Unmet Legal, Social and Cultural Needs of Māori with Disabilities", p.146.

²⁷⁵ Established in Aotearoa/New Zealand in 1887, the British Medical Association of New Zealand became the Medical Association of New Zealand in 1976.

²⁷⁶ Also the previous South African War, though to a lesser extent.

²⁷⁷ Margaret Tennant. *The Fabric of Welfare: Voluntary Organisations, Government and Welfare in New Zealand, 1840–2005*. Bridget Williams Books, 2007., p.99.

²⁷⁸ Refer to Introduction for discussion of conceptual models of disability.

veterans began. The Soldier's Civil Re-establishment League (later Rehabilitation League NZ) was founded in 1930 and was,

'...established with assistance from patriotic and Art Union funds with a belated government contribution of £2000...In 1941 the renamed Disabled Serviceman's Rehabilitation League became a quasi-governmental organisation, its links with government being administrative as well as financial from this time...in 1961 it became more generally responsible for the rehabilitation, training, sheltered employment and placement in work of disabled people. In 1969, the league (known from 1974 as Rehabilitation League NZ) became the official government agency for the assessment and training of disabled people...A decades long transition from voluntary to government agency was largely complete'.²⁷⁹

The two major polio epidemics of 1916 and 1924/25 had led to many people, mostly children, with physical impairments.²⁸⁰ In response to concerns around the lack of health and rehabilitation services, as well as employment opportunities for these children, the New Zealand Crippled Children Society (now CCS Disability Action) was launched in 1935. Founded by Alexander Gillies, an orthopaedic surgeon and Charles Norwood of the Wellington Rotary Club, the New Zealand Crippled Children Society (CCS) was gifted a large property in Takapuna. This became the Wilson Home which provided specialist support for the convalescence and rehabilitation of children with physical impairment, including those with polio and cerebral palsy. Earlier on, there was some evidence of engagement by CCS with Māori, whereby in a 1939 document, CCS refer to the, '...“reluctance of Māori parents to seek advice”, [hoping] that with time and education, existing “prejudices” would diminish'.²⁸¹ Moore and Tennant aptly point out that the onus appeared to be on '...Māori gaining greater understanding of [CCS], not

²⁷⁹ Tennant, *The Fabric of Welfare: Voluntary Organisations, Government and Welfare in New Zealand, 1840–2005*, p.154.

²⁸⁰ Mathilde Schorer reports the estimated number of children affected by polio as five thousand. For example, refer to Mathilde Theresia Maria Schorer, “From the New Zealand Crippled Children Society to CCS Disability Action: A social and political history of a disability organisation in Aotearoa New Zealand moving from charity to social action.” ((Unpublished Masters Thesis). Massey University, 2012).

²⁸¹ Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*, pp.23–24.

on [CCS] understanding Māori reluctance to use its services'.²⁸² Tennant highlights further CCS reports which,

'...[lament] the "deeply rooted indifference" of Māori "to many deformities...which Europeans look upon with horror", and the reluctance of Māori families to relinquish their children for hospital treatment...There was an inquisitorial suggestion that postmen might be utilised to report on untreated Māori cases – a proposal rightly rejected at the CCS annual conference as likely to raise parental objections'.²⁸³

Decades on however, in 1960, CCS did seek Māori representation on their national council and branch committees.²⁸⁴

Māori health developments from the early 1900s onwards had involved numerous voluntary initiatives impacting on the health and well-being of Māori. Many of these were initiated and led by Māori women. This included the work of the Women's Health League. The league was founded by district nurse Robina Cameron, with the support of Te Arawa elders in 1937 who worked with the Department of Health and hospital boards. Further initiatives following World War II included the establishment of Te Ropu Wahine Maori Toko i te Ora (the Maori Women's Welfare League) in 1951. The founding president of whom was Dame Whina Cooper, and founding patron, Te Arika Te Puea Herangi.²⁸⁵ The Department of Māori Affairs provided funding and administrative support whilst,

'...its officers played a major role in setting up branches throughout the country...[however] conference minutes suggested there were early points of tension between the department and the league...its members were to challenge

²⁸² Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*, pp.23–24.

²⁸³ Tennant, *The Fabric of Welfare: Voluntary Organisations, Government and Welfare in New Zealand, 1840–2005*, p.101.

²⁸⁴ Moore and Tennant, *Who is responsible for the provision of support services for people with disabilities? A discussion paper*.

²⁸⁵ Durie, *Whaiora: Māori Health Development*.

assumptions that their organisation existed to do the work of the Māori Affairs Department, but on a voluntary basis.²⁸⁶

In the post-war years the Department of Health and hospital boards were the main disability service providers, along with the Department of Labour which focused on employment placements, and the Department of Social Security which administered financial support.²⁸⁷ The adoption of the Disabled Persons Employment Promotion Act 1960 was a means for organisations to employ people with lived experience of disability in ‘sheltered workshops’. However, this allowed for the exploitation of people as working conditions for employees weren’t protected, and employers were exempted from needing to pay people for the work that they did. After decades of advocacy for change, the Disabled Persons Employment Promotion Act was finally repealed in 2007. Hickey highlights the repeal of the legislation recognised, at long last,

‘...equal participation of persons with disabilities in society and...inclusion as full citizens worthy of equal treatment in law. For persons who identify as living with intellectual/learning impairments, the repeal of the [Disabled Persons Employment Promotion Act was] more significant in that it stop[ped] the exploitation of their labour and [gave] value to their work which [had] often been done without payment’.²⁸⁸

The Workers’ Compensation for Accidents Act over time was considered limited and outdated as it did not cover personal injury. In 1966, a Royal Commission on Compensation for Injury recommended that the Crown provide ‘no-fault’ insurance for all personal injuries. This led to the adoption of the Accident Compensation Act 1972 (the ACC Act) and the establishment of the Accident Compensation Commission (later the Accident Compensation Corporation).

²⁸⁶ Tennant, *The Fabric of Welfare: Voluntary Organisations, Government and Welfare in New Zealand, 1840–2005*, pp.167–168.

²⁸⁷ Tennant, *The Fabric of Welfare: Voluntary Organisations, Government and Welfare in New Zealand, 1840–2005*.

²⁸⁸ Hickey, “The Unmet Legal, Social and Cultural Needs of Māori with Disabilities”, p.152

Numerous criticisms have been made of the ACC Act,²⁸⁹ due to the inequities it creates as a result of differential Crown responses to impairment (depending on the mechanism of impairment – accidental injury vs non-injury-related impairments). Stace points out that it was the Crown parliamentarians, who, having,

‘...served in recent wars and [having] seen terrible injuries [who] supported this no-fault compensation scheme to ensure others would not have to struggle as they or their injured colleagues had. But [the ACC Act] favoured one group: workers injured by accident’.²⁹⁰

In response to criticisms, the Disabled Persons Community Welfare Act 1975²⁹¹ was enacted to provide for financial and other assistance for people with lived experience of disability. However, inequities have persisted as ‘...provisions for people injured by accident are generally far more generous and holistic than those whose similar impairment is not accident-related’.²⁹² In contrast, ‘...invalid benefit recipients [are] significantly disadvantaged compared with the often more financially enriched ACC recipients’.²⁹³

The Health Act 1956 had restructured the public health system into 18 District Health Offices providing for public health, and maternal and child health services, and 29 (locally elected) Hospital Boards that provided for hospitals, and hospital and community services. The Department of Health comprised five divisions. These were the: Division of Public Hygiene; Division of Hospitals; Division of Nursing; Division of Mental Hygiene; and the Division of Dental Hygiene. In 1960, the Board of Health established a Māori Health Committee to provide expert

²⁸⁹ Stace, “Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy”; Hickey, “The Unmet Legal, Social and Cultural Needs of Māori with Disabilities.”

²⁹⁰ Stace, “Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy”, p.111.

²⁹¹ The Disabled Persons Community Welfare Act 1975 also aimed to support organisations and that provided services for people with lived experience of disability, and legislated compliance for the New Zealand Standard building code 4121 which included accessibility guidelines.

²⁹² Stace, “Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy”, p.111–112.

²⁹³ Hickey, “The Unmet Legal, Social and Cultural Needs of Māori with Disabilities”, p.146

advice on Māori health. This was later expanded to include the health of Polynesian people and in 1967 became the Māori and Polynesian Health Committee.

Around 1960, Crown monitoring of Māori had,

‘...put figures to popular perceptions: “Māoris appear in disproportionate numbers in the Court records and their educational achievements (but not their capacity) are below par.” Under sustained fire for ignoring their own party’s policies, Labour ministers were attempting to find more efficient ways and mechanisms for interacting with Māori and solving the problems arising from urban resettlement. Prime Minister Nash, in particular, had become increasingly aware of a general Māori disquiet about, or even hostility to, the Department of Māori Affairs...’²⁹⁴

This resulted in the Department of Māori Affairs-led development of ‘The Hunn Report’²⁹⁵ (as it was referred to), which, although not commissioned by the newly-elected National Government, was released by it soon after Labour lost the election. The report,

‘...a product of Crown assumptions and priorities, did not reflect [Māori] oft expressed aspirations for Crown recognition of rangatiratanga. In urging, instead, a speeding up of official programmes, it sought to provide both the solution to Māori social and economic problems and to “the Māori problem” perceived by the state. Its recommendations aimed to hasten the assumed natural evolutionary path towards the ‘integrationist’ version of assimilation and (ultimately) the “distant end-result” of “final blending”. Efforts to accommodate ways of “seeing and doing” that were different from those of Anglo centric culture were not on any state agenda’.²⁹⁶

What the report did demonstrate however, and for the first time, was a number of trends across socioeconomic and health indicators (for example, land settlement and titles, housing,

²⁹⁴ Richard S Hill, *Māori and the State: Crown-Māori Relations in New Zealand/Aotearoa 1950–2000*. (Wellington: Victoria University Press, 2009), p.87.

²⁹⁵ Jack Kent Hunn, *Report on Department of Maori Affairs: with statistical supplement, 24 August 1960*. (Wellington: Govt. Printer, 1961).

²⁹⁶ Hill, *Māori and the State: Crown-Māori Relations in New Zealand/Aotearoa 1950–2000*, pp.91–92.

education, employment, health, crime amongst others)²⁹⁷ that related to Māori health and well-being. The report had,

‘...led to general public awareness of the adverse socio-economic situation of both urban and rural Māori, and also generated a great deal of debate over proposed efforts to overcome their problems (and problems of society at large). Many pākehā still opposed spending state resources on Māori. In the publicity surrounding the report’s release, and in the extended discussions which followed, the government sought to persuade the pākehā constituency that ‘special measures’ to assist Māori as individuals were legitimate so long as they were geared to assimilative, ‘public good’ ends. Many were seemingly won over to the view that significant socio-economic improvements should and could be achieved within Māoridom, building upon (in Hunn’s assessment) the “quite remarkable strides” taken by Māori in recent decades”.²⁹⁸

Hill points out that, despite the,

‘...relative lack of Māori engagement in the Hunn recommendations, however, in the early 1960s Māori reaction was generally positive. This reflected a number of factors: the Hunn report’s identification of the large socio-economic disparities between Māori and pākehā; its call for action to achieve ‘equality’ between the races by closing these gaps; Hunn’s endorsement of special state measures to assist this aim, and politicians’ willingness to address the matter seriously; the consideration the report gave to at least some Māori views; and Crown willingness to engage in some degree of Māori consultation at the implementation stage of the report...The report’s rapid endorsement ‘in principle’ by the Minister of Māori Affairs on behalf of the Crown gave hope that a bright social and economic future for Māoridom might finally be achievable. report...The report’s rapid endorsement “in principle” by the Minister of

²⁹⁷ Hunn, *Report on Department of Maori Affairs: with statistical supplement*, 24 August 1960.

²⁹⁸ Hill, *Māori and the State: Crown-Māori Relations in New Zealand/Aotearoa 1950–2000*, p.97.

Māori Affairs on behalf of the Crown gave hope that a bright social and economic future for Māoridom might finally be achievable'.²⁹⁹

However, by the middle of 1961, this perception appeared to change.^{300,301} Hill highlights that,

'...second thoughts about official aims were emerging in some quarters as the import of Hunn's message began to sink home. A number of Māori who had benefited from the new educational opportunities in the cities, for example, while welcoming the Hunn report's thrust regarding socio-economic equality for Maori, also saw that it embodied...politics of assimilation'.³⁰²

Hill notes that commentators had observed the '..."deep suspicion" that its endorsement of "integration" was a cover for full assimilation'.³⁰³ The Hunn report's,

'...concessions to Māoriness were increasingly seen to be tokenistic – even, in the eyes of some, to be touristic...[it was criticised for] lacking any interest in Māori culture and for failing to recognise Māori aspirations for rangatiratanga...Some Māori...were already looking sceptically upon the desirability of joining the more materialistic and individualistic way of life of the pākehā. One wrote to the editor of the *Listener* that "the biggest problem for the Māori is not how he can master the European way of life, but trying to decide whether or not it is a way of life worth mastering. And a lot of us are convinced that it isn't"³⁰⁴

In 1974 the Department of Health released the White Paper, *A Health Service for New Zealand* which criticised the dual health system and outlined several proposals. These included: integration of health services that focused on meeting the health needs of communities;

²⁹⁹ Hill, *Māori and the State: Crown-Māori Relations in New Zealand/Aotearoa 1950–2000*, pp.97–98.

³⁰⁰ Hill, *Māori and the State: Crown-Māori Relations in New Zealand/Aotearoa 1950–2000*.

³⁰¹ Māori Synod of the Presbyterian Church of New Zealand, *A Māori view of the "Hunn Report"*, (Christchurch: Presbyterian Church of New Zealand, 1961).

³⁰² Hill, *Māori and the State: Crown-Māori Relations in New Zealand/Aotearoa 1950–2000*, p.98.

³⁰³ Hill, *Māori and the State: Crown-Māori Relations in New Zealand/Aotearoa 1950–2000*, p.98.

³⁰⁴ Hill, *Māori and the State: Crown-Māori Relations in New Zealand/Aotearoa 1950–2000*, pp.98–99.

facilitating a health system whereby access to health services was related to health needs not capacity to pay; and establishing 14 Regional Health Authorities to replace the existing Hospital Boards as a means of achieving this.³⁰⁵ However, in keeping with previous activity around the preservation of medical hegemony,³⁰⁶ there was considerable resistance to the White Paper by the Medical Association of New Zealand³⁰⁷ and other medical interest groups. Medical practitioners, once again, viewed this as a threat to their corporate business model of health and well-being, and the newly-elected National Government in 1975 did not progress the proposals delineated in the White Paper. Instead, the government established a Special Advisory Committee on Health Services Organisation resulting in the health reforms of the 1980s.

Over this period there is no documented evidence that the Crown involved Māori with lived experience of disability in: formal consultation; information gathering, defining and identifying issues; deciding on solutions; or implementing health and disability sector policy. This serves to illustrate that Māori with lived experience of disability have been made invisible by Crown engagement with Māori generally, or when it comes to engagement with health and disability sector interest groups.

DEINSTITUTIONALISATION

Amanda Smith highlights that, in 1928,

‘...the Mental Defectives Amendment Bill, which amended the Mental Defectives Act, allowed for the emergence of institutions primarily for the care of “mentally deficient” children. Institutionalisation was prompted by moves to separate the

³⁰⁵ The intention was for the Regional Health Authorities to be more accountable for public funding, take responsibility for population-based health and psychiatric hospitals that were previously provided for by the Department of Health, as well as improve integration with primary healthcare.

³⁰⁶ For example, refer to earlier discussion around the creation of the dual health and disability system.

³⁰⁷ Medical Association of New Zealand. *An improved health service for New Zealand : submissions by the Medical Association of New Zealand (MANZ) on the 1974 Government White Paper, A health service for New Zealand*. Wellington, 1975.

“mentally ill” from the “mentally deficient”. What followed was the development of a number of psychopaedic institutions in New Zealand...

The purpose of institutions was custodial and intended to meet basic needs whilst relieving the community and families of the burden of caring for their intellectually disabled family members. In many cases admissions were voluntary until the Mental Health Act in 1969 simplified the process of committing patients to mental hospitals...

The Mental Health Act 1969 also supported the strengthening of the medical model, whereby doctors were experts and power holders. Individuals were subjected to a “medical gaze”. Power by clinicians was enacted through the medical assessment, symptoms detection and diagnosis. Many of these “patients”, and in particular people with intellectual disability who were considered to have “problematic behaviour”, were placed in institutions under the Mental Health Act (1969)”.³⁰⁸

The establishment of the Intellectually Handicapped Children’s Parents Association (later IHC) in 1949 signalled the rise of parental advocacy. The founders were parents of a child with Down Syndrome, ‘...who wanted him to have an education and to live at home. At that time children with intellectual impairment were among those least likely to access education, and were often sent to institutional care’.³⁰⁹ The Intellectually Handicapped Children’s Parents Association campaigned for better supports for their children’s education, and for community residential opportunities. This was also recommended by the World Health Organization at the time.³¹⁰ However, the government’s 1953 release of the *Intellectually handicapped children report / report of the Consultative Committee set up by the Hon. the Minister of Education in August 1951*³¹¹ disappointed many, as did not regard best practice of the era outlined by the World

³⁰⁸ Amanda Smith, “Experiences of the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003: A Discourse Analysis.” ((Unpublished Doctoral thesis) AUT University, 2015), pp.48-49.

³⁰⁹ Stace, “Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy”, p.108.

³¹⁰ Julia Millen, *Breaking barriers: IHC’s first 50 years*. (Wellington, N.Z.: IHC New Zealand, 1999).

³¹¹ Consultative Committee on Intellectually Handicapped Children *Intellectually handicapped children report / report of the Consultative Committee set up by the Minister of Education in August 1951*. Department of Education; Wellington, 1953.

Health Organization's recommendations.³¹² Known as the Aitken report (after the committee's chair), Aitkin who was also a doctor, recommended that, '...disabled and mentally ill people be housed in large "mental deficiency colonies" containing several hundred people'.³¹³ The Aitkin report thus recommended that parents leave their children in these institutions from as early as five years of age.

Crown legislative and policy actions to date had thus led to,

'...many people with an intellectual disability [being] housed in public psychiatric or psychopaedic institutions. These large institutions cared for more than 3,000 people nationwide...Once a person with a disability entered an institution it became their "world" with all activities taking place inside its boundaries. For instance, one dormitory at Templeton housed 106 people...who shared clothes and were required to work on the farm or around the institution regardless of their age'.³¹⁴

Māori, who were institutionalised at a very young age, were,

'...completely isolated from their culture and birthright. Some of these people did not speak English on admission, and there was no Māori language spoken in the institution. Most Māori people with a Māori name were given new English names. Experiences of institutionalisation and separation from whānau have had a lasting impact on the people concerned'.³¹⁵

³¹² Millen, *Breaking barriers: IHC's first 50 years.*"; Stace, "Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy."

³¹³ Stace, "Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy", p.109.

³¹⁴ National Advisory Committee on Health and Disability, *To Have an Ordinary Life - Kia Whai Oranga 'Noa': Background Papers to Inform the National Advisory Committee on Health and Disability Information About the Lives of Adults with an Intellectual Disability in New Zealand.* Ministry of Health (Wellington: 2004). [http://www.moh.govt.nz/notebook/nbbooks.nsf/0/01C3D18A8584E882CC257A17000604BE/\\$file/ToHaveOrdLifeBkgrdPapers.pdf](http://www.moh.govt.nz/notebook/nbbooks.nsf/0/01C3D18A8584E882CC257A17000604BE/$file/ToHaveOrdLifeBkgrdPapers.pdf), p.29.

³¹⁵ National Advisory Committee on Health and Disability, *To Have an Ordinary Life - Kia Whai Oranga 'Noa': Background Papers to Inform the National Advisory Committee on Health and Disability Information About the Lives of Adults with an Intellectual Disability in New Zealand*, p.156.

Brigit Mirfin-Veitch and Jennifer Conder’s research into the abuse of people with lived experience of learning/intellectual disability (including Māori children and adults) within Crown institutions detail horrific accounts of sexual, physical abuse, emotional and psychological abuse along with neglect and spiritual abuse. Due to a lack of Crown documentation and record keeping, it is difficult to ascertain the numbers of Māori children and adults who, taken away from their whānau were subjected to years of violence and neglect.³¹⁶

Ken Mason’s 1991 review, *Atawhaitia: The Māori Trustee Report on the Care of Māori under the Protection of Personal and Property Rights Act 1988 and Part X of the Māori Affairs Act 1953* found that Māori were over-represented among those with lived experience of disability within institutional care. Māori comprised 32 per cent of patients in the Tairāwhiti Area Health Board region, 30 per cent at Tokanui Hospital, 21 per cent in the Hawkes Bay Area Health Board region, and 31 per cent in Lake Alice Hospital. Mason’s report recommended that the Māori Trustee play a primary role in ensuring that the health and well-being of Māori who were institutionalised was protected.³¹⁷ However, none of the recommendations made by the report were implemented as policy.³¹⁸

Ratima and Ratima contend that,

‘...[h]istorically, disability support services have not only been unresponsive to Māori – they have been destructive. Services consistently dismissed Māori cultural preferences. Some of the most striking examples relate to the impact of institutionalisation on Māori with intellectual disabilities and their whānau...

One Māori woman related her experience of being taken, as a child, from her ailing koro (grandfather) upon the death of her kuia (grandmother). She had always lived with them, and in those days children with an intellectual disability did not go to

³¹⁶ Brigit Mirfin-Veitch and Jennifer Conder. 2017. *“Institutions are places of abuse”: The Experiences of Disabled Children and Adults in State Care between 1950-1992*. The Donald Beasley Institute (Dunedin). https://www.hrc.co.nz/files/3415/0103/3949/Institutions_are_places_of_abuse_-_The_experiences_of_disabled_children_and_adults_in_State_care_.pdf.

³¹⁷ Ken Mason, *Atawhaitia: The Māori Trustee Report on the Care of Māori under the Protection of Personal and Property Rights Act 1988 and Part X of the Māori Affairs Act 1953*. (Wellington: Māori Trustee, 1991).

³¹⁸ Durie, *Whaiora: Māori Health Development*.

school, so she had spent her days with her kuia whom she described as the centre of her life. The staff in the institution she was placed in spoke no Māori and she spoke no English. Staff promptly renamed her an English name for their convenience. Over the years she was moved from one institution to another and her original notes and files were lost. No-one remembers who she really is. She has lost her identity, and efforts to try and locate family have failed. She has also lost the ability to speak Māori'.³¹⁹

Since the 1940s, the idea of institutionalisation for people with lived experience of disability had been challenged by parents, but also by other groups. A 1959 report by the New Zealand Branch of the British Medical Association rejected the 'out-of-date ideas' of the Aitken report and instead recommended that small residential homes be provided in the community with extra-mural care.³²⁰ In 1972 a Royal Commission of Inquiry into Hospital and Related Services (the Royal Commission) was held. Their report, *Services for the Mentally Handicapped* was published in 1973. The publication of the report occurred despite the fact the Royal Commission had been dissolved by the incoming Labour government. However, by the time it was dissolved, the Royal Commission had obtained sufficient information to be able to comment on psychopaedic services (though not on psychiatric services, which was within the original scope).³²¹

Highlighting that from 1952 to 1972, the numbers in the 'psychopaedic hospitals' had increased from 549 to 2017 people, the report was scathing of the institutionalisation policy of the Crown, stating,

'...we utterly reject the view of the "Aitken Committee" that the majority of mentally handicapped persons should be in large institutions and that parents should be

³¹⁹ Ratima and Ratima, "Māori Experience of Disability and Disability Support Services." In *Hauora: Māori Standards of Health IV. A study of the years 2000–2005*, p.192.

³²⁰ Charles Burns, *The mental deficiency services: an analysis of existing policy and the community's requirements: a report*. (Wellington: British Medical Association. New Zealand Branch. Mental Deficiency Subcommittee, 1959).

³²¹ Royal Commission of Inquiry into Hospital and Related Services, *Services for the Mentally Handicapped*. (Wellington: Royal Commission of Inquiry into Hospital and Related Services, 1973).

encouraged to place them there at the age of 5. We do not accept the view expressed in the 1956 annual report of the (then) Mental Hygiene Division of the Department of Health “By and large it can be said that the intellectually handicapped are happier amongst their own...This can be achieved by residence in colonies much larger in size...It is clear...that economy – of money and staff – has been a factor determining the policy to be followed”.³²²

The Royal Commission was unanimous in its recommendations of transference from large institutions to community care, and for the Crown to increase support for community-based services. This began the process known as ‘deinstitutionalisation’ which continued until the 2000s, where the last institution to close was Kimberly in 2006.³²³ The 1988 *April Report* of the Royal Commission on Social Policy continued to advocate for deinstitutionalisation, and for the ‘normalisation’ of people with lived experience of disability, as members of their communities.³²⁴ However, commentators point out that, what had actually facilitated deinstitutionalisation, was not so much any Royal Commissions of Inquiry, but rather, the fact deinstitutionalisation was, ‘...highly resonant with the then prevalent New Right discourse of reducing the role of the state and the extent of its involvement in both our economy and society’.³²⁵ In which case, ‘...the cynical conclusion could be drawn that deinstitutionalisation was not embraced on moral but on cost-cutting grounds.’³²⁶

Durie refers to the ‘illusion of integration’, criticising the lack of careful and coordinated planning of deinstitutionalisation, with the focus appearing to be on reducing the size of large hospitals through sourcing accommodation in the community instead. Not only was there a lack of appropriate resource allocation, there was no support for providing appropriate services

³²² Royal Commission of Inquiry into Hospital and Related Services, *Services for the Mentally Handicapped*, pp.14–15.

³²³ Stace, “Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy.”

³²⁴ Royal Commission on Social Policy, *The April Report, Volumes I to IV*. (Wellington: New Zealand, 1988).

³²⁵ Jo Barnes and Paul Harris, “Still Kicking? The Royal Commission on Social Policy, 20 Years On.” *Social Policy Journal of New Zealand* 2011. no. 37: 1–13. <https://www.msd.govt.nz/about-msd-and-our-work/publications-resources/journals-and-magazines/social-policy-journal/spj37/37-still-kicking-the-royal-commission-on-social-policy-20-years-on.html>, p.7.

³²⁶ Barnes and Harris, “Still Kicking? The Royal Commission on Social Policy, 20 Years On.”, p.8.

for people in the community, or providing support for whānau.³²⁷ The negative impacts for Māori have been highlighted, where,

‘...the whole-sale discharge of patients into the community... pre-supposed that the community did care and that families were ready and able to pick up where the hospital left off...Nor were resources allocated in a fair manner. Any economic savings by hospitals ignored the fact that the burden of care fell disproportionately on families and community support workers...Far from uniting people...with their communities of origin, the more frequent experience was the creation of an illusion of integration, while retaining barriers based on stigma, discrimination, inadequate social functioning and limited financial means...Missing was any ready recognition that living in the community was by itself an insufficient goal...In that respect, Māori ran the risk of being twice alienated, from community and from culture’.³²⁸

Smith notes that,

‘...the move from institution to community may be viewed as a change in location for service delivery rather than a change in the way that people with intellectual disabilities have been both conceptualised and supported...placement in the community does not equal inclusion in the community as people with intellectual disabilities still experience a high level of marginalisation.’³²⁹

Ratima and Ratima also highlight that,

‘...[at a] philosophical level the change was embraced as a mechanism to enable disabled people to more fully participate in New Zealand society. The implementation, however, was strongly criticised for inadequate planning and

³²⁷ Mason Durie, “Mental health and Māori development,” *Australian and New Zealand Journal of Psychiatry* 33, no. 1 (1999), <https://www.tandfonline.com/doi/abs/10.1046/j.1440-1614.1999.00526.x>.

³²⁸ Durie, “Mental health and Māori development”, pp.7–8.

³²⁹ Smith, “Experiences of the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003: A Discourse Analysis.”, p.13.

resourcing to facilitate a reasonable and supported transition to the community, particularly for those who had been institutionalised for many years'.³³⁰

In addition, Smith points out,

'...[a]nother element of the deinstitutionalisation movement was the enactment of the Mental Health (Compulsory Assessment and Treatment) Act (MH (CAT) Act) 1992. The MH (CAT) Act 1992 replaced the previous MHA 1969. Importantly, the Act made a distinction between the needs of the mental health population and the intellectual disability population.

The Act separated out that which is treatable (mental illness or disorder) from that which is not (intellectual disability). Previously, although in many cases housed in separate locations, people with the above conditions were under the one statute'.³³¹

Other commentators have signalled the emergence of (re)institutionalisation, as an unintended consequence of deinstitutionalisation, secondary to its implementation having been undermined by cost-cutting.³³² For example, Beverley Burrell and Henrietta Trip note that,

'...[t]he emergence of (re)institutionalisation is becoming apparent. Some people with an intellectual disability remain captive in systems that, first, appear focused on fiscal accountability (controlling staff allocations) and then, second, on individuals and their goals, dreams and aspirations in what may be considered closed settings...The issue of the extent to which community-based services resemble institutional care, resulting in a form of re-institutionalisation, must be addressed'.³³³

³³⁰ Ratima and Ratima, "Māori Experience of Disability and Disability Support Services." *In Hauora: Māori Standards of Health IV. A study of the years 2000–2005*, p.193.

³³¹ Smith, "Experiences of the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003: A Discourse Analysis.", pp.51-52.

³³² Beverley Burrell and Henrietta Trip, "Reform and community care: has de-institutionalisation delivered for people with intellectual disability?," *Nursing Inquiry* 18, no. 2 (2011), <https://doi.org/10.1111/j.1440-1800.2011.00522.x>.

³³³ Burrell and Trip, "Reform and community care: has de-institutionalisation delivered for people with intellectual disability?," p.181.

The health reforms of the 1980s

The Area Health Boards Act 1983 established 14 Area Health Boards responsible for the planning and delivery of government-funded health services (including population health and primary care) in their geographically defined area health districts. The role of the Department of Health centred on developing policy, providing advice to the Minister of Health, and providing guidance to the Area Health Boards on their performance monitoring and evaluation. From 1984 the Department of Health allocated funding to each Area Health Board based on a population-based funding formula. The funding was capped. However, the Area Health Boards Act 1983 had made no provisions at all for Māori health (though the Minister of Health did end up appointing Māori members to all the Area Health Boards in 1989, ostensibly as a response to the lack of Māori candidates being voted on the Area Health Boards through local elections). The following year in 1984, a Board of Health Standing Committee on Māori Health was established to provide the Department of Health with Māori health advice.

Williams notes that,

‘...[t]hroughout the early 1980s articulation by Māori of Māori concerns stirred the Department of Health out of the inertia noted by Hunn...Encouraged by the growing attention to the status of Māori health, Māori professionals were at the forefront of representations for greater Māori participation and leadership in social policy. What made the public and politicians really sit up, however, was the 1980 Pōmare Report on Māori health figures from 1955 to 1970’.³³⁴

The report, *Maori Standards of Health: A study of the 20 year period 1955–1975*, though highlighting the reduction in life expectancy gaps for Māori compared with non-Māori, revealed marked health inequities across a range of health indicators, including communicable and non-communicable diseases.³³⁵ Following this, the Maori Women’s Welfare League released the ground-breaking report, *Rapuora: Health and Maori Women* in 1984. Based on community-based research that had been led, developed, and undertaken by Māori women for

³³⁴ Williams, *More Power to Do the Work: Maori and the Health System in the Twentieth Century*, p.28.

³³⁵ Eru W Pōmare, *Maori Standards of Health: A study of the 20 year period 1955–1975*, (Wellington, 1980).

Māori women,³³⁶ the report had far-reaching influence on Māori health research, as well as Māori health development.

Rapuora discussed the holistic aspects of Māori health and well-being as encompassing interrelated elements of physical (*tinana*), mental (*hinengaro*), spiritual (*wairua*) and *whānau*.

‘To say that a person is a psychosomatic unity, a personality formed jointly by physical and mental processes, only partly embraces the Māori concept. A study of Māori health must follow more than two strands. *Tinana* is the physical element of the individual and *hinengaro* the mental state, but these do not make up the whole. *Wairua*, the spirit and *whānau*, the immediate and wider family, complete the shimmering depths of the health *pounamu*, the precious touchstone of Māoridom’^{337,338}

The report made a number of recommendations. For example, that the Departments of Health and Māori Affairs support marae based community health initiatives, and hospital boards be encouraged to use Māori in an advisory, consultative capacity in relation to the delivery of healthcare. Specifically, the report recommended the development of Māori health policy with the following aims:

- ‘1) To promote an holistic view of health encompassing the interrelated physical, mental and spiritual aspects of being.
- 2) To foster a renewed Māori pride in good health with *te rangatahi* as the most important target group.
- 3) To strengthen *whānau* as a *poutokomanawa* of Māori health.

³³⁶ Elizabeth Murchie, *Rapuora: Health and Maori Women*, (Wellington: The Maori Women’s Welfare League, 1984).

³³⁷ Murchie, *Rapuora: Health and Maori Women*, p.81.

³³⁸ Italics in original.

- 4) To attain parity with European New Zealanders in life expectancy and incidence of disease.
- 5) To achieve proportional representation in the health professions.
- 6) To establish a Māori Board of Health which controls a share of health care resources to cater for Māori health needs'.^{339,340}

Rapuora also recommended that, 'Māori organisations plan united action on health under the umbrella of the Minister of Māori Affairs who should be requested to convene such a hui'.³⁴¹ This recommendation led to Hui Whakaoranga held in 1984.

'Hui Whakaoranga was held at Hoani Waititi Marae, Glen Eden, Auckland in 1984 with the theme of promoting a positive view of Māori health. The Hui was sponsored by the Department of Health and the programme was worked out in consultation with the New Zealand Maori Women's Welfare League, the New Zealand Maori Council, the Hoani Waititi Marae Committee and the Departments of Māori Affairs and Education.

The objectives of the Hui Whakaoranga were: 1) To provide an opportunity and forum for organisations and individuals concerned with Māori health to meet, discuss and share ideas, experiences and information related to health matters, 2) To promote a view of the positive aspects of Māori health, 3) To develop a mechanism to plan, co-ordinate, monitor and evaluate intervention programmes related to Māori health'.³⁴²

The hui was planned around various themes including those of *te taha tinana* (physical well-being), *te taha wairua* (spiritual well-being), *te taha hinengaro* (mental well-being) and *te taha*

³³⁹ Murchie, *Rapuora: Health and Maori Women*.

³⁴⁰ Italics in original.

³⁴¹ Murchie, *Rapuora: Health and Maori Women*.

³⁴² Department of Health, *Hui Whakaoranga: Māori Health Planning Workshop – Hoani Waititi Marae 19–22 March 1984*, (Wellington: Department of Health, 1984), p.7.

whānau. A number of the recommendations that arose out of the hui reiterated those of *Rapuora*. The Department of Health report on Hui Whakaoranga stated,

‘...the Department [of Health] has a responsibility to inform Māori people what resources are available and how access to them can be gained. It also involves being a facilitator and co-ordinator, thereby acting in a supportive way to Māori people and Māori health initiatives’.³⁴³

Williams highlights that Hui Whakaoranga,

‘...reaffirmed objectives that would remain constant over the next twenty years. Māori wanted a fairer share of health resources and a say in where they went; they wanted to play a larger and more influential part in the greater effort needed to improve Māori health; they wanted Māori determination of local health needs, which varied widely among different communities, both urban and rural...

In his annual report the Director-General formally confirmed that the hui’s recommendations were part of government policy’.³⁴⁴

Hui Whakaoranga also aligned with the Hui Taumata – Māori Economic Summit Conference (held at Parliament that same year – the objective of which was to launch a decade of Māori development). Following Hui Whakaoranga, the Department of Health identified Māori health as one of its four priorities, and in 1984 created a Māori health project team. However this was disestablished three years later in 1987, along with the Standing Committee on Māori Health in 1988.³⁴⁵

A Ministerial Advisory Committee on Māori Health was appointed in 1989 by the Minister of Health to primarily provide advice to the Minister of Health. It also provided advice to the Department of Health on Māori health policy formulation. The Ministerial Advisory Committee

³⁴³ Department of Health, *Hui Whakaoranga: Māori Health Planning Workshop – Hoani Waititi Marae 19–22 March 1984*, pp.8–9.

³⁴⁴ Williams, *More Power to Do the Work: Maori and the Health System in the Twentieth Century*, pp.30–31.

³⁴⁵ The other nine Board of Health Standing Committees were also disestablished at this time.

on Māori Health also developed policy guidelines for Area Health Boards with regard to supporting Māori participation in the policy, planning and delivery of, health services to area health districts. In 1990, the Māori Health Policy Unit was established in the Department of Health. However, three years later all the staff had resigned. A review at the time into how the Department of Health could meet the Crown's Māori health objectives noted:

'While there was no single reason for the resignations, they cannot be seen as entirely coincidental. A confidential report to the Department in June 1992 had warned that the Māori unit was under-resourced and not universally accepted within the Department, nor always well regarded. It lacked a high profile and was consulted by colleagues on an ad hoc basis'.³⁴⁶

The review recommended, 'urgent, substantial and comprehensive action',³⁴⁷ and as a result a Deputy Director-General of Māori Health was established along with a new Māori Health Directorate, Te Kete Hauora.³⁴⁸

Durie highlights this decade as one that involved a shift in emphasis around Crown objectives for Māori health. The Department of Health had recognised the need for Area Health Boards to foster relationships with local Iwi. This had resulted in appointment by some area health boards of Māori health liaison officers, and community health workers by the end of the decade. It was the health system reforms of the 1990s however, that had considerable impacts on Māori health and disability services, through the devolution of responsibility for delivery of health and disability services to Māori providers.³⁴⁹

³⁴⁶ Hekia Parata and Mason Durie, *Māori Health Review: A Report for the Department of Health on how it can meet the Government's Māori health objectives*. (Wellington: Department of Health, 1993). [http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/44A4176CB3911D3D4C2565D700185E57/\\$file/Maori%20health%20review.pdf](http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/44A4176CB3911D3D4C2565D700185E57/$file/Maori%20health%20review.pdf), p.12.

³⁴⁷ Parata and Durie. *Māori Health Review: A Report for the Department of Health on how it can meet the Government's Māori health objectives*, p.4.

³⁴⁸ Te Kete Hauora was disestablished by the Director-General of Health in 2016.

³⁴⁹ Durie, *Whaiora: Māori Health Development*.

The health reforms of the 1990s

In the early 1990s, the incoming National Government undertook an extensive reform of the health sector. In 1991, the newly-appointed Minister of Health released *Your health and the public health*³⁵⁰ which proposed the new structure for the provision of health services.³⁵¹ The Health and Disability Services Act 1993 was enacted, 'to reform the public funding and provision of health and disability services in order to,' —

- a) Secure for the people of New Zealand—
 - i. The best health; and
 - ii. The best care and support for those in need of services; and
 - iii. The greatest independence for people with disabilities — that is reasonably achievable with the amount of funding provided; and
- b) Facilitate access to personal health services and to disability services; and
- c) Achieve appropriate standards of health and disability services'.³⁵²

Section 8 (e) of the Health and Disability Services Act required the Minister of Health, before entering into a funding agreement with a purchaser, to give written notice of the Crown's objectives in relation to the special needs of Māori and other particular communities or people for those services.³⁵³

³⁵⁰ Simon Upton, *Your health and the public health – summary: A statement of government health policy*. (Wellington: Department of Health, 1991).

³⁵¹ A Health Reforms Group was established in the Department of the Prime Minister and Cabinet to oversee the implementation of the health reforms.

³⁵² Health and Disability Services Act 1993.

³⁵³ Health and Disability Services Act, s.(8)(e).

The health reforms involved:

- separating the purchase and provision of health services and establishment of a competitive health service market approach
- creating the four Regional Health Authorities intended to purchase services from a range of health providers in the competitive health service market
- creating a Public Health Commission intended to purchase services³⁵⁴
- transforming the Area Health Boards into 23 Crown Health Enterprises designed to be managed on a corporate basis
- replacing the Department of Health with a new Ministry of Health
- creating a national advisory committee on health and disability services, and a national ethics committee
- relocating the disability support budget to the new Regional Health Authorities in order to amalgamate the funding and delivery of disability support services which had been previously split between the Department of Health (Vote Health) and the Department of Social Welfare (Vote Social Welfare).

In response to the health reforms and the establishment of a quasi-market environment, there was an intensification in the numbers of providers within the non-government, non-profit sector. These included Māori owned and governed providers, including disability service providers.³⁵⁵

The 1991 Green and White paper, *Your health and the public health*, outlined the vision for the new health sector. It indicated that the health system reforms would generate opportunities

³⁵⁴ The Public Health Commission was disestablished two years following, in 1995.

³⁵⁵ Sue Crengle. "The development of Maori primary care services." *Pacific Health Dialog* 7, no. 1 (2000): 48–53.

for Māori health development. Following this, the Department of Health and Te Puni Kōkiri published the policy statement on Māori health, *Whāia te ora mo te iwi. Strive for the good health of the people*. The statement outlined the Crown's 'legislative and regulatory response to Māori health issues' and set out the Crown's objectives for Māori health.³⁵⁶ The statement also highlighted those government agencies responsible for,

'...ensuring the Government's outcomes for Māori health are pursued. They are the Department of Health which has overall responsibility for advising on health policy; the Public Health Commission which is responsible for promoting the health status of all New Zealanders; and Te Puni Kōkiri (the Ministry of Māori Development) which has a statutory responsibility to promote increases in the levels of achievement attained by Māori with respect to health. Te Puni Kōkiri is also required to liaise with and monitor each department and agency that has a responsibility to provide health services to or for Māori'.³⁵⁷

The Crown's stated objectives for Māori health were to underpin the Public Health Commission's and four Regional Health Authorities' approaches toward the purchasing of health and disability services. The two principal responsibilities to improve health and disability services for Māori were through developing: 1) delivery of services by Māori providers to Māori, and 2) developing culturally appropriate services from 'mainstream' providers.

These were reinforced via the Department of Health's annual policy guidelines to the Regional Health Authorities in 1992. The guidelines '...provided more information about how they would take into account Māori health needs. The guidelines were far more detailed and management-oriented than the 1990 guidelines to [Area Health Boards]'.³⁵⁸

³⁵⁶ Department of Health, *Whāia te ora mo te iwi. Strive for the good health of the people*, Department of Health (Wellington, 1992), p.18.

³⁵⁷ Department of Health, *Whāia te ora mo te iwi. Strive for the good health of the people.*, p.25.

³⁵⁸ Williams, *More power to do the work: Māori and the health system in the twentieth century*, p.50.

Williams observes that,

‘...[p]ut out in 1992 at the same time as the draft health legislation, *Whāia te ora mo te iwi* seemed something of an afterthought, and anecdotal evidence is that it was put together in a rush. It certainly failed to explain how the concepts it promoted would be put into practice. [However] *Whāia te ora mo te iwi* promoted a clear commitment to an important place for Māori in the health sector, placing the responsibility for Māori health progress with the RHAs’.³⁵⁹

Not everyone was enthused however, ‘perhaps because of the way the new approach seemed to consign to oblivion all the work that had gone into the Māori health programmes with the Department of Health and Area Health Boards during the 1980s’.³⁶⁰ Patricia Laing and Eru Pōmare pointed out that the,

‘...dissolution of the area health boards meant that Māori had to reopen their case for special consideration, based on the unsatisfactory state of Māori health and on Treaty obligations, with the more remote and commercially oriented Regional Health Authorities and Crown Health Enterprises. When Māori expressed their unease about the lack of a Treaty clause in the Health and Disability Services Bill, the government gave notice that it did not consider health an Article II issue’.³⁶¹

Williams also reports that during the consultation on the proposed health reforms,

‘Māori working in the government had tried to obtain a more positive acknowledgement of the Treaty in the government’s health policy than that in *Whāia te ora*. There had been rumours that Māori interests were going to challenge the Government regarding the place of health as a taonga under Article II, a position explicitly rejected by [the Minister of Health’s] policy statement...And ever present

³⁵⁹ Williams, *More power to do the work: Māori and the health system in the twentieth century*, p.50.

³⁶⁰ Williams, *More power to do the work: Māori and the health system in the twentieth century*, p.50.

³⁶¹ Laing and Pōmare, “Māori health and the health care reforms”, p.146.

was the underlying suspicion that the government was offloading its responsibilities via the RHAs'.³⁶²

Additionally, Laing and Pōmare criticised the fact that,

'...the idea of holistic health care has been replaced with that of an integrated approach that "must be taken to manage total care for individuals and families and to address the problems arising from current fragmentation of funding". In relation to Māori, the fragmentation that demands a more integrated approach is much more fundamental than simply a question of funding. It relates to attempts to alienate Māori from their indigenous healing system...It relates to the threads that weave people, society and the environment into one fabric. The idea of culturally diverse systems of health care provision has been replaced by the idea of "flexibility in styles of western health care delivery"...Māori believe that unless health is defined in Māori terms, Māori will always have lower health status than the rest of the population'.³⁶³

Ten years on from both Hui Whakaoranga and Hui Taumata, Te Ara Ahu Whakamua, the Māori Health Decade Hui was held in Rotorua in 1994.³⁶⁴ Its purpose was to,

'...lay the foundation for the future direction of Māori health over the next decade. The hui provided a forum at which government agencies were able to meet with Māori health service planners and providers to determine Māori health aspirations for Māori health development in the future and to define their own roles in relation to these developments'.³⁶⁵

³⁶² Williams, *More power to do the work: Māori and the health system in the twentieth century*, p.51.

³⁶³ Laing and Pōmare, "Māori health and the health care reforms", p.151.

³⁶⁴ Te Ara Ahu Whakamua was organised by Te Puni Kōkiri, the Public Health Commission, and the Ministry of Health.

³⁶⁵ Public Health Commission, *He Matariki: A Strategic Plan for Māori Public Health*, (Wellington: Public Health Commission, 1995), p.18.

Te Ara Ahu Whakamua focussed on five questions. These were ^{366,367}: 1)What constitutes a healthy Māori?; 2) How should Māori health be measured?; 3) How can government agencies contribute to Māori health?; 4) What policies should be put in place to achieve healthy Māori?; and 5) What objectives should be set for the year 2000?

With regards to addressing questions 3 and 4, delegates and speakers identified that government agencies could contribute to Māori health by:³⁶⁸

- handing resources over to Māori
- creating a 'level playing field' so that Māori can compete on equal terms
- being accountable for the effectiveness of their programmes for Māori
- listening to Māori and keeping them informed
- employing and involving Māori at all levels
- clearly defining their roles and responsibilities
- working together, avoiding overlap and duplication.

³⁶⁶ Te Puni Kōkiri, *Te Ara Ahu Whakamua: Proceedings of the Māori Health Decade Hui* (Wellington: Te Puni Kōkiri, 1994)., p.6.

³⁶⁷ Public Health Commission, *He Matariki: A Strategic Plan for Māori Public Health*, p.18.

³⁶⁸ Te Puni Kōkiri, *Te Ara Ahu Whakamua: Proceedings of the Māori Health Decade Hui*, p.6.

Delegates and speakers also identified that policies to put in place to achieve healthy Māori are those that:³⁶⁹

- are developed by Māori for Māori
- are based on consultation and good information
- raise the status of te reo and tikanga Māori
- ensure access on an equal basis
- promote the unique qualities and talents of Māori.

Following Te Ara Ahu Whakamua, the Public Health Commission in 1995 published *He Matariki: A Strategic Plan for Māori Public Health*, stating that the,

‘...emphasis on Māori control over Māori health development and a greater role for Iwi/Māori in the purchasing and provision of health services prescribes a role for government agencies which emphasises the need for collaboration and a commitment to relinquishing resources to Māori for Māori health development’.³⁷⁰

In addition, the Public Health Commission highlighted that ‘...few Māori organisations [were] delivering national health services to Māori’,³⁷¹ stating, ‘...nevertheless, many Māori groups wish to be involved in the purchase and provision of public health services’.³⁷² Thus, in response to the ‘significant barriers to health development for Māori’,³⁷³ the Public Health Commission urged for,

³⁶⁹ Te Puni Kōkiri, *Te Ara Ahu Whakamua: Proceedings of the Māori Health Decade Hui*, p.6.

³⁷⁰ Public Health Commission, *He Matariki: A Strategic Plan for Māori Public Health*, p.19.

³⁷¹ Public Health Commission, *He Matariki: A Strategic Plan for Māori Public Health*, p.81.

³⁷² Public Health Commission, *He Matariki: A Strategic Plan for Māori Public Health*, p.81.

³⁷³ Public Health Commission, *He Matariki: A Strategic Plan for Māori Public Health*.

‘...contractual arrangements with Māori providers that recognise the impact of lack of continuity of funding, under-funding, and rigid purchasing criteria on their ability to build and sustain health infrastructures so that Māori have the opportunity to enjoy at least the same level of health status as non-Māori’.³⁷⁴

The health reforms in the early 1990s introduced considerable changes to disability support services (DSS). Proponents of the health reforms had critiqued the provision of DSS as ad hoc and ineffective. For example, the Area Health Boards, the Department of Health and the Department of Social Welfare were all responsible for the planning, funding and delivery of DSS.³⁷⁵ They also made the argument that,

‘...people with multiple disabilities found it difficult to get services for their different kinds of disabilities, as they were channelled through their primary disability. Disabled people were faced with a situation where they were forced to access inappropriate services, as the services were tied with inflexible and complicated funding mechanisms’.³⁷⁶

The health reforms were couched as addressing such issues through the creation of one source of funding, and through offering improved access and choice for clients, secondary to the establishment of a quasi-market at the service-provision level.³⁷⁷ However,

‘...a negative aspect was that disabled people saw this move as placing their services in the domain of vote “health” which traditionally categorised them as “sick”. The reforms could also be viewed...as part of the broader scheme, the aim of which is to dismantle or fundamentally re-design the welfare state in New Zealand. The reform process was seen to have viewed...those on disability support, as objects to be managed more economically...[Also,] service organisations were forced to adopt

³⁷⁴ Public Health Commission, *He Matariki: A Strategic Plan for Māori Public Health*.

³⁷⁵ Jenny Shipley, Minister of Social Welfare and Simon Upton, Minister of Health, *Support for independence for people with disabilities, a new deal. A government statement on the funding and delivery of health and disability services*. (Wellington: Department of Social Welfare and the Department of Health, 1992).

³⁷⁶ Lawrence and Alam, “Disability support services in a liberalised economy – A NZ case study”, p.191.

³⁷⁷ Lawrence and Alam, “Disability support services in a liberalised economy – A NZ case study.”

managerial technologies in order to compete for funding. Little evidence was available about how this might affect the daily lives of the clients'.³⁷⁸

Research examining whether or not DSS had improved following the health reforms found that, although the procedures for assessments did appear to have improved, there was inadequate funding for the provision of DSS to actually meet the needs of the increased numbers of people who were being assessed as a result of the improved procedures.³⁷⁹

'People with disability tend to live in families with below average incomes, and do not seem to have benefited from any prioritisation of government expenditure. The increase in the number of assessments (68 per cent between 1997 and 1998) has not been matched with increased budget allocations (4 per cent). In effect, the amount available per person was virtually halved in one year. This places a great burden on...staff, their clients, and more particularly on the carers who have had to bear the private cost of the transfer of responsibility away from the state. The deinstitutionalisation of people with mental and physical disability was meant to be accompanied by a corresponding increase in support in the community. That support is increasingly expected to come from family or private service providers.'³⁸⁰

The newly elected coalition government in 1996, was also unenthusiastic about the quasi-market model approach and focussed instead on a collaborative one. Also, three of the four established Regional Health Authorities had amassed significant financial deficits. Thus, in 1998, the government merged the four Regional Health Authorities into the Health Funding Authority, whose function was to purchase from, and contract with, a range of health and disability service providers, as well as monitor and evaluate provider performance, and monitor the health needs of the population. The Crown Health Enterprises were restructured into 23 not-for-profit Hospital and Health Services. These entities provided services for their

³⁷⁸ Lawrence and Alam, "Disability support services in a liberalised economy – A NZ case study.", p.192.

³⁷⁹ Lawrence and Alam, "Disability support services in a liberalised economy – A NZ case study."

³⁸⁰ Lawrence and Alam, "Disability support services in a liberalised economy – A NZ case study.", p.204.

populations, contracting with the Health Funding Authority as the purchaser – the focus was no longer on making a surplus.

On the health reforms overall, Williams notes that the,

‘...effect of the reorganisation disruptions or of the policy changes on Māori health and development could only be assessed against some alternative and only over time. Greater Māori involvement and influence in the health sector, in Māori health organisations and autonomous bodies, in participation in the mainstream and through growing political, professional and economic influence, however, were unmistakable through the 1990s. Māori influence in the health system was growing but depended more on operational involvement in health services than on representation at board level in local health bodies’.³⁸¹

Williams also points out however, that,

‘...Māori health and development concerns still remained subordinate to the political beliefs of the wider population...Any autonomy that involved public funding or government-conferred status came with strings attached...[and although, greater] autonomy and improved health were all a part of the same objective for Māori. The Crown, on the other hand, did not see autonomy as a longer-term solution to the place of Māori in New Zealand’.³⁸²

Regarding the impacts on the health reforms specifically on Māori disability providers, the information in the literature is sparse. The National Advisory Committee on Health and Disability highlighted that,

‘...the loss of institutional memory around contracting as a result of continual restructuring of the Ministry of Health. At times it has meant that Māori providers

³⁸¹ Williams, *More Power to Do the Work: Maori and the Health System in the Twentieth Century*, p.85.

³⁸² Williams, *More Power to Do the Work: Maori and the Health System in the Twentieth Century*, p.88.

have had to go back to square one in relationship development with the Ministry of Health...[In addition,] the funding that was once allocated for Māori provider service development is now allocated to all providers of disability services to deliver culturally appropriate services to Māori. This includes those providers who have no Māori clients, whilst existing Māori providers continue to try and strengthen their services under very difficult circumstances’.³⁸³

Ratima and Ratima have also stated that,

‘...Māori development ideology fostered the emergence of a range of Māori-specific health providers across health issues. However, the area of disability support competed alongside the range of other priorities and lacked the strength of advocacy of other areas such as child health and mental health. Relative to other health areas, it seems that Māori development had lesser impact...few Māori disability support services have emerged...and there are indications that disabled Māori may not have had the same access to Māori development initiatives as other Māori’.³⁸⁴

Social and Rights-based Model approaches

Several activities have resulted through the advent of approaches that have been outlined by Social and Rights-based Models of disability.³⁸⁵ These were led by disability advocates and activists, and included: the International Year of the Disabled in 1981, and the founding of the pan-disability organisation, Disabled Persons Assembly NZ in 1983, the Parent to Parent advocacy group for parents of children with lived experience of disability, and that of People First, a consumer group of people with lived experience of learning/intellectual disability in 1987 (initially under the umbrella of IHC, but later becoming independent).

³⁸³ National Advisory Committee on Health and Disability, *To Have an Ordinary Life – Kia Whai Oranga ‘Noa’: Background Papers to Inform the National Advisory Committee on Health and Disability Information About the Lives of Adults with an Intellectual Disability in New Zealand*, p.167.

³⁸⁴ Ratima and Ratima, “Māori Experience of Disability and Disability Support Services.” *In Hauora: Māori Standards of Health IV. A study of the years 2000–2005*, p.193.

³⁸⁵ Refer to Introduction for discussion of conceptual models of disability.

An amendment by the Crown to the Education Act 1989 also established a policy of inclusion, mandating all primary and secondary schools to admit students with lived experience of disability, stating, ‘...people who have special educational needs (whether because of disability or otherwise) have the same rights to enrol and receive education at State schools as people who do not’.³⁸⁶ The amendment to the Education Act resulted in the Crown supporting a dual education system. This consisted of increasing numbers of children with lived experience of disability in primary and secondary schools, but with many others still in segregated environments.

The Crown’s response to the issue of a dual system was the divisive policy of ‘Special Education 2000’. The policy proposed the ‘mainstreaming’ of children with ‘special educational needs’ into schools, and closing all other alternatives. However, proposed resourcing to support the ‘mainstreaming’ of children was considered to be markedly inadequate. This resulted in widespread opposition to the policy from parents.³⁸⁷

In 1993, the Human Rights Act was adopted which prohibited discrimination against people on the grounds of disability.³⁸⁸ However, the Human Rights Commission report, *Human Rights in New Zealand Today/Nga Tika Tangata O Te Motu* highlighted considerable concerns by people with lived experience of disability around the implementation of the Human Rights Act, with regard to the provision for ‘reasonable accommodation’.

‘The failure of society at large to recognise the barriers it creates for disabled people and to actively consider how to accommodate their differences has led to some dissatisfaction with the [Human Rights Act] HRA provision for “reasonable accommodation”. Many of the consultation participants felt it provides a lower level

³⁸⁶ Education Act 1989, s 8 (1).

³⁸⁷ Stace, “Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy.”

³⁸⁸ Human Rights Act 1993.

of rights than for non-disabled people, and mocks the purpose of the Act by providing an easy “escape clause” for non-compliance’.³⁸⁹

Summary

The Crown’s approach to disability issues has been reductionist and ableist, often employing the same strategies of segregation, suppression, and paternalism that characterise the Crown’s approach to Māori. Evidence from the 1840s demonstrates that the evolution of the Crown’s approaches to addressing health and disability issues for Māori has involved purposeful exclusion of Māori from access to hospital and disability services. However, the many activities undertaken by Māori in order to advance Māori health and well-being, although not specifically directed towards disability, will likely have had positive impacts for Māori with lived experience of disability. This is despite having occurred within the context of legislation supporting the Crown’s agenda for assimilation.

Services that have been available to Māori with lived experience of disability have generally been Pākehā-centric, and conflicted with Māori worldviews of health and well-being. Pākehā-centric approaches have also included segregation and removal of Māori with lived experience of disability from their whānau, assimilation of Māori through the suppression of cultural practices, and attempts to institute processes in order to systematically eliminate ‘undesirables’ on the basis of policies underpinned by eugenics ideologies. These ideologies have contributed to the establishment of a series of institutions based on paternalistic and culturally unsafe approaches to the health and well-being needs of Māori with lived experience of disability, causing immeasurable damage for those who have been lost from their whānau, and for those who have been abused whilst in state care.

Crown policy and legislation have, at times, enshrined in law that Māori with lived experience of disability are not full citizens worthy of equal treatment under the law. Crown policy and

³⁸⁹ Human Rights Commission. (2004). *Human rights in New Zealand today: Nga tika tangata o te Motu*. New Zealand: Wellington. p.81.

legislation have also embedded various models of disability such as the Medical Model favoured in the health and disability sector, or the Economic Model within the labour sector. The Crown's imposition of a series of colonial Western models and systems of thought, for example, the Tragedy/Charity, Medical and Rehabilitation models have also undermined Māori holistic worldviews of health and well-being. Policy has also led to, or increased inequities between Māori and non-Māori with lived experience of disability, and between Māori with lived experience of disability, as a result of differential Crown responses to impairment (depending on the mechanism of impairment – accidental injury versus non-injury-related impairments).

Crown approaches have also led to frequent health reforms, which, in part, were politically and/or economically motivated. But they disrupted or prevented progress towards meeting aspirations and needs of Māori with lived experience of disability. Reforms or policy change have often occurred without sufficient resource to effectively implement changes in such a way as to better meet the needs of Māori with lived experience of disability, and there is no documented evidence of effective engagement with Māori with lived experience of disability on the part of the Crown. Initiatives, institutions and processes have frequently been disestablished within a short period of establishment.

Overall, the Crown's approach to Māori health and well-being, and to disability since the 1840s has not acknowledged the rights of Māori to be self-determining. Instead, it has restricted the opportunity for Māori with lived experience of disability to develop, establish, and sustain Māori approaches to supporting health and well-being.

Chapter III – The Contemporary Context

Introduction

This chapter outlines the Crown’s contemporary response (from the 2000s onwards) to the health and well-being of people with lived experience of disability in Aotearoa/New Zealand. A description of Crown approaches to disability is provided, with a primary focus on the Crown’s current disability framework as it pertains to the health and disability sector. Following this, an outline of international human rights instruments and frameworks of relevance to Māori with lived experience of disability in Aotearoa/New Zealand is presented. Of these, the United Nations Convention on the Rights of Persons with Disabilities, the United Nations Convention on the Rights of the Child, and the United Nations Declaration on the Rights of Indigenous Peoples are considered in-depth. A summary of key issues is then presented at the end of the chapter.

The Crown’s disability framework in relation to the health and disability sector

Figure 1 shows an overview of the Crown’s health and disability system. The Crown’s response to the health and well-being of people with lived experience of disability is primarily through a complex, ‘semi-devolved’³⁹⁰ health and disability system. In general, the Crown takes two

³⁹⁰ Ministry of Health, *Briefing to the Incoming Minister of Health, 2017: The New Zealand Health and Disability System*, Ministry of Health (Wellington, 2017), https://www.health.govt.nz/system/files/documents/publications/briefing-to-the-incoming-minister-of-health-2017-the-new-zealand-health-and-disability-system_0.pdf.

approaches to meet the health and well-being needs of people with lived experience of disability:

1. Provision as part of general services: Health services and other system-wide supports are provided to achieve improved health outcomes. These services are provided through a range of organisations such as the 20 district health boards. The expectation of service is (sometimes stated and other times implied) that it will also meet the disability needs of people.
2. Specific disability support services: Providing specific disability supports³⁹¹ to people with lived experience of disability who meet 'eligibility criteria'.

These approaches have evolved over decades³⁹² and are formalised through a range of mechanisms including legislative, strategic, operational, procurement and delivery of services.

These include:

1. Health and disability sector arrangements as set out in legislation, which also establishes roles and functions in the health and disability sector.
2. Guidance and expectations of the health and disability sector, outlined in key strategy documents, most notably, the *New Zealand Disability Strategy*.
3. Regulation and operational policy on the provision of health and disability services by agencies.
4. Procurement and provision of disability support services.

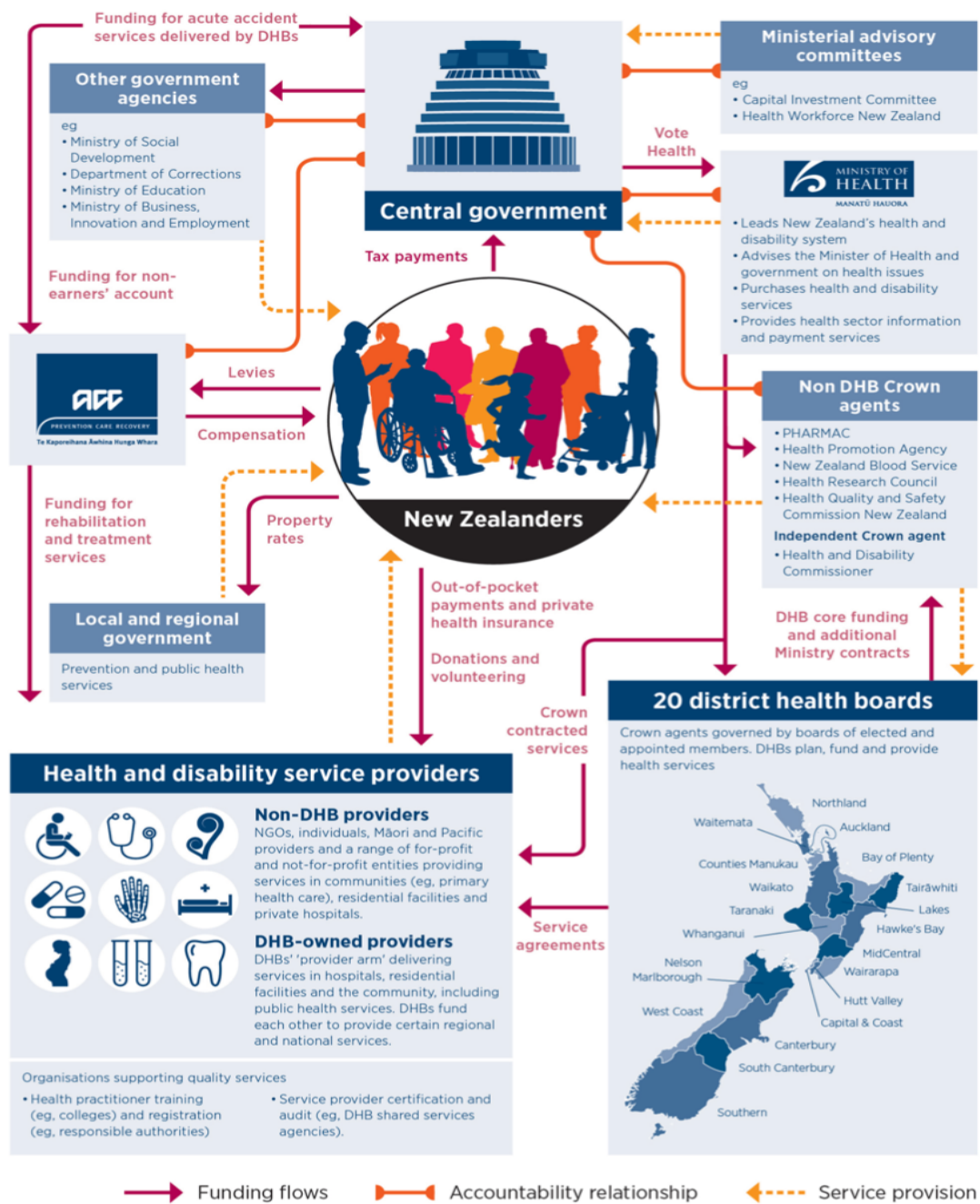
³⁹¹ In the New Zealand Public Health and Disability Act 2000, disability support services are defined as including: 'goods, services, and facilities—

(a) provided to people with disabilities for their care or support or to promote their inclusion and participation in society, and independence; or

(b) provided for purposes related or incidental to the care or support of people with disabilities or to the promotion of the inclusion and participation in society, and independence of such people'.

³⁹² Refer to Chapter II for further discussion.

Figure 1: Overview of the Crown's health and disability system



Source: Ministry of Health³⁹³

³⁹³ Minister of Health, *New Zealand Health Strategy: Future direction*, (Wellington: Ministry of Health, 2016).

Health and disability sector arrangements

The New Zealand Public Health and Disability Act 2000 (the NZPHD Act) is the overarching legislation for the health and disability sector. The purpose of the NZPHD Act is to:

‘...provide for the public funding and provision of personal health services, public health services, and disability support services, and to establish new publicly-owned health and disability organisations...’³⁹⁴

The NZPHD Act also makes explicit that the function of the health and disability sector is to: provide mechanisms for Māori to ‘...contribute to decision-making on, and to participate in the delivery of, health and disability services...[to give effect to] the principles of the Treaty of Waitangi...’³⁹⁵; to ‘...promote the inclusion and participation in society and independence of people with disabilities...’³⁹⁶; and to ‘...reduce disparities by improving health outcomes for Māori...’³⁹⁷

At the time it was enacted, the NZPHD Act provided for the establishment of 21 district health boards (DHBs). Since 2000, two have merged so there are now 20 DHBs. The Ministry of Health (MoH) describes DHBs as administering:

‘...most of the day-to-day business of the [health] system, and nearly three-quarters of the funding. They plan, manage, provide and purchase health services for the population of their district; implement government health and disability policy; and ensure services’³⁹⁸

In practice, this means that DHBs are responsible for delivering the majority of quality health and disability services to their domicile population. As there is also the directive for each DHB,

³⁹⁴ New Zealand Public Health and Disability Act 2000, s3(1).

³⁹⁵ New Zealand Public Health and Disability Act 2000, s.4.

³⁹⁶ New Zealand Public Health and Disability Act 2000, s22(1)(d).

³⁹⁷ New Zealand Public Health and Disability Act 2000, s22(1)(e).

³⁹⁸ Ministry of Health, *Briefing to the Incoming Minister of Health, 2017: The New Zealand Health and Disability System*.

(in both of its funder and provider functions) to, ‘...reduce health disparities by improving health outcomes for Māori’,³⁹⁹ Crown expectations apply both to DHB hospital-level services, and through the services they purchase in the community from a range of entities. For example, primary health organisations (PHOs), private hospital or health services, non-governmental organisations (NGOs), and Māori providers.

District health boards are governed by a board, comprised partially of publicly elected members and those members appointed by the Minister of Health (the Minister). There are expectations that a board will be representative of the local Māori population, and as a minimum, they must have two Māori members.⁴⁰⁰ There are no explicit requirements for people with lived experience of disability to be represented on a board. However, there are implicit requirements under Section 29 of the Crown Entities Act 2004 which requires the Minister of Health to only appoint members with the requisite skillset and experience for the job, and sets the expectation for ‘diversity’ to be promoted.⁴⁰¹ In which case, appointment of board members should in part be based on lived experience of disability. District health boards are also required to have a Disability Support Advisory Committee whose functions are to give the board advice on—

(a) the disability support needs of the resident population of the DHB, and

(b) priorities for use of the disability support funding provided.⁴⁰²

District health boards have a role in providing disability support services – usually limited to services for people aged over 65 years. When it was drafted, the NZPHD Act envisaged devolution of disability support service funding from the MoH to DHBs over time.⁴⁰³ However,

³⁹⁹ Ministry of Health, *Operational Policy Framework 2018/19*, Ministry of Health (Wellington, 2018), <https://nsfl.health.govt.nz/accountability/operational-policy-framework-0/operational-policy-framework-201819.,s3.10.2>.

⁴⁰⁰ New Zealand Public Health and Disability Act 2000, s29(4).

⁴⁰¹ Crown Entities Act 2004, s.29.

⁴⁰² New Zealand Public Health and Disability Act 2000, s4.

⁴⁰³ Alixe Bonardi, *The balance between choice and control: Risk management in New Zealand intellectual disability services*, Eunice Kennedy Shriver Center Publications (Massachusetts, 2009), https://escholarship.umassmed.edu/cgi/viewcontent.cgi?article=1054&context=shriver_pp.

this did not happen in its entirety. Instead, the MoH primarily retained its purchasing role, and currently funds around \$1.2 billion worth of disability support services, generally for those aged under 65 years. Of these, the MoH acknowledges, ‘...many support services are currently set up as “one size fits all” services, and are not appropriately tailored to individuals’ needs’.⁴⁰⁴ The 2002 MoH report *Disability Support Services: Increasing participation and independence* states that,

‘The DSS reforms between 1993 and 1997 led to significant gains in some areas, and far more people received DSS than in the past. However, a high degree of unmet need was highlighted...

In July 2001 the Government decided that: planning and funding for DSS for people aged 65 and over would be separated from that for younger people with disabilities. The proposal to devolve DSS funding and planning for older people to DHBs is dependent on DHBs demonstrating capability to provide an integrated continuum of care for this population group [and] funding and planning for DSS for younger people would remain with the Ministry, pending further analysis of options for meeting their needs, and development of a strategic direction before July 2004’.⁴⁰⁵

The rationale given was the, ‘...[recognition] that disability in older people is generally related to deteriorating health, and that older people’s support needs are closely entwined with their health needs’.⁴⁰⁶ Additionally, the,

‘...decision reflected concern from the disability sector that DHBs would not understand disability issues as they are identified in the [New Zealand Disability

⁴⁰⁴ Ministry of Health, *Briefing to the Incoming Minister of Health, 2017: The New Zealand Health and Disability System*, p.27.

⁴⁰⁵ Ministry of Health, *Disability Support Services: Increasing participation and independence*. (Wellington: Ministry of Health, 2002), pp.4–5.

⁴⁰⁶ Ministry of Health, *Disability Support Services: Increasing participation and independence*, pp.13.

Strategy], and that this could lead to the inappropriate medicalisation of services for [younger people]'.⁴⁰⁷

IMPLICATIONS OF FRAGMENTED SERVICES FOR MĀORI WITH LIVED EXPERIENCE OF DISABILITY

Ratima and Ratima have pointed out the,

'...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. As well, Māori have a shorter life expectancy than non-Māori and therefore fewer Māori survive to old age. The implication is that disability support service funding criteria based on age (e.g., eligibility restricted to those aged 65 years and over) discriminate against Māori and advantage non-Māori due to their longer life expectancy'.⁴⁰⁸

John Fink also highlights that, within the area of cerebro-vascular accidents (or stroke),

'...at a young age [stroke] creates additional burdens on family/whānau and support systems. Earning capacity is lost for patients and, often, carers. Worse still, the fact that funding for and access to rehabilitation services in New Zealand is much more restricted for patients under 65 years of age than those 65 years of age or greater means that there is institutionalised bias against Māori and Pacific Island Stroke patients in our public health system. This requires redress with urgency'.⁴⁰⁹

⁴⁰⁷ Ministry of Health. *Disability Support Services: Increasing participation and independence*. (Wellington: Ministry of Health, 2002), pp.13.

⁴⁰⁸ Ratima and Ratima, "Māori Experience of Disability and Disability Support Services." In *Hauora: Māori Standards of Health IV. A Study of the Years 2000-2005*, p.191.

⁴⁰⁹ John Fink, "Ethnic Trends in Stroke in New Zealand: Closing the Gaps or Widening?" *The New Zealand Medical Journal* 119, no. 1245 (2006): 1–3.
<http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.558.9384&rep=rep1&type=pdf>, p.1.

Research by Andrea Corbett, Karen Francis, and Ysanne Chapman found that,

‘...expectations of Māori are no different than any other ethnic family group experiencing the legacy of [cerebro-vascular accidents (CVA)]. The partners and whānau required information and access to services to assist them to care during hospitalisation and following discharge of the person who had experienced a CVA. The study highlighted the burden imposed on some partners and whānau to provide personal care during the hospitalisation and rehabilitation phases of the illness trajectory.’⁴¹⁰

The authors however, report that,

‘...the scope of supportive community care is limited for this group. Health services that enable Māori who have had a CVA to remain in their own communities are truncated and often withdrawn before Māori have recovered to a stage of achieving minimal independence. Thus increasing demands are made of whānau at a time when their needs for support are also high’.⁴¹¹

It is clear that the MoH were aware that Māori have, ‘...earlier onset of disabling and age-related conditions...One-third of Māori aged 45–64 years reported a disability compared to one-quarter of the total population in this age group’.⁴¹² The MoH also demonstrated consideration of the risks that a split may cause with regard to the,

‘...critical issue [of] clarifying which groups make up “younger people with disabilities” eligible for DSS, and the range of DSS they can access. The current definition of “disability” is outdated...and once DSS funding is split, “age-related” will not be part of the definition. However, some flexibility must be maintained to take account of the

⁴¹⁰ Andrea Corbett, Karen Francis, and Ysanne Chapman, “The Experience of Whānau Caring for Members Disabled from the Effects of a Cerebro-Vascular Accident.” *Contemporary Nurse* 22, no. 2 (2006): 255-63. <https://doi.org/10.5172/conu.2006.22.2.255>, p.261.

⁴¹¹ Corbett, Francis, and Chapman, “The Experience of Whānau Caring for Members Disabled from the Effects of a Cerebro-Vascular Accident.”

⁴¹² Ministry of Health, *Disability Support Services: Increasing participation and independence*, p.2.

needs of groups that may be affected by the new older people/younger people divide, such as:

[1] people with a long-term disability who turn 65 but do not have a disability associated with the ageing process [and]

[2] people under 65 who have health and disability support needs that are similar to those more commonly experienced in old age'.⁴¹³

An earlier Cabinet paper in 2000 had also acknowledged that,

'[Although there] are some good arguments for separately funding DSS that have a weak link to health services. In practice, however, it is difficult to establish a good working definition to do so. Grey areas would make coordination with providers more difficult, and create confusion about who is accountable for which services so that people may fall through cracks'.⁴¹⁴

Regardless, the intended devolution to DHBs did not happen (though it is unclear why). Despite the assertions of the 2002 MoH report (with regard to 'age-related' not being part of any definition in the context of DSS), the MoH currently states,

'The Ministry of Health does not generally fund disability support services for people with...conditions more commonly associated with ageing...'⁴¹⁵

The operational description for the MoH funded DSS client group also states the MoH does not fund DSS for,

⁴¹³ Ministry of Health, *Disability Support Services: Increasing participation and independence*, p.29.

⁴¹⁴ Minister of Health, *Memorandum to Cabinet Social Policy and Health Committee Sector Changes and Disability Support Services Funding Options*. (Wellington, 2000). <https://www.beehive.govt.nz/feature/sector-changes-and-disability-support-services-funding-options-22.>, Accessed 21 June 2019.

⁴¹⁵ Ministry of Health. *Am I eligible for Ministry-funded support services?*. <https://www.health.govt.nz/your-health/services-and-support/disability-services/getting-support-disability/am-i-eligible-ministry-funded-support-services>. Accessed 21 June 2019.

‘...people with conditions or situations covered by other funders including...support for people who first present for assessment for long term supports between ages 50 and 65 who are clinically assessed by a DHB clinician or needs assessor as being “close in interest” to older people...’.⁴¹⁶

The terminology, ‘close in interest to older people [refers to people]...with long-term conditions more commonly experienced by older people and requiring integrated health and disability support services’.⁴¹⁷ The MoH states that,

‘...Cabinet decided to transfer responsibility for some disability groups to DHBs. Funding responsibility for DSS for people with psychiatric disability transferred to DHBs in 2001 and for people with age-related disability in 2003. The latter group included: people who first present for assessment for DSS at age 65 and over, and people aged 50 and 65 who are clinically assessed as “close in interest” to older people (having poorer health and disability status than the general population and conditions/disabilities normally acquired at age 65 or over...

The intent of this decision was to support access to integrated health and support services for people with long-term conditions more commonly experienced by older people...

The following criteria are used to determine whether a person’s support services are funded through a DHB Health of Older People (HOP) funding stream: the person has a disability, which is likely to continue for a minimum of six months and result in the reduction of independent function to the extent that ongoing support is required [and either has] three or more advanced chronic conditions with multiple co-morbidities [or has] a vulnerable state of health arising from a complex interaction of medical and social problems (is “frail”) and requires integrated health and disability

⁴¹⁶ Ministry of Health, *Operational Description Ministry of Health Funded Disability Support Services Client Group*. Ministry of Health (Wellington: Ministry of Health, 2011), p.6.

⁴¹⁷ Ministry of Health, *Operational Description Ministry of Health Funded Disability Support Services Client Group*, p.6.

support services and close health management to ensure health is maintained at an optimal level'.⁴¹⁸

The MoH then goes on to state that people, '...assessed as not meeting these criteria may be able to access support through DHBs' Long-term Supports Chronic Health Conditions funding'.⁴¹⁹

The issue identified is whether the designed fragmentation of an already fragmented system of funding, with no follow-through on full devolution to DHBs, nor evaluation of the impacts of such policy on Māori with lived experience of disability is likely to have contributed to the inequities demonstrated for Māori with lived experience of disability and their whānau carers. It does not appear that considerations of the equity implications for Māori of an age-related split in DSS planning and funding were duly undertaken. With regard to this issue, Ratima and Ratima have aptly pointed out that criteria which, '...make good sense when funding services for non-Māori are not necessarily transferable to Māori if equity is a central goal'.⁴²⁰

OTHER HEALTH CROWN AGENCIES

The NZPHD Act also provides for the following four other health Crown agencies:

- Pharmaceutical Management Agency (PHARMAC)
- New Zealand Blood Service
- Health Quality and Safety Commission
- Health Promotion Agency.

⁴¹⁸ Ministry of Health, *Operational Description Ministry of Health Funded Disability Support Services Client Group*, pp.10–11.

⁴¹⁹ Ministry of Health, *Operational Description Ministry of Health Funded Disability Support Services Client Group*, p.11.

⁴²⁰ Ratima and Ratima. "Māori Experience of Disability and Disability Support Services." In *Hauora: Māori Standards of Health Iv. A Study of the Years 2000-2005*, p.191.

These agencies have minimal guidance via the legislation but do have a focus on meeting population health and disability needs in some way. Of these entities, only the Health Quality & Safety Commission has a statutory objective explicitly relevant to disability support services through leading and coordinating work ‘...across the health and disability sector for the purposes of—

(a) monitoring and improving the quality and safety of health and disability support services; and

(b) helping providers across the health and disability sector to improve the quality and safety of health and disability support services’.⁴²¹

Three other agencies set up under different legislation with health and disability sector functions are relevant to the Crown’s disability framework as it pertains to the health and disability system.⁴²² These are: the Accident Compensation Corporation (ACC), the Health Research Council of New Zealand, and the Health and Disability Commissioner.

- ACC funds a range of services for people who experience injury resulting from an accident.⁴²³
- The Health Research Council of New Zealand was established under the Health Research Council Act 1990 and is the principle government funder of health research.⁴²⁴
- The Health and Disability Commissioner is an independent Crown entity. It is therefore not subject to government policy directions in the same way as other health sector agencies. Its role is to ensure the rights of health and disability service consumers are

⁴²¹ New Zealand Public Health and Disability Act 2000, s59B.

⁴²² Ministry of Health, *Briefing to the Incoming Minister of Health, 2017: The New Zealand Health and Disability System*.

⁴²³ Accident Compensation Act 1972; Accident Compensation Act 2001.

⁴²⁴ Health Research Council Act 1990.

upheld, and does this primarily through resolving complaints and holding providers to account for their practices.⁴²⁵

Other pieces of health legislation relevant to Māori with lived experience of disability include: the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, and the Mental Health (Compulsory Assessment and Treatment) Act 1992. Both are administered by the MoH. The Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 allows for the authorisation of the provision of ‘appropriate options’ for compulsory care and rehabilitation to people with lived experience of a learning/intellectual disability who have been charged with, or convicted of, an imprisonable offence.^{426,427} The MoH describes a number of purposes of the Mental Health (Compulsory Assessment and Treatment) Act 1992 including to:

- define the circumstances in which compulsory assessment and treatment may occur
- ensure that both vulnerable individuals and the public are protected from harm
- ensure that the rights of patients and proposed patients are protected
- ensure that assessment and treatment occur in the least restrictive manner consistent with safety provide a legal framework consistent with good clinical practice, and
- promote accountability for actions taken under the Act.⁴²⁸

⁴²⁵ Health and Disability Commissioner Act 1994; Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996.

⁴²⁶ Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003.

⁴²⁷ Application of the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 creates two categories of care recipient. These are: 1) special care recipients (who must always receive care and rehabilitation in a secure facility) and 2) care recipients who can, depending on their individual circumstances, either receive care and rehabilitation in a secure facility or in a supervised setting. Refer to Ministry of Health, *A Guide to the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003*, Ministry of Health (Wellington, 2004), <https://www.health.govt.nz/system/files/documents/publications/idccrguidelines-intellectualdisability.pdf>.

⁴²⁸ Ministry of Health, *Guidelines to the Mental Health (Compulsory Assessment and Treatment) Act 1992*, (Wellington: Ministry of Health, 2012), <https://www.health.govt.nz/system/files/documents/publications/guide-to-mental-health-act.pdf>, p.1.

The MoH states that the,

‘...[Mental Health (Compulsory Assessment and Treatment)] Act is not a comprehensive framework for mental health treatment. It should instead be thought of as an entry point to services for people experiencing a mental illness which causes or may cause serious harm to themselves or others’.⁴²⁹

The fact that compulsory assessment and treatment is referred to as an entry point to services however, does highlight certain limitations regarding the implementation of preventive care.

Guidance to, and expectations of the health and disability sector

The Minister of Health retains a stewardship role in the health and disability sector, and through the MoH, maintains an overview of the whole system including the regulatory environment, as well as setting policy direction.⁴³⁰ Under the NZPHD Act, the Minister must have a strategy for health services, called ‘the New Zealand health strategy’ which provides a framework for the Government’s overall direction of the health and disability sector.⁴³¹

The second and ‘refreshed’ *New Zealand Health Strategy* (NZHS) was released in 2016 and sets out a series of high-level themes relevant to the future direction of the health and disability sector. The NZHS has less of an explicit focus on Māori health and disability outcomes than the earlier strategy released in 2000. But like its predecessor, the NZHS is guided by a set of principles that include, ‘acknowledging the special relationship between Māori and the Crown under the Treaty of Waitangi’.⁴³²

There is very little reference made to the health and well-being of people with lived experience of disability in the NZHS, but it does note:

⁴²⁹ Ministry of Health, *Guidelines to the Mental Health (Compulsory Assessment and Treatment) Act 1992.*, p.1.

⁴³⁰ Ministry of Health, *Briefing to the Incoming Minister of Health, 2017: The New Zealand Health and Disability System.*

⁴³¹ New Zealand Public Health and Disability Act 2000, s8(1).

⁴³² Minister of Health, *New Zealand Health Strategy: Future direction*, (Wellington: Ministry of Health, 2016).

‘This health strategy provides direction for providing health services for people with disabilities. Many of its themes are also relevant to disability support services that health system organisations fund and provide, and they will inform the updated New Zealand Disability Strategy’.⁴³³

The NZPHD Act also provides for a Minister of the Crown with responsibility for disability issues to determine a strategy for disability support services. Called ‘the New Zealand disability strategy’, it provides the framework for the government’s overall direction of the disability sector in improving disability support services.⁴³⁴ There is also an associate Minister of health with responsibility for disability issues.

THE NEW ZEALAND DISABILITY STRATEGY

The first *New Zealand Disability Strategy* (NZDS) was launched in 2001. Leading up to this, the then new Labour Government had instituted a Minister for Disability Issues in 1999. The Minister for Disability Issues established the Office for Disability Issues in the Ministry of Social Development (previously the Department of Social Welfare). The first NZDS was based on the Social Model of disability. The NZDS outlined 15 objectives, each associated with their own action points.

With respect to Māori with lived experience of disability, Objective 11 stated the NZDS would, ‘promote the involvement of disabled Māori so their culture is understood and recognised’. However, Nikora et al., highlight the, ‘...ambiguous wording...while one can read a reference to Māori culture...it is equally valid to read a reference to the culture of disability...’.⁴³⁵ They go on to state,

‘Indeed, while actions under objective 11 seek to involve Māori in planning services and leadership roles, it is not clear as to whether this means any Māori, or disabled Māori...These aforementioned examples suggest to the reader that the strategy in

⁴³³ Minister of Health, *New Zealand Health Strategy: Future direction*.

⁴³⁴ New Zealand Public Health and Disability Act 2000, s8(2).

⁴³⁵ Nikora et al., *Disabled Maori and Disability Support Options: A Report Prepared for the Ministry of Health*, p.23.

respect to Māori...was either hastily conceived, or simply not well thought through'.⁴³⁶

As with the Minister's NZHS, the NZDS was updated in 2016. Its vision states,

'New Zealand is a non-disabling society — a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen'.⁴³⁷

The current NZDS has eight high-level outcome areas. It identifies that it will be guided by 'the principles of te Tiriti o Waitangi' (adopting principles of participation, partnership and protection), and will guide the activities of government agencies over a 10-year period, in line with its vision. The NZDS usually has an associated disability action plan that sets out priorities across government agencies, approved by a Ministerial Committee on Disability Issues, and agreed to by Cabinet. The most recent disability action plan (2014–18) was due to be updated in 2017 according to the Office for Disability Issues (ODI). The ODI states, '...in this section you can read the full *Disability Action Plan 2014–2018* and previous plans. The plan will be updated in 2017 to align with the new Strategy'.⁴³⁸ However, there have been no further updates to this effect. The Government states that an outcomes framework to monitor the strategy is currently under development.⁴³⁹ However, the progress report as at September 2018 for the *Disability Action Plan 2014–2018* shows that only seven out of the 28 actions were actually completed.⁴⁴⁰

⁴³⁶ Nikora et al., *Disabled Maori and Disability Support Options: A report prepared for the Ministry of Health*, p.24.

⁴³⁷ Office for Disability Issues, *New Zealand Disability Strategy 2016-2026*, Ministry of Social Development (Wellington, 2016).

⁴³⁸ Office for Disability Issues. *New Zealand Disability Strategy*: <https://www.odi.govt.nz/nz-disability-strategy/> Accessed 1 February 2019.

⁴³⁹ New Zealand Government, *The New Zealand Government's response to 'the list of issues prior to submission of the combined second and third periodic review of New Zealand'*, United Nations (New York, 2019), <https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/second-periodic-review/>.

⁴⁴⁰ Office for Disability Issues. *Disability Action Plan 2014–2018 Progress Report September 2018*, (Wellington: Ministry of Social Development, 2018).

<https://www.odi.govt.nz/nz-disability-strategy/disability-action-plan/#Progressreport>.

The implementation of the NZDS and disability action plan is supported by the ODI which describes itself as the, ‘...the focal point within government on disability issues’.⁴⁴¹ The ODI is a small policy team (and is not responsible for service delivery, as an example), housed within the Ministry of Social Development. They also hold the responsibility for coordinating and reporting on the implementation of the United Nations Convention on the Rights of Persons with Disabilities. The ODI has delegated responsibility from the Ministry of Social Development for administering the New Zealand Sign Language Act 2006.⁴⁴²

Whāia Te Ao Mārama – the Māori Disability Action Plan 2018–2022 (a refresh of the Māori Disability Action Plan 2014–2018) describes what the MoH has committed to do to support Māori with lived experience of disability. The action plan also provides examples of actions that disability providers, other organisations, whānau and tāngata whaikaha⁴⁴³ can take.

Whāia Te Ao Mārama aligns with the NZHS, the NZDS, and *He Korowai Oranga* (description in the following section), and its implementation is overseen and monitored by Te Ao Mārama, the Māori disability advisory group.⁴⁴⁴ Te Ao Mārama is made up of experts external to the MoH, including Māori with lived experience of disability, Māori working in the disability sector, and experts in Māori culture.⁴⁴⁵ However, with regard to progress, it appears that the implementation of *Whāia te Ao Mārama* is behind schedule. This could be because *Whāia te Ao Mārama* is not one of the key priority areas in the overall work programme for the Disability Directorate (instead these are: system transformation, funded family care, high and complex bed management, and financial sustainability).

⁴⁴¹ Office for Disability Issues. <https://www.odi.govt.nz/about-us/home/> Accessed 1 February 2019.

⁴⁴² New Zealand Sign Language Act 2006.

⁴⁴³ Refer to Introduction for a further explanation of Māori terms used to describe Māori with lived experience of disability.

⁴⁴⁴ Ministry of Health, *Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan*, Ministry of Health (Wellington: Ministry of Health, 2018), <https://www.health.govt.nz/publication/whaia-te-ao-marama-2018-2022-maori-disability-action-plan>.

⁴⁴⁵ Ministry of Health. Te Ao Mārama Group, <https://www.health.govt.nz/our-work/disability-services/maori-disability-support-services/te-ao-marama-group>. Accessed 1 February 2019.

OTHER RELEVANT STRATEGY AND POLICY

Although not required by any legislation, the Māori health strategy, *He Korowai Oranga* (2014) is intended to guide the Government and the health and disability sector to achieve its aims for Māori. It provides detail on how the aims of the headline health and disability strategies (the NZHS and NZDS), as well as how other specific health sector strategies such as the *Primary Health Care Strategy* (2001), can be achieved for Māori. Its overarching aims are Pae Ora (healthy futures), underpinned by Whānau Ora (healthy families), Wai Ora (healthy environments) and Mauri Ora (healthy individuals). Its framework emphasises that success relies on the Crown working in partnership with Māori.⁴⁴⁶ However, the Māori health strategy does not have an associated action plan, or assigned budget. The MoH has indicated that an action plan is now under development.⁴⁴⁷

There are also a number of specific policy documents that guide health and disability services that have relevance to Māori with lived experience of disability. For example, in respite services,⁴⁴⁸ and prevention and management of the abuse of people who are receiving disability support services funded by the Crown.⁴⁴⁹

The MoH, as part of their stewardship role, also sets annual expectations for health Crown entities⁴⁵⁰ and endorses annual planning guidance. For example, business rules, policy and guideline principles for DHBs are set out in the operational policy framework (OPF).⁴⁵¹ The OPF provides more detail to the legislated obligations of DHBs, including an expectation that DHBs,

⁴⁴⁶ Ministry of Health, *He Korowai Oranga: Māori Health Strategy*.

⁴⁴⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g Ministry of Health.

⁴⁴⁸ Ministry of Health, *Transforming Respite: Disability Support Services Respite Strategy 2017 to 2022*, (Wellington: Ministry of Health, 2017), <https://www.health.govt.nz/publication/transforming-respite-disability-support-services-respite-strategy-2017-2022>.

⁴⁴⁹ Ministry of Health, *The Prevention and Management of Abuse: Guide for services funded by Disability Support Services*, (Wellington: Ministry of Health, 2016), <https://www.health.govt.nz/system/files/documents/publications/prevention-management-abuse-guide-services-funded-dss-nov16.pdf>.

⁴⁵⁰ Hon Dr David Clark, *Letter of Expectations for district health boards and subsidiary entities for 2019/20*, (Wellington: Minister of Health, 2018).

⁴⁵¹ Ministry of Health, *Operational Policy Framework 2018/19*.

‘...implement initiatives to reduce inequalities of service access and provision for Māori with disabilities’.⁴⁵² The annual plan and statement of intent guidelines provide direction for DHBs to be able to meet their minimum legislative and Ministerial obligations. For example, regarding disability, the current guidelines direct DHBs to:⁴⁵³

- Commit to ongoing training for front line staff and clinicians that provide advice and information on what needs to be considered when interacting with a person with a disability, and report on what percentage of staff have completed the training by the end of quarter 4 2019/20.
- Outline in the plan how the DHB collects and manages patient information to ensure DHB staff know which patients have visual, hearing, physical and/or intellectual disabilities.

For the above actions pertaining to disability, there is also an expectation that DHBs demonstrate an equity focus, with clear actions to improve Māori health outcomes.

Current Ministry of Health’s structure

The MoH’s organisational structure (as at October 2018) re-introduced both a disability directorate and a Māori health directorate. Earlier iterations of both directorates – a disability support services directorate and Te Kete Hauora (the Māori health business unit), had been disestablished under previous restructures of the MoH.

In the creation of the disability directorate, the Director-General of Health noted that it would have,

‘...responsibility for providing the oversight of “end-to-end” activities and functions for the disability community. This includes purchasing disability support services for

⁴⁵² Ministry of Health, *Operational Policy Framework 2018/19.*, clause 2.3.6(e).

⁴⁵³ Ministry of Health, *2019/20 Annual Plan and Planning Priorities Guidance: Incorporating the Statement of Intent and Statement of Performance Expectations*, (Wellington: Ministry of Health, 2019), [https://nsfl.health.govt.nz/annual-plan-guidelines-201920.](https://nsfl.health.govt.nz/annual-plan-guidelines-201920), p.32

people with a long-term physical, intellectual and/or sensory impairment that require ongoing Government support to enhance their health and wellbeing, as well as advising on disability policy and ensuring disabled people receive the health care services they need'.⁴⁵⁴

There is no reference to Māori with lived experience of disability in any part of the document on organisational structure. For example, the re-establishment of a Māori health directorate was designed to have,

'...an explicit focus on the Crown's Treaty obligations to protect and improve Māori health outcomes, by providing strategic advice and guidance on Māori health improvement in a collaborative and integrated manner across the Ministry and the sector'.⁴⁵⁵

Of note, 'disability' is absent from this description. It does not appear that Māori with lived experience of disability were explicitly considered in the restructure process, and were not an explicit part of the rationale for the organisational structure. Additionally, Te Ao Mārama were not consulted on the organisational restructure of the MoH.

A number of stated key design principles for the new structure include⁴⁵⁶: clear responsibilities; functional alignment/collaborative operating model; and sector and customer engagement. Despite these principles, the need to have clarity around Māori with lived experience of disability, or to have focus on the way the MoH meets its Treaty of Waitangi obligations for Māori with lived experience of disability, do not appear to have been considered in the decision-making process.

⁴⁵⁴ Ashley Bloomfield, *Delivering on the Ministry's Sector Leadership and Stewardship Roles: Final decision document on changes to the Ministry's second-tier structure*. (Wellington: Ministry of Health, 2018). [https://www.health.govt.nz/about-ministry/leadership-ministry/executive-leadership-team/changes-ministrys-second-tier-structure.](https://www.health.govt.nz/about-ministry/leadership-ministry/executive-leadership-team/changes-ministrys-second-tier-structure), p 10.

⁴⁵⁵ Bloomfield, *Delivering on the Ministry's Sector Leadership and Stewardship Roles: Final decision document on changes to the Ministry's second-tier structure*, p 9.

⁴⁵⁶ Bloomfield, *Delivering on the Ministry's Sector Leadership and Stewardship Roles: Final decision document on changes to the Ministry's second-tier structure*.

Other Crown organisations responsible for health and disability

services

There are a number of Crown organisations that provide or are responsible for delivery of health and disability support services, despite this not being their primary function.⁴⁵⁷

HEALTH AND DISABILITY SUPPORT SERVICES IN PRISONS

Section 75(1) of the Corrections Act 2004 states that a person in prison is, ‘...entitled to receive medical treatment that is reasonably necessary’,⁴⁵⁸ and section 75(2) states that the standard of healthcare available to people in prison, ‘...must be reasonably equivalent to the standard of healthcare available to the public’.⁴⁵⁹ To achieve this, the Department of Corrections provides: primary healthcare services to people in prison (including primary mental health services); dental healthcare (primary acute only); basic emergency care; pharmaceuticals and user charges; and some disability support services.⁴⁶⁰ Other health and disability services are provided through DHBs under a memorandum of understanding (MOU) with the MoH.⁴⁶¹

The MoH (through Vote: Health) funds public health and hospital level services for people in prisons. These include public health and preventive services, and all secondary/tertiary

⁴⁵⁷ The national strategic, funding and service delivery context for disability is determined by governmental departmental roles and responsibilities. The main agencies supporting disabled people within the context of the health and disability sector framework are: the Ministry of Health, district health boards, ACC, the Ministry for Children (through Memoranda of Understanding), and the Department of Corrections (through Memoranda of Understanding).

Other Crown organisations that currently fund disability support services are: the Ministry of Education which funds learning support for people with learning impairments, the Ministry of Social Development which funds income, employment and community participation assistance and supports, the Ministry of Transport, the Housing New Zealand Corporation, the Department of Internal Affairs, the Ministry of Business, Innovation and Employment and Veterans Affairs New Zealand.

⁴⁵⁸ Corrections Act 2004, s 75(1).

⁴⁵⁹ Corrections Act 2004, s 75(2).

⁴⁶⁰ Department of Corrections. Health care. https://www.corrections.govt.nz/working_with_offenders/prison_sentences/being_in_prison/health_care.html, Accessed 1 February 2019.

⁴⁶¹ Ministry of Health and the Department of Corrections, *Memorandum of Understanding between the Ministry of Health and the Department of Corrections*, Ministry of Health and the Department of Corrections (Wellington, 2012).

healthcare services such as specialist mental health; alcohol and drug services; maternity and Well Child Tamariki Ora services; and disability support services. The Department of Corrections also states that people in prison who are eligible for disability support services receive the same level of support as they would in the wider community, funded through local DHB disability support services.⁴⁶² District health boards provide forensic mental health services at a regional level. A quarter of the DHBs (Waitemata, Waikato, Capital & Coast, Canterbury, and Southern) act as hosts for regional mental health services.⁴⁶³ These five DHBs provide care for people with mental illness and/or learning/intellectual disability within the context of the criminal justice system.⁴⁶⁴

HEALTH AND DISABILITY SUPPORT SERVICES IN THE MINISTRY FOR CHILDREN CARE AND PROTECTION AND YOUTH JUSTICE RESIDENCES

As part of its statutory duties and powers, the Ministry for Children provides residential care for children and young people in care and protection and youth justice residences. Prior to 2009, Child, Youth and Family (a former agency of the Ministry of Social Development), led the provision of health and disability support services for children and youth in their residences.⁴⁶⁵ In 2009, changes were made to the planning, responsibility, and delivery of primary healthcare and disability support services to the Child, Youth and Family residential services. An MOU between DHBs with care and protection and/or youth residences in their domicile,⁴⁶⁶ and the Ministry of Social Development was established. The MOU outlined the DHB's responsibility for

⁴⁶² Department of Corrections. Health care. https://www.corrections.govt.nz/working_with_offenders/prison_sentences/being_in_prison/health_care.html, Accessed 1 February 2019.

⁴⁶³ Ministry of Health, Directors of Area Mental Health Services contact list <https://www.health.govt.nz/our-work/mental-health-and-addictions/mental-health/directors-area-mental-health-services-contact-list>., Accessed 1 February 2019.

⁴⁶⁴ These include forensic hospital inpatient hospital services, court liaison teams, community forensic services, assessments and transfer of mentally unwell individuals in prison to secure hospital facilities; and in-reach specialist services (secondary mental healthcare) in prison settings.

⁴⁶⁵ National Health Board Business Unit, *Services for Children and Young People - Health Services for Children and Young People in Child Youth and Family (CYF) Care and Protection and Youth Justice Residences: Tier Level Two Services Specification*, (Wellington: DHBNZ and Ministry of Health, 2011).

⁴⁶⁶ These are: Counties Manukau, MidCentral, Hutt Valley, Canterbury and Southern (previously Otago) district health boards.

the delivery of comprehensive health and disability services for children and young within their domicile.⁴⁶⁷ The DHBs tender contracts to local primary health organisations and other providers.⁴⁶⁸ There is also an MOU between Child, Youth and Family and MoH Disability Support Services for the funding and provision of disability support services to children and young people in care and protection and youth justice residences. Currently there are 13 MOUs between the Ministry for Children and/or the Ministry of Social Development and the MoH and/or DHBs (including the two described, though these specific MOU have not been updated since the dissolution of Child, Youth and Family).⁴⁶⁹

Procurement and provision of disability support services

Disability support services (DSS) are stated to be available to people who have a physical, learning/intellectual or sensory disability (or a combination of these), that is likely to continue for at least six months and, ‘...limits their ability to function independently, to the extent that ongoing support is required’.⁴⁷⁰ As previously discussed, the MoH generally does not fund DSS for personal health conditions, mental health conditions, or conditions more commonly associated with ageing. Nor does the MoH fund services for disability caused by accident or injury as these are funded by ACC.

In order to access DSS, the most common approach is for a person to have a needs assessment through a Needs Assessment and Service Coordination Service (NASC), contracted to the MoH. In addition to carrying out the needs assessment, the NASC reviews eligibility for MoH funded

⁴⁶⁷ National Health Board Business Unit, *Services for Children and Young People - Health Services for Children and Young People in Child Youth and Family (CYF) Care and Protection and Youth Justice Residences: Tier Level Two Services Specification*.

⁴⁶⁸ Paula T. King, *E kore koe e ngaro: Opportunities to improve continuity of primary care for people who are, or have been, imprisoned within the Greater Wellington Region*, (Wellington: Regional Public Health, 2012), <http://www.rph.org.nz/content/fc81418d-c1cc-4f03-b311-32d8b52cc47b.cmr>.

⁴⁶⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 17 Oranga Tamariki Response.

⁴⁷⁰ Ministry of Health, Am I eligible for Ministry-funded support services? <https://www.health.govt.nz/your-health/services-and-support/disability-services/getting-support-disability/am-i-eligible-ministry-funded-support-services>., Accessed 1 February 2019.

support, and outlines the services available.⁴⁷¹ According to the MoH, services include the following:

- Equipment and modifications for people with lived experience of disability (including modifications to home/vehicles and providing equipment on long term loan).⁴⁷²
- Home and community support services (such as household management, for example, meal preparation and personal care such as help with eating).⁴⁷³
- Hearing and vision services (such as hearing aids, cochlear implants, children’s spectacles and contact lenses).^{474, 475}
- Community residential support services to assist people to live in a supported community environment, such as a shared home or groups of small homes or flats.⁴⁷⁶

There is inconsistency however, between the expectations of the legislation, and the prescriptive nature of the purchasing guidelines for DSS procurement. For example, with regard to equipment and modification services, the NZPHD Act states the purpose of the Act to be, ‘...the promotion of the inclusion and participation in society and independence of people with

⁴⁷¹ Ministry of Health, Needs Assessment and Service Coordination services <https://www.health.govt.nz/your-health/services-and-support/disability-services/getting-support-disability/needs-assessment-and-service-coordination-services>., Accessed 1 February 2019.

⁴⁷² Ministry of Health, Equipment and modifications for disabled people. <https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/equipment-and-modifications-disabled-people>., Accessed 1 February 2019.

⁴⁷³ Ministry of Health, Home and Community Support Services. <https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/home-and-community-support-services>., Accessed 1 February 2019.

⁴⁷⁴ Ministry of Health, Hearing and Vision Services. <https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/hearing-and-vision-services>., Accessed 1 February 2019.

⁴⁷⁵ However, this subsidy is only available for children or young people 15 years of age or under, and provided the parent/guardian or child has a valid community services card, or the child or young person has a current high use health card.

⁴⁷⁶ Ministry of Health, Community Residential Support Services. <https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/community-residential-support-services>., Accessed 1 February 2019.

disabilities',⁴⁷⁷ yet the MoH provide strict eligibility access criteria. For example, the provision of equipment for a person who is unable to manage getting around their home, but not to support people getting out and about in their community (for those people who can manage getting around their home).⁴⁷⁸

Table 6 presents expenditure on equipment and modification services (EMS) for Māori and non-Māori by financial year for the period 2014/15 to 2017/18. The table shows that the proportion of Māori utilising EMS services has increased over the period between 2014/15 to 2017/18 (8.9 to 10.2 per cent) but the proportion of expenditure for Māori has actually decreased over the period between 2014/15 to 2017/18 (15.0 to 13.9 per cent).

Table 6: Expenditure on equipment and modification services (EMS) for Māori and non-Māori by financial year for the period 2014/15 to 2017/18 (All figures in NZ dollars \$)

Financial year	2014/15	2015/16	2016/17	2017/18
Number of clients				
Māori	3535	3706	4131	4275
Non-Māori	36007	36191	36822	37729
Total number of clients per year	39542	39897	40953	42004
Proportion of clients (%)				
Māori	8.9	9.3	10.1	10.2
Non-Māori	91.1	90.7	89.9	89.8
Total %	100	100	100	100
Expenditure (\$)				
Māori	\$6312317	\$6317502	\$6615066	\$7851342
Non-Māori	\$35819734	\$36945854	\$41227191	\$48504085

⁴⁷⁷ New Zealand Public Health and Disability Act 2000, s.(3)(1)(a)(ii).

⁴⁷⁸ Ministry of Health, *Equipment and Modification Services: Equipment Manual*, (Wellington: Ministry of Health, 2014). <https://www.health.govt.nz/system/files/documents/pages/equipment-manual-nov2014.pdf>.

Financial year	2014/15	2015/16	2016/17	2017/18
Total \$ expenditure per year	\$6312317	\$6317502	\$6615066	\$7851342
Proportion of expenditure (%)				
Māori	15.0	14.0	13.8	13.9
Non-Māori	85.0	85.4	86.2	86.1
Total %	100	100	100	100

Source: Ministry of Health⁴⁷⁹

MĀORI-OWNED AND MĀORI-GOVERNED PROVIDERS

Disability support services are delivered by a range of providers in the community, including some of the approximately 280 Māori-owned and -governed providers (Māori providers) operating across the country.⁴⁸⁰ Table 7a presents the MoH DSS expenditure by provider category and financial year. The table shows that there are only 33 Māori providers (3.4 per cent) out of a large sector of 980 providers (96.6 per cent). For the 2017/18 year, Māori providers received only 3.9 per cent out of the total DSS expenditure.

Table 7b presents the 33 Māori disability providers by geographic area and range of services. It appears there are Māori providers offering some kind of DSS across most of the country. There are also two providers that are considered by the MoH to be ‘national’ in scope. What this means is not entirely clear, but from the publicly available information on the providers, it appears to mean services may be offered in more than once centre.⁴⁸¹

⁴⁷⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g Ministry of Health.

⁴⁸⁰ The figure of 280 is approximate according to the Ministry of Health. Refer to Ministry of Health, *Funding to Māori Health Providers by the Ministry of Health and District Health Boards 2011/12 to 2015/16*, (Wellington: Ministry of Health, 2017). <https://www.health.govt.nz/system/files/documents/publications/funding-to-maori-health-providersv2.pdf>.

⁴⁸¹ For example, Te Roopu Taurima o Manukau Trust states that it has offices in Auckland, Whangarei, Hamilton and Christchurch. Refer to, Te Roopu Taurima <https://www.terooputaurima.org.nz.>, Accessed 21 June 2019.

From this information, there appear to be no Māori disability providers in the following six DHB areas: Taranaki, Mid-Central, Hutt Valley, Wairarapa, Nelson-Marlborough, and South Canterbury. Additionally, not all geographic regions within a DHB area are covered by Māori disability providers. For example, in the Southern DHB area, a provider offers services in Southland, but it is not clear that services are also available in the Otago district.

It is impossible to say whether the number or range of services Māori disability providers are contracted to provide is appropriate to the level of Māori disability support based on the available information, as the MoH has not provided specific details of the contracts nor the level of funding. As is indicated elsewhere in the report,⁴⁸² it is difficult also to determine the needs of Māori with lived experience of disability by DHB region as, in general, DHBs do not have accurate data for planning and monitoring services. As one DHB states,

‘...[the] DHB does not collect patient data/information specific to a person’s disability or impairment. There is therefore no basis for understanding how well we respond to those with impairment or disability’.⁴⁸³

The MoH did provide funding detail for capacity and capability funding to the providers through the Māori Provider Development Scheme. However, as many of these providers also offer other health services (for example, Ngāti Porou Hauora Charitable Trust which also delivers comprehensive primary healthcare services), there was no way to determine whether this funding was related specifically to the capacity and capability of providers around delivery of DSS.

⁴⁸² Refer to Chapter V for further discussion.

⁴⁸³ Index of supplementary information provided to the researcher under the OIA – Responses from District Health Boards: 11c Northland DHB response.

Table 7a: Ministry of Health Disability Support Services (DSS) expenditure by provider category and financial year
(All figures in NZ dollars \$)

Provider category	No.	%	2013/14	%	2014/15	%	2015/16	%	2016/17	%	2017/18	%
Māori-owned and -governed providers (assessed through the MPDS)	33	3.4	\$48509661	4.5	\$48119599	4.3	\$47617008	4.1	\$47074020	4.1	\$49332004	3.9
All other providers including those that also deliver services to Māori	947	96.6	\$1038256970	95.5	\$1077941719	95.7	\$1119865731	95.9	\$1140913801	95.9	\$1206198058	96.1
Total DSS	980	100	\$1086766631	100	\$1126061318	100	\$1167482739	100	\$1187987821	100	\$1255530062	100

Source: Ministry of Health⁴⁸⁴

⁴⁸⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1za Ministry of Health.

Table 7b: Māori-owned and Māori-governed disability providers by geographic area and range of services⁴⁸⁵

	Māori-owned and Māori-governed disability provider	Geographic area ⁴⁸⁶	Description of services
1	Hokianga Health Enterprise Trust ⁴⁸⁷	Northland	Home and community support
2	Huakina Development Trust	Auckland	Home and community support
3	Huria Trust	Bay of Plenty	Māori disability services
4	Kāpō Māori Aotearoa/New Zealand Ltd	Hastings/ National	Disability information advisory service (DIAS) Specialist kāpō Māori and whānau service
5	Korowai Aroha Health Centre	Lakes & Bay of Plenty	Home and community support
6	Kotuku Trust	Auckland	Community residential support
7	Ngā Kete Maturanga Pounamu Charitable Trust	Southland	Disability information advisory service (DIAS)
8	Ngāti Hine Health Trust	Northland	Community residential support Home and community support

⁴⁸⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1za Ministry of Health.

⁴⁸⁶ The information provided by the Ministry of Health sometimes refers to a specific town or city area and sometimes refers to a wider DHB district (or districts). The information was cross referenced with information available on provider or DHB websites where available and any inconsistencies are noted in footnotes. It is not deemed an inconsistency, for example, if a provider delivers services in Counties Manukau DHB but the table refers to the Auckland region generally.

⁴⁸⁷ Although acknowledged by the Ministry of Health and Northland DHB as a Māori provider, and self identifying as such, the provider's website also notes that the '...Trust is an organisation owned and governed by Māori (but not exclusively Māori)...'. Hokianga Health, <http://www.hokiangahealth.org.nz/HHET2017/base2.php?page=home.>, Accessed 21 June 2019.

Māori-owned and Māori-governed disability provider		Geographic area ⁴⁸⁶	Description of services
9	Ngāti Porou Hauora Charitable Trust	Tairāwhiti	Home and community support Māori disability services (DIAS) Community residential support Supported living
10	Poutini Waioara	West Coast	Community day services
11	Rakeiwhenua Trust	Taneatua	Māori disability services (DIAS)
12	Raukawa Charitable Trust Board	Tokoroa ⁴⁸⁸	Māori disability services (DIAS)
13	Raukura Hauora o Tainui Trust	Hamilton	Māori disability services (DIAS)
14	Taikura Trust	Auckland	Needs assessment and service coordination
15	Taumarunui Community Kokiri Enterprises Limited	Taumarunui	Community residential support
16	Te Hauora o Te Hiku o Te Ika Trust	Northland	Home and community support
17	Te Hauora O Tauranganui A Kiwa Limited	Tairāwhiti	Community day services Home and community support
18	Te Kohao Health Limited	Hamilton	Home and community support
19	Te Korowai Hauora o Hauraki Incorporated	Hamilton ⁴⁸⁹	Home and community support Māori disability services (DIAS)

⁴⁸⁸ Services are also provided in Putaruru, Tirau, Matamata, Cambridge and Te Awamutu. Raukawa Charitable Trust. Māori Disability Service, <https://www.raukawa.org.nz/rct/health-and-social-development-unit/maori-disability-service/>, Accessed 21 June 2019.

⁴⁸⁹ Although the Ministry of Health information states that Te Korowai Hauora o Hauraki Incorporated provides services with a focus on Hamilton, the provider's website indicates that its services are not provided in Hamilton, and instead the provider has offices in Thames (head office), Paeroa, Te Aroha,

	Māori-owned and Māori-governed disability provider	Geographic area⁴⁸⁶	Description of services
20	Te Oranganui Trust Incorporated	Whanganui	Home and community support Supported living Māori disability services (DIAS) Community residential support
21	Te Puna Ora o Mataatua Charitable Trust	Lakes & Bay of Plenty	Home and community support
22	Te Roopu Manaaki I Te Hunga Hauā Incorporated	Lakes & Bay of Plenty	Community residential support
23	Te Roopu Taurima o Manukau Trust	National	Community residential support Choices in community living Community day services Regional supported accommodation services
24	Te Rūnanga o Ngati Whātua	Northland & Auckland	Home and community support
25	Te Rūnanga o Toa Rangatira Incorporated	Capital & Coast	Community day services
26	Te Tai O Marokura Charitable Trust	Canterbury	Community support Māori disability service
27	Te Taiwhenua o Heretaunga Trust	Hawke's Bay	Home and community support
28	Te Tomika Trust	Lakes & Bay of Plenty	Community residential support Community day services

Coromandel and Whitianga. Te Korowai Hauora o Hauraki, http://www.korowai.co.nz/kaumtua_services/disability_advisory_information_services_dias., Accessed 21 June 2019.

	Māori-owned and Māori-governed disability provider	Geographic area ⁴⁸⁶	Description of services
29	Te Whanau Tokotokorangi Charitable Trust	Lakes & Bay of Plenty	Community residential support Community day services Māori disability services (DIAS)
30	The Ngati Maniapoto Marae Pact Trust Incorporated	Waikato	Māori disability services (DIAS)
31	Tui Ora Limited	Taranaki	Māori disability services (DIAS)
32	Tuwharetoa Health Charitable Trust	Lakes & Bay of Plenty	Home and community support Community day services Māori disability services (DIAS)
33	Whaioranga Trust	Lakes & Bay of Plenty	Home and community support

Source: Ministry of Health⁴⁹⁰

Almost 25 years ago, in a report commissioned by the National Advisory Committee on Core Health and Disability Support Services, Ratima et al., advised,

‘In the immediate future the majority of Māori users of disability support services will remain users of mainstream service options. It is therefore essential that mainstream services incorporate Māori perspectives and understandings...

However, culturally appropriate mainstream services alone will be insufficient to meet Māori needs. A significant proportion of Māori people with disabilities will only feel comfortable, and will achieve better outcomes, with services which operate within a Māori cultural context. This gap would be best filled by services funded especially to meet Māori needs. Māori specific providers are more likely

⁴⁹⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1za Ministry of Health.

to be viewed by the Māori community as user friendly, maintain strong links with Māori institutions, have access to informal Māori networks, and be conversant in tikanga Māori and Te reo Māori'.⁴⁹¹

The National Advisory Committee on Health and Disability in 2004 also highlighted that the,

'...emergence of Māori disability support service providers is providing a focus, and at times a voice, for Māori with disabilities. It also enables the further development and implementation of kaupapa Māori service models to assist in meeting the needs of Māori with disabilities in a holistic way. Māori service providers are increasing, and in some cases upskilling, the non-Māori disability support service workforce. It also encourages the development of a culturally effective information dissemination service for Māori with disabilities and their families'.⁴⁹²

It appears however, that almost 25 years on from the advice of Ratima et al., Māori with lived experience of disability have few options when it comes to accessing disability support services provided by Māori. The information shows there are potentially only 33 providers nationwide, and geographically there are a number of areas where they are not available. Thus, Māori with lived experience of disability are still likely to be using mainstream services potentially through lack of other options. Yet, Ratima et al., found that when Māori with lived experience of disability were asked,

'...whether aspects of tikanga Māori should be part of disability support services the overwhelming response was affirmative. Respondents felt the use of te reo,

⁴⁹¹ Mihi M Ratima, Mason H Durie, GR Allan, PS Morrison, A Gillies, and John A Waldon. *He Anga Whakamana: A Framework for the Delivery of Disability Support Services for Māori*. (Palmerston North: Te Pūmanawa Hauora, Massey University, 1995).
<http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/37D7A973746694CF4C2565D700185D8B?opendocument>, p.48.

⁴⁹² National Advisory Committee on Health and Disability, *To Have an Ordinary Life – Kia Whai Oranga 'Noa': Background Papers to Inform the National Advisory Committee on Health and Disability Information About the Lives of Adults with an Intellectual Disability in New Zealand*, p.167.

waiata, karakia, marae based services, and trained staff to assist Māori disabled to learn Māori language were particularly necessary in disability support services. Other consumers preferred the inclusion of all aspects of tikanga Māori. In particular, respondents agreed that Māori are most comfortable with Māori staff who understand Māori ways and te reo Māori'.⁴⁹³

Research by Nikora et al., also found that overall, Māori with lived experience of disability and their whānau carers were, '...dissatisfied, or barely satisfied, with the mainstream services provided. Given the options, most would prefer a Māori provider'.⁴⁹⁴ The authors reported Māori with lived experience of disability and their whānau carers as being,

'...critical of mainstream and support services. They reported a desperate need for Māori appropriate service providers who were responsive to the needs of whānau. With regard mainstream organisations, they commented on the lack of Māori staff to engage with.

In addition, whānau carers sometimes felt as if they were being made to feel guilty for asking for assistance. And when they failed to obtain assistance whanau carers often felt as if it was their own fault and that they were inadequate. Racism, a sense of powerlessness, a lack of control, starting on the back foot, a lack of visibility are how [they] characterised interactions with providers'.⁴⁹⁵

Additionally, Jansen, Bacal, and Crengle reported barriers to services for Māori with lived experience of disability which included, '...negative or racist health provider attitudes toward Māori, and being talked 'down to' or treated with disrespect by staff'.⁴⁹⁶ The

⁴⁹³ Ratima et al., *He Anga Whakamana: A Framework for the Delivery of Disability Support Services for Māori*, p.21.

⁴⁹⁴ Nikora et al., *Disabled Maori and Disability Support Options: A Report Prepared for the Ministry of Health*, p.47.

⁴⁹⁵ Nikora et al., *Disabled Maori and Disability Support Options: A Report Prepared for the Ministry of Health*, pp.58–59.

⁴⁹⁶ Jansen, Bacal, and Crengle, *He Ritenga Whakaaro: Māori Experiences of Health Services*, p.9.

authors also found that, in general, health and disability services, ‘...do not provide the same quality or level of care to Māori as to non-Māori, in part because of different cultural mores. Māori participants reported that providers lacked respect and understanding and did not listen to them’.⁴⁹⁷

Research by Higgins et al., around experiences of Kāpō Māori tamariki and their whānau report that,

‘...many whānau talked about their experiences of being stereotyped by professionals. Disabling, racist and gendered stereotyping limited the possibilities for some whānau and their children. For example, one whānau had dealings with a geneticist, who was keen to trace their child’s condition through their whakapapa. This whānau found the experience insulting and highlighted their experience of racist stereotyping. One mother found that the services that she received for her son was different to a Pākehā friend’s family. She also recounted how she felt that she was discriminated against on the basis of being both Māori and a single mother’.⁴⁹⁸

The National Advisory Committee on Health and Disability also found that, for Māori with learning/intellectual disability, there was consensus that,

‘...non-Māori service providers were not providing a culturally appropriate service...They expressed the view that a Māori provider should be the first choice for the facilitation of kaupapa Māori processes for a disabled Māori, enabling

⁴⁹⁷ Jansen, Bacal, and Crengle, *He Ritenga Whakaaro: Māori Experiences of Health Services*, p.58.

⁴⁹⁸ Nancy Higgins, Hazel Phillips, Karen Stobbs, Graham Wilson, and Hannah Pascoe, *Summary of the Findings - Growing up Kāpō Māori: Accessing Paediatric Ophthalmology Services*, (Hastings: Ngāti Kāpo O Aotearoa Inc., 2012)., pp.10–11.

them and their whānau to make informed decisions about their future options and choices'.⁴⁹⁹

Additionally, researchers examining the accessibility of health and disability providers for Māori with lived experience of disability in the Murihiku/Southland region found that,

'Many organisations appeared not to fully understand their Treaty of Waitangi obligations: There appeared to be a misunderstanding between a non-racial, human rights approach of respect for all people, no matter the ethnicity, and the concept of the importance of tikaka Māori practice for services provided for Māori.

Māori attendance at most organisations was generally less than 5% and 72% of organisations employed less than 5% Māori staff (although 8 (28%) organisations were sole practices). Although most organisations said they would ask their clients what approach to health care they preferred, it was not clear they could actually accommodate a client's wish for a more holistic, Māori-focussed approach to health. Many described offering to refer the client to a local Māori health provider if necessary...

For both Māori and government organisations interviewed, tikaka Māori practice was explicit. These values were integral to practice and the concept of Whānau Ora was well understood and observed by these organisations. The understanding of the concept of "Whānau Ora" amongst other organisations was poor; few of these organisations were able to fully articulate its meaning'.⁵⁰⁰

⁴⁹⁹ National Advisory Committee on Health and Disability, *To Have an Ordinary Life – Kia Whai Oranga 'Noa': Background Papers to Inform the National Advisory Committee on Health and Disability Information About the Lives of Adults with an Intellectual Disability in New Zealand*, p.164–165.

⁵⁰⁰ The Centre for Health, Activity, and Rehabilitation Research, *Hauā Mana Māori: Living Unique and Enriched Lives - a Report for the Health Research Council and the Ministry of Health*, (Dunedin: University of Otago, 2014). <https://www.otago.ac.nz/physio/otago066906.pdf>, p.3–4.

The authors reported that,

‘...unless the organisation was specifically a Māori health provider, the percentage of Māori clients seen was low (about 5%), as were the number of Māori staff employed (0 - 2 staff members). This said, a number of organisations only had one or two staff in total. The reasons why so few Māori accessed their service had either not been thought about by the organisation or was unknown.’⁵⁰¹

Ratima and Ratima assert that,

‘If equity is to be a central goal, action will be required...in the disability sector to ensure quality Māori-specific and mainstream disability support services that meet high professional and cultural standards.

These services will acknowledge that disabled Māori have needs related to impairment and to being Māori, and should aim to facilitate maximum functioning and wellness as Māori. Among other things, this will require greater attention to culturally appropriate needs- assessment and service co-ordination, areas that have long been neglected for Māori. Levels of service funding should reflect the additional resources required to meet cultural needs’.⁵⁰²

Higgins et al., also advise that health and disability services (amongst others),

‘...need to become more culturally consonant so that Māori can maintain a strong identity as Māori...and that non-Māori professionals be committed to supporting the principles of the Treaty and Māori self-determination. They also need to be supported to become culturally aware and learn te reo Māori me ona tikanga. In

⁵⁰¹ Leigh Hale, Katrina Potiki Bryant, Aimee L Ward, Amy Falloon, Aroha Montgomery, Brigit Mirfin-Veitch, Kelly Tikao, and Stephan Milosavljevic, “Organisational Views on Health Care Access for Hauā (Disabled) Māori in Murihiku (Southland), Aotearoa New Zealand: A Mixed Methods Approach.” *New Zealand Journal of Physiotherapy* 46, no. 2 (2018). 51–66., p.59.

⁵⁰² Ratima and Ratima, “Māori Experience of Disability and Disability Support Services.” In *Hauora: Māori Standards of Health Iv. A Study of the Years 2000-2005*, p.196.

general, timely and welcoming services that meet whānau needs should be available. However, this research has shown that whānau usually do get on with their lives even if there are barriers to accessing health and education services because of cultural dissonance, bureaucratic labyrinths, geographic location, or service unavailability'.⁵⁰³

FUNDED FAMILY CARE

The policy for funded family care supports 'eligible' people with lived experience of disability to employ their parents or family members to provide them with care and/or household management. Historically, the MoH had excluded parents and resident family members from payment for the provision of various disability support services to their children. Legal action in 2012 claimed that the exclusion amounted to unlawful discrimination against them on the basis of their family status. Following the legal action, the MoH introduced funded family care.⁵⁰⁴

The specifics of this policy are subject to proposed amendment at the time of writing, including the intention to repeal Part 4A of the New Zealand Public Health and Disability Act 2000.⁵⁰⁵ Part 4A was inserted on 21 May 2013 via Section 4 of the New Zealand Public Health and Disability Amendment Act 2013. It provided for the MoH and DHBS to have family care policies (in which case, determining the eligibility access criteria) for persons to be paid to provide health and/or disability services to family members. As a result, uptake was low. An evaluation found,

⁵⁰³ Nancy Higgins, Hazel Phillips, Christine Cowan, Benita Wakefield, and Kelly Tikao. *Growing up Kāpo Māori: Whānau, Identity, Cultural Well-Being and Health / E Tipu Kāpo Māori Nei: Whānaungatanga, Māramatanga, Māoritanga, Hauoratanga*. (Dunedin: Donald Beasley Institute and Ngāti Kāpo O Aotearoa Inc., 2010). <http://www.donaldbeasley.org.nz/assets/Uploads/publications/Growing-up-kapo-Maori.pdf>, p.236.

⁵⁰⁴ Artemis Research, *Evaluation of Funded Family Care*, (Wellington: Ministry of Health, 2015). <https://www.health.govt.nz/publication/evaluation-funded-family-care>.

⁵⁰⁵ Ministry of Health Funded Family Care, <https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/funded-family-care>., Accessed 1 February 2019.

‘There is no doubt the [funded family care] policy is effective for some but its overall effectiveness is constrained by its limited uptake by those who could potentially benefit from it. As at 1 April 2015, only 191 adult disabled persons nationwide were accessing [funded family care] (compared with 1600 forecast)’.⁵⁰⁶

It was also considered a restrictive programme that did not fulfil the recommendations of the 2012 legal action. In September 2018, the Government announced plans to change funded family care, (including the intention to repeal Part 4A of the NZ Public Health and Disability Act).⁵⁰⁷ As the then Associate Minister of Health, Hon James Shaw, said in a press release,

‘...[t]here have been consistent calls for Part 4A to be repealed because it is discriminatory. In particular, Part 4A has been inconsistent with human rights legislation because it denies families the right to complain about breaches of their human rights relating to family care policies’.⁵⁰⁸

The report, *Targeted engagement on Funded Family Care and Paid Family Care* was published in November 2018, although the extent of engagement with Māori with lived experience of disability is unclear (the report authors appear to identify a need for further engagement with Māori with lived experience of disability, and other groups).⁵⁰⁹ At the time of writing, progress to date with regard to the amendment of the policy and repeal of

⁵⁰⁶ Artemis Research, *Evaluation of Funded Family Care*, p.iv.

⁵⁰⁷ New Zealand Government. *The New Zealand Government’s Response to ‘the List of Issues Prior to Submission of the Combined Second and Third Periodic Review of New Zealand’*. United Nations (New York: 2019). <https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/second-periodic-review/>.

⁵⁰⁸ Hon David Clark and Hon James Shaw, “Making Funded Family Care fairer”, 27 September 2018 <https://www.beehive.govt.nz/release/making-funded-family-care-fairer>.

⁵⁰⁹ Sapere Research Group, *Paid Family Care Discussion: Funded Family Care and Other Schemes in New Zealand*, (Auckland: Carers New Zealand, 2018). <http://carers.net.nz/wp-content/uploads/2018/05/Paid-Family-Care-Discussion-Paper-FINAL-24-April-2018.pdf>.

Part 4A is indeterminate.⁵¹⁰ Currently access to funded family care is through the same NASC process as other services.⁵¹¹

DISABILITY SUPPORT SYSTEM TRANSFORMATION PROJECT

Different models of disability support have been sought for a number of years⁵¹² and most recently the Government is prototyping a disability support system transformation project called Mana Whaikaha, in the MidCentral DHB area for around 1600 people with lived experience of disability. The prototype's Enabling Good Lives principles include giving people with lived experience of disability more options and decision-making authority about their supports and lives to improve their outcomes, and to create a more cost-effective disability support system.⁵¹³ The prototype began operations at the end of 2018. As at 24 January 2019, around 17 per cent of people in the 'uptake' for the disability transformation prototype identified as Māori. One in five people in MidCentral identify as Māori.⁵¹⁴ An initial report on baseline data gathering in MidCentral was expected to be available in December 2018,⁵¹⁵ but has not been published to date.

⁵¹⁰ For example, Ministry of Health, Funded Family Care. <https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/funded-family-care>. Accessed 21 June 2019.

⁵¹¹ Ministry of Health. Funded Family Care questions and answers. <https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/funded-family-care/funded-family-care-questions-and-answers#getffc>., Accessed 1 February 2019.

⁵¹² Refer to Chapter II for further discussion.

⁵¹³ Office of the Minister for Disability Issues and Office of the Associate Minister of Health, *Transforming the disability support system: Approval to commence MidCentral Prototype* (2018), <https://www.health.govt.nz/system/files/documents/media/dss-transformation-cabinet-paper-appendices-approval-commence-prototype.pdf>.

⁵¹⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁵¹⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1ka MoH Response 3 Appendix Confirmed DSS Te Ao Mārama Minutes October 2018.

International human rights instruments and frameworks

The following sections outline international human rights instruments and frameworks that are of relevance to Māori with lived experience of disability in Aotearoa/New Zealand. Of these, the Convention on the Rights of Persons with Disabilities, the Convention on the Rights of the Child, and the Declaration on the Rights of Indigenous Peoples are discussed in-depth.

Since the inauguration in 1948 of the Universal Declaration of Human Rights which set out basic human rights that must be protected for everyone, the United Nations (UN) has adopted a number of broader international human rights instruments such as the International Bill of Human Rights which comprises the: Universal Declaration of Human Rights and two covenants which came into force in 1976.⁵¹⁶ These are the International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights. Both were ratified by Aotearoa/New Zealand in 1978. In addition to the International Bill of Human Rights, there are four Conventions that lay out a universal framework of minimum standards for respecting, protecting and fulfilling human rights. These are:⁵¹⁷

⁵¹⁶ The two subsequent Optional Protocols to the International Covenant on Civil and Political Rights and the Optional Protocol to the International Covenant on Economic, Social and Cultural Rights also comprise the International Bill of Rights. The First Optional Protocol to the International Covenant on Civil and Political Rights establishes a complaints and inquiry mechanism, allowing individuals to complain to the Human Rights Council about human rights violations. The Second Optional Protocol abolishes the death penalty. The Optional Protocol to the International Covenant on Economic, Social and Cultural Rights also establishes a complaints and inquiry mechanism. Aotearoa/New Zealand has ratified the two Optional Protocols to the International Covenant on Civil and Political Rights but not the Optional Protocol to the International Covenant on Economic, Social and Cultural Rights.

⁵¹⁷ The Office of the High Commissioner for Human Rights (UN Human Rights). Status of ratification <http://indicators.ohchr.org.>, Accessed 1 February 2019.

1. The International Convention on the Elimination of All Forms of Racial Discrimination (which came into force 1969 and ratified by Aotearoa/New Zealand in 1972);
2. The Convention on the Elimination of All Forms of Discrimination against Women (which came into force 1981 and ratified by Aotearoa/New Zealand in 1985);
3. The Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (which came into force 1987 and ratified by Aotearoa/New Zealand in 1989); and
4. The Convention on the Rights of the Child (which came into force in 1990 and ratified by Aotearoa/New Zealand in 1993).

The UN has also focused on promoting and protecting the rights of specific population groups, particularly for people that are most likely to experience exclusion and marginalisation. Such key human rights instruments include the UN Convention on the Rights of Persons with Disabilities and the UN Nations Declaration on the Rights of Indigenous Peoples (discussed in the following sections).

The United Nations Convention on the Rights of Persons with Disabilities

Adopted by the UN General Assembly (the General Assembly) in 2006, and entering into force in 2008, the UN Convention on the Rights of Persons with Disabilities (the UNCRPD) was ratified by Aotearoa/New Zealand in 2008.

‘The Convention on the Rights of Persons with Disabilities...signalled a “paradigm shift” from traditional charity-oriented, medical-based approaches to disability to one based on human rights...It offers sufficient standards of protection for the

civil, cultural, economic, political and social rights of persons with disabilities on the basis of inclusion, equality and non-discrimination'.⁵¹⁸

Aotearoa/New Zealand was actively involved in the drafting of the UNCRPD. For example, the chair of the Ad Hoc Committee was a New Zealander, and several people with lived experience of disability were part of the official delegation, with the ODI providing secretariat support.⁵¹⁹ However, there is no clear evidence in the available literature that Māori with lived experience of disability ever participated in the development of the UNCRPD.

Implementation of the UNCRPD in Aotearoa/New Zealand is overseen by the ODI within the Ministry of Social Development, and in collaboration with the Disabled People's Organisations (DPO) Coalition (specified under Article 4(3) of the UNCRPD). The DPO Coalition currently comprises seven organisations made up of and/or primarily governed by, people with lived experience of disability. These are: Kāpō Māori Aotearoa New Zealand Inc.; Association of Blind Citizens of New Zealand Inc.; Balance Aotearoa; Deaf Aotearoa New Zealand Inc.; Disabled Persons Assembly New Zealand Inc.; Muscular Dystrophy Association of New Zealand Inc.; and People First New Zealand Inc.

Under Article 26 of the Vienna Convention on the Law of Treaties 1969 which Aotearoa/New Zealand signed in 1971, 'every treaty in force is binding upon the parties to it and must be performed by them in good faith'.⁵²⁰ However, Aotearoa/New Zealand has a dualist approach to international law, which distinguishes between the government's domestic and international obligations. Under this principle, international conventions are only directly enforceable in domestic law to the extent that parliament has expressly incorporated them into statute. The explanatory note to the Disability (United Nations

⁵¹⁸ The Office of the High Commissioner for Human Rights (UN Human Rights), "Human rights of persons with disabilities", <https://www.ohchr.org/EN/Issues/Disability/Pages/DisabilityIndex.aspx>, Accessed 1 February 2019.

⁵¹⁹ Stace, "Moving Beyond Love and Luck: Building Right Relationships and Respecting Lived Experience in New Zealand Autism Policy."

⁵²⁰ UN General Assembly, *Vienna Convention on the Law of Treaties*, (Vienna: United Nations, 1969).

Convention on the Rights of Persons with Disabilities) Bill 2008 states that, ‘historically, New Zealand has set a high standard for ratification of international human rights treaties and will ratify only when the Government is satisfied that our laws, policies, and practices are not inconsistent with the treaty at issue’. An analysis undertaken prior to the adoption of the UNCRPD to ensure compliance of domestic law led to the introduction of an Omnibus Bill, however only consequential amendments were made. There has been the realisation that the substantial changes needed to be made were significantly underestimated.⁵²¹

The Optional Protocol on the UNCRPD, which came into force at the same time as the UNCRPD, was acceded by Aotearoa/New Zealand in October 2016. It gives the Committee on the Rights of Persons with Disabilities (the Committee) further capacities. For example, the Committee is able to look at complaints filed by individuals or groups around breaches of rights, and instigate inquiries where there is evidence of human rights violations.

As a member state, Aotearoa/New Zealand is required to periodically report to the Committee about how well the rights articulated within the UNCRPD are being implemented by the government.⁵²² The Committee then makes comments and recommendations about the progress of human rights for people with lived experience of disability in Aotearoa/ New Zealand, based on their review.⁵²³ Contributions (in the forms of submissions and reports) to the member state’s periodic review are also made by national human rights institutes, and civil society organisations.

⁵²¹ Sylvia Bell, Judy McGregor, and Margaret Wilson. Convention on the Rights of Disabled Persons: A Remaining Dilemma for New Zealand?”. *New Zealand Journal of Public and International Law*. 2015."13(2): 277–296.
<https://heinonline.org/HOL/LandingPage?handle=hein.journals/nzjpubin13&div=24&id=&page=&t=1557107985>.

⁵²² The periodic review occurs approximately every four years.

⁵²³ The Committee the Rights of Persons with Disabilities is also responsible for interpreting the UNCRPD, and issues General Comments, providing clarification and guidance on specific articles of the UNCRPD.

The Committee's concluding observations on the initial report of Aotearoa/New Zealand in 2014, identified a number of areas of concern and made 34 recommendations to the government to improve its implementation of the UNCRPD. Of particular note are the Committee's concerns regarding lack of access to services for Māori children with lived experience of disability, and lack of access to information in te reo Māori (particularly regarding New Zealand Sign Language), health outcome inequities, and low employment levels for Māori with lived experience of disability. The report states,

'17. The Committee is concerned that it is still the case that some children with disabilities, especially Māori children with disabilities, have difficulty in accessing some government services, including health and education services.

18. The Committee recommends that this work be increased to ensure that all children with disabilities are able to access government and related services, including to receive support to express their views.

43. The Committee is concerned that it is still the case that Māori people with disabilities find it more difficult to access information in their own language. Māori people who are deaf find accessing information in New Zealand Sign Language even more difficult, owing to the lack of interpreters from Māori into New Zealand Sign Language.

44. The Committee recommends that greater efforts be made to enable Māori and Pacific people with disabilities, and especially those who are deaf and deaf-blind, to access information.

53. The Committee is concerned that Māori people have the poorest health outcomes in New Zealand. The Committee is also concerned that the prevalence of disability is higher in the Māori population as a result of poverty and disadvantages.

54. The Committee recommends that measures be strengthened to enhance the health outcomes of Māori and Pacific persons with disabilities.

55. The Committee is concerned that the employment levels in New Zealand for persons with disabilities, and especially for Māori and Pacific people with disabilities, are still low.

56. The Committee recommends that further steps be taken to increase the employment levels of persons with disabilities'.⁵²⁴

The Special Rapporteur on the rights of persons with disabilities (the Special Rapporteur), as part of the special procedures mandate, was established in 2014. Reporting to the Human Rights Council, the Special Rapporteur has the mandate to collect information on human rights violations and provide recommendations with regard to promote and protect human rights, imparting technical support to that end.

FRAMEWORK TO PROMOTE, PROTECT AND MONITOR IMPLEMENTATION OF THE UNCRPD IN AOTEAROA/NEW ZEALAND

In October 2010, the government established a framework involving functions both within, and independent of, government to meet Article 33's requirements to promote, protect and monitor implementation of the UNCRPD. The framework consists of:^{525,526}

1. The Ministerial Committee on Disability Issues as the implementation coordination mechanism within government.
2. The ODI which has functioned as the 'government focal point on disability' since its establishment in 2002 under the *New Zealand Disability Strategy*.

⁵²⁴ Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of New Zealand*, CRPD/C/NZL/CO/1. (New York: United Nations, 2014). <https://www.ohchr.org/en/countries/asiaregion/pages/nzindex.aspx>.

⁵²⁵ Office for Disability Issues, "Framework to promote, protect and monitor implementation of the Convention." [https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/nzs-monitoring-framework/.](https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/nzs-monitoring-framework/), Accessed 1 February 2019.

⁵²⁶ Hon Tariana Turia, Minister for Disability Issues, "Notice of independent monitoring mechanism", *New Zealand Gazette* (2011), p.4448.

3. The Independent Monitoring Mechanism (the IMM).

INDEPENDENT MONITORING MECHANISM

Designated by government, the IMM consists of three organisations: the DPO Coalition, the Office of the Ombudsman, and the Human Rights Commission. The first Disability Rights Commissioner was appointed in 2011. They provide independent advice to the government on disability issues and whom holds power of enquiry. The first was Paul Gibson, and the current is Paula Tesoriero – both of whom have lived experiences of disability.

The role of the IMM is to promote, protect and monitor the government’s implementation of the UNCRPD. The additional functions of the IMM (as designated by the Minister for Disability Issues) are:⁵²⁷

- a) developing indicators in consultation with public and private sector agencies
- b) identifying priority areas drawing on their existing programmes of work
- c) measuring progress by analysing legislation, policy, and practice affecting disabled people, and
- d) engaging with the government to establish a comprehensive reporting process in relation to the [UNCRPD] that includes engagement with civil society, integration across public agencies, and clear accountability for publicising reports and following up recommendations.

⁵²⁷ Hon Tariana Turia, Minister for Disability Issues, “Notice of independent monitoring mechanism.”, p. 4448.

THE COMBINED SECOND AND THIRD PERIODIC REVIEW OF AOTEAROA/NEW ZEALAND

In November 2017, the IMM provided a submission to the Committee with suggestions for the Committee's *List of issues prior to submission of the combined second and third periodic reports of New Zealand*.⁵²⁸ The IMM identified six key priority areas in their submission.

These were:

1. Data – addressing large gaps in disaggregated disability data
2. Education – supporting an education system that is fully inclusive
3. Employment – supporting full participation in the labour force
4. Seclusion and restraint – addressing overuse of seclusion and restraint, including for people in detention
5. Information and communication – addressing lack of fundamental information being communicated in accessible ways, and
6. Housing – addressing the lack of accessible housing in Aotearoa/New Zealand.⁵²⁹

The Committee released its 'List of Issues' prior to submission of the combined second and third periodic reports of New Zealand in March 2018 (which included the IMM's six priority areas). A year later (in early March 2019), the Government released *The New Zealand Government's response to 'the List of Issues Prior to Submission of the Combined Second and Third Periodic Review of New Zealand'*.⁵³⁰ The IMM will in 2019 produce a country

⁵²⁸ The Committee on the Rights of Persons with Disabilities has a list of issues that comprise the questions to be raised with the member state undergoing periodic review.

⁵²⁹ Other civil society organisations can, and have, made submissions to the Committee on the UNCRPD.

⁵³⁰ New Zealand Government. 2019. *The New Zealand Government's Response to 'the List of Issues Prior to Submission of the Combined Second and Third Periodic Review of New Zealand'*. United Nations. United

report to the Government, and can elect to submit a shadow report to the Committee. In preparation, the DPO Coalition has commissioned a series of issue-specific research reports, the first of which will be on housing. The Government delegation will appear before the Committee in Geneva during the review (later in 2020), followed by the Committee's release of their 'Concluding Observations'. The Government then releases a follow-up response to the 'Concluding Observations' (end of 2020).⁵³¹

Table 8 provides an overview of the MoH's stated contribution to the implementation of the UNCRPD articles in Aotearoa/New Zealand. A comment is made by the researcher where information is required to provide context to the MoH statements.

Nations (New York). <https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/second-periodic-review/>.

⁵³¹ Office for Disability Issues, *New Zealand's second review against the UN Convention on the Rights of Persons with Disabilities*. <https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/second-periodic-review/>., Accessed 31 March 2019.

Table 8: Ministry of Health role and contribution to implementation of the United Nations Convention on the Rights of Persons with Disabilities by articles⁵³²

Article	Ministry of Health	Comment
Article 3 General principles	No information provided.	No comment.
Article 4 General obligations	No information provided.	No comment.
Article 5 Equality and non-discrimination	Funded family care, ‘...allows payments of people to care for resident family members assessed as having high or very high needs relating to disability, long term chronic health conditions, mental health and addiction and aged care needs’. ⁵³³	Historically, the MoH had excluded parents and resident family members from payment for the provision of various disability support services to their children. Legal action in 2012 claimed that the exclusion amounted to unlawful discrimination against them on the basis of their family status. Following the legal action, the MoH introduced funded family care. ⁵³⁴ Although an evaluation of this funded family care programme found ‘there is no doubt the FFC policy is effective for some but its overall effectiveness is constrained by its limited uptake’. ⁵³⁵

⁵³² The Ministry of Health provides a general overview of its response to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which includes, ‘... the focus on Māori is expressly recognised through the New Zealand Disability Strategy (the Strategy) as the primary vehicle for Government’s progressive implementation of the CRPD... The Strategy guides the work of government agencies on disability issues from 2016-2026. The principles of both Te Tiriti o Waitangi and the UNCRPD guide the way the Strategy is implemented; they are for everyone and apply to Māori and non-Māori, disabled people and non-disabled people.’

⁵³³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1b Ministry of Health.

⁵³⁴ Artemis Research, *Evaluation of Funded Family Care*.

⁵³⁵ Artemis Research, *Evaluation of Funded Family Care*, p.iv.

Article	Ministry of Health	Comment
		<p>It was also considered a restrictive programme that did not fulfil the recommendations of the 2012 legal action.</p> <p>In September 2018, the Government announced plans to change health service ‘Funded Family Care’, including the intention to repeal Part 4A, NZ Public Health and Disability Act 2000.⁵³⁶</p> <p>As the then Associate Minister of Health, Hon James Shaw, said in a press release, ‘[t]here have been consistent calls for Part 4A to be repealed because it is discriminatory. In particular, Part 4A has been inconsistent with human rights legislation because it denies families the right to complain about breaches of their human rights relating to family care policies’.⁵³⁷</p>
Article 6 Women with disabilities	No information provided.	No comment.
Article 7 Children with disabilities	No information provided.	No comment.
Article 8 Awareness-raising	No information provided.	No comment.
Article 9 Accessibility	No information provided.	No comment.
Article 10 Right to life	No information provided.	No comment.
Article 11	No information provided.	No comment.

⁵³⁶ New Zealand Government, *The New Zealand Government’s Response to ‘the List of Issues Prior to Submission of the Combined Second and Third Periodic Review of New Zealand’*, (Wellington: New Zealand Government, 2019), <https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/second-periodic-review/>.

⁵³⁷ Hon David Clark and Hon James Shaw, “Making Funded Family Care fairer.”

Article	Ministry of Health	Comment
Situations of risk and humanitarian emergencies		
Article 12 Equal recognition before the law	The Ministry has been progressing work on supported decision making, ‘...which is a process of providing the information, resources and tools needed to enable a person to make their own decisions’. ⁵³⁸	MoH work in this area includes trialling supported decision making in the disability transformation project in the MidCentral DHB region.
Article 13 Access to justice	No information provided.	No comment.
Article 14 Liberty and security of persons	‘Mental Health Act and compliance with CRPD’. ⁵³⁹	<p>As reported to the UN Committee on the Rights of Persons with Disabilities:</p> <p>‘Under the Mental Health Act, a person can be treated without their consent during the assessment period and the first month of a compulsory treatment order. A person cannot then be required to accept treatment without consent unless a psychiatrist who has been appointed by the Mental Health Review Tribunal considers the treatment to be in the interests of the patient.</p> <p>In 2019, the Government initiated a review and revision of the guidelines implementing the Act to align the application of the current legislation as closely as possible with the CRPD. This will include a review of processes for consent and second opinions under the Act.’⁵⁴⁰</p>

⁵³⁸ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g Ministry of Health.

⁵³⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g Ministry of Health.

⁵⁴⁰ New Zealand Government, *The New Zealand Government’s Response to ‘the List of Issues Prior to Submission of the Combined Second and Third Periodic Review of New Zealand’*.

Article	Ministry of Health	Comment
Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment	'Seclusion in mental health services'. ⁵⁴¹	As reported to the UN Committee on the Rights of Persons with Disabilities: 'No legal measures have been taken to eliminate these practices, however the Government is committed to reducing the use of seclusion, restraints and other similar measures.' ⁵⁴²
Article 16 Freedom from exploitation	No information provided.	No comment.
Article 17 Right to bodily integrity	'The Ministry has been progressing work under Action 7(b) of the Disability Action Plan, working with Disabled People's Organisations and disability sector groups to improve safeguards for disabled people against unconsented sterilisation, including consideration of legislative protective measures. In 2018, the Ministry held a hui with the project reference group, which included a representative from the Te Ao Mārama group'. ⁵⁴³	As reported to the UN Committee on the Rights of Persons with Disabilities: '...[u]nder current legislation, non-consensual sterilisation of disabled people is lawful in NZ where: <ul style="list-style-type: none"> • it is medically necessary • the person does not have the capacity to give informed consent to that procedure, and • where the person's clinical needs and welfare cannot be adequately addressed in other ways.'⁵⁴⁴ Note Action 7(b) has not been completed and the provision that allows unconsented sterilisation remains in legislation.
Article 18 Liberty of movement and nationality	No information provided.	No comment.

⁵⁴¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g Ministry of Health.

⁵⁴² New Zealand Government, *The New Zealand Government's Response to 'the List of Issues Prior to Submission of the Combined Second and Third Periodic Review of New Zealand'*.

⁵⁴³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁵⁴⁴ New Zealand Government, *The New Zealand Government's Response to 'the List of Issues Prior to Submission of the Combined Second and Third Periodic Review of New Zealand'*.

Article	Ministry of Health	Comment
Article 19 Living independently and being included in the community	<p>The Ministry funds a range of disability support services that support people to live independently, including:</p> <ul style="list-style-type: none"> • Community residential services to ‘...assist disabled people to live in a supported community environment.’ • Choices in community living, ‘...an option for people to be supported in a different way instead of moving into community residential care.’ • Supported living, which ‘...helps disabled people to live independently by providing support in those areas of their life where help is needed.’ • Funded family care • Disability system transformation • Equipment and modification services, which ‘...cover equipment, housing modifications and vehicle purchase and modifications’.⁵⁴⁵ 	No comment.
Article 20 Personal mobility	No information provided.	No comment.
Article 21 Freedom of expression and opinion, and access to information	<p>The Ministry supports access to information through:</p> <ul style="list-style-type: none"> • Website compliance with Government Web Standards • Accessible downloads from its website • High contrast versions of material, eg of the Ministry website • Some information is available in NZ Sign Language • Some information is available in easy-to-read versions 	<p>Although it does not provide a list of achievements in this area, the Ministry also states DHBs have planning priorities including:</p> <ul style="list-style-type: none"> • Promoting the use of the Health Passport, ‘...which provides detailed information about a disabled patient including how they like to be communicated with.’ • Introduction of e-learning modules for staff and clinicians to provide advice and information on interacting with a disabled patient

⁵⁴⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

Article	Ministry of Health	Comment
	<ul style="list-style-type: none"> All video content carries captions and has transcripts Its funded disability information advisory services, which, ‘...provide information that is accessible to and appropriate for the needs of disabled consumers and the public’.⁵⁴⁶ 	<ul style="list-style-type: none"> Translation services.⁵⁴⁷ <p>Note also that the MoH website information does not currently comply with web accessibility standards, and not all documents are available in accessible formats.</p> <p>Updated government web standards come into effect in July 2019.⁵⁴⁸</p>
Article 22 Respect for privacy	The Ministry’s data collection is protected by data protection and privacy legislation, including the Privacy Act 1993 and the Health Information Privacy Code 1994. All of the Ministry’s population health databases adhere to these standards. ⁵⁴⁹	No comment.
Article 23 Respect for home and the family	No information provided.	No comment.
Article 24 Education	No information provided.	No comment.
Article 25 Health	<p>The Ministry is the lead agency for advising on the implementation of Article 25 in New Zealand and the goal of disabled people having the highest attainable standards of health and well-being are included in the <i>New Zealand Disability Strategy</i>.</p> <p>‘While New Zealand has achieved good overall progress</p>	No comment.

⁵⁴⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁵⁴⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁵⁴⁸ New Zealand Government, “Web Standards effective from July 2019.”, <https://www.digital.govt.nz/standards-and-guidance/nz-government-web-standards/new-web-standards-for-july-2019/>., Accessed 1 April 2019.

⁵⁴⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g Ministry of Health.

Article	Ministry of Health	Comment
	<p>in the nation's health, challenges remain. Important inequities in health persist between different groups, which are most pronounced for Māori. The Government requires a focus on improving Māori health and addressing equity gaps'. A Māori health action plan, to support implementation of <i>He Korowai Oranga</i>, the Māori Health Strategy, is being developed by the Ministry for the coming year.⁵⁵⁰</p>	
<p>Article 26 Habilitation and rehabilitation</p>	<p>'Most rehabilitation services, including for health, mental health and age-related rehabilitation are generally accessed through district health boards. The Ministry of Health is one of the main rehabilitation funders, funding disability-specific rehabilitation, including assistive technology for people with long-term physical, intellectual and sensory disabilities.'⁵⁵¹</p> <p><i>Refer to Table 6 on equipment modification services expenditure.</i></p>	<p>The MoH states, 'Obligations for Māori rehabilitation are recognised through Te Tiriti o Waitangi. Health and disability services for Māori are expected to be based on Māori thinking and behaviour and Māori ways of healing, care and rehabilitation'.⁵⁵² However there is no evidence provided on what the Ministry does to ensure this happens. The Ministry states elsewhere that it does not keep information on the number of Māori-owned and Māori-</p>

⁵⁵⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g Ministry of Health.

⁵⁵¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g Ministry of Health.

⁵⁵² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g Ministry of Health.

Article	Ministry of Health	Comment
		<p>governed disability service providers.⁵⁵³</p> <p>No detail is given on habilitation in the MoH response.</p>
<p>Article 27 Work and employment</p>	<p>No information provided.</p>	<p><i>Refer to Chapter V for information on numbers of Māori staff in Crown organisations.</i></p>
<p>Article 28 Adequate standard of living and social protection</p>	<p>No information provided.</p>	<p>No comment.</p>
<p>Article 29 Participation in political and public life</p>	<p>No information provided.</p>	<p>No core/sustainability funding for Disabled People’s Organisations and other groups to, as per A29. (b)(ii), ‘...represent persons with disabilities at international, national, regional and local levels’.</p>
<p>Article 30 Participation in cultural life</p>	<p>The Ministry for Culture and Heritage is the lead agency for Article 30.</p> <p>But <i>Whāia Te Ao Mārama</i>,⁵⁵³ aims to enable Māori disabled to achieve their aspirations, and reduce barriers that may impede</p>	<p>The MoH’s response focuses on cultural competency of caregivers and workers in the disability sector. No information is provided through the OIA on, for example, ensuring access to disability equipment.</p>

⁵⁵³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1b Ministry of Health.

Article	Ministry of Health	Comment
	Māori disabled and their whānau from gaining better outcomes’.	Note also that ‘Te Ao Māori’ is one of the four goals of <i>Whāia Te Ao Mārama</i> but there is no evidence in Crown information of this being explicitly resourced.
Article 31 Statistics and data collection	<p>‘Ministry is a key supplier of health data on disabled people’, although the Office for Disability Issues is the overall lead agency for implementing Article 31.</p> <p>The Ministry routinely collects disability data on its Māori disability support services client group and uses this for strategic and business planning as well as monitoring implementation of <i>Whāia Te Ao Mārama</i>.</p> <p>‘Currently it is not possible to measure the health status of the disability population in New Zealand, including Māori with disability. This is because disabled people cannot be identified in some national health surveys.</p> <p>There is a Disability Data and Evidence Working Group and its working on indicators for the 8 outcome domains of the NZDS.⁵⁵⁴</p>	<p>The MoH also notes:</p> <p>‘The Washington Group Short Set (WGSS) has been added to the 2018/19 New Zealand Health Survey for adults and children. The WGSS questions are not designed to produce counts or rates of disabled people in New Zealand. They are used, like other demographic characteristics such as sex and ethnic group, to allow the comparison of outcomes for different population sub-groups. These questions will therefore allow comparisons to be made between disabled and non-disabled people. It will allow comparisons to be made between Māori with and without disability.⁵⁵⁵</p> <p><i>Refer to Chapter V, which highlights considerable gaps in Crown data for Māori with lived experience of disability.</i></p>
Article 32 International cooperation	No information provided.	No comment.
Article 33 National implementation and monitoring	No information provided.	No comment.

⁵⁵⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g Ministry of Health.

⁵⁵⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g Ministry of Health.

The United Nations Convention on the Rights of the Child

The UN Convention on the Rights of the Child (the UNCROC)⁵⁵⁶ was adopted by the General Assembly in 1989 and ratified by Aotearoa/New Zealand in 1993. Member states are required to report to the Committee on the Rights of the Child every five years. Aotearoa/New Zealand last reported to the UN in September 2016. The sixth periodic review will occur in 2021. Implementation of the UNCROC in Aotearoa/New Zealand is overseen by MSD.

The UNCROC comprises 54 Articles that lay out a universal framework of minimum standards for respecting, protecting and fulfilling human rights of children. There are four principles which underlay the UNCROC. These are:⁵⁵⁷

1. the right to protection from discrimination
2. the best interests of the child should be the primary consideration in all matters that affect them
3. the rights to life, survival and development, and
4. the right to a view, and for that view to be heard.

There are four articles which relate more broadly to the health and well-being of Māori children with lived experience of disability. These are: Article 2 (right to be free from discrimination); Article 23 (rights of children with disability); Article 24 (right to health); and Article 30 (right to culture and/or religion).⁵⁵⁸ However, of note, there is no specific

⁵⁵⁶ For the purposes of the United Nations Convention on the Rights of the Child, a 'child' refers to 'every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier'. UN General Assembly, "Convention on the Rights of the Child.", (New York: United Nations, 1989).

⁵⁵⁷ UN General Assembly, "Convention on the Rights of the Child.", (New York: United Nations, 1989).

⁵⁵⁸ UN General Assembly, "Convention on the Rights of the Child."

mention in the UNCROC regarding the rights of Indigenous children with lived experience of disability.

The Committee on the Rights of the Child released the *Concluding observations on the fifth periodic report of New Zealand* based on the fifth periodic review of Aotearoa/New Zealand in 2016. The report made over a dozen recommendations pertaining to the rights of Māori children in addition to the rights of children with lived experience of disability. However, it made only one recommendation which relates to Māori children with lived experience of disability.⁵⁵⁹ The report recommended that Aotearoa/New Zealand,

‘Strengthen its efforts to combat the marginalization and discrimination of children with disabilities in their access to health, education, care and protection services, with particular attention to Maori children with disabilities...and undertake awareness-raising campaigns aimed at government officials, the public and families to combat the stigmatization of and prejudice against children with disabilities and promote a positive image of these children’.⁵⁶⁰

The United Nations Declaration on the Rights of Indigenous Peoples

The UN Declaration on the Rights of Indigenous Peoples (the UNDRIP) was adopted by the General Assembly in September 2007.⁵⁶¹ Aotearoa/ New Zealand was one of the four votes

⁵⁵⁹ This occurs in recommendation 30 (b) under section G – Disability, basic health and welfare; pertaining to articles: 6, 18 (3), 23, 24, 26, 27 (1–3) and 33.

⁵⁶⁰ Committee on the Rights of the Child, *Concluding observations on the fifth periodic report of New Zealand CRC/C/NZL/CO/5*, United Nations (New York, 2016), https://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=En&CountryID=124.

⁵⁶¹ The United Nations Declaration on the Rights of Indigenous Peoples took over two decades to draft. Efforts to draft an instrument addressing the promotion and protection of human rights for Indigenous peoples globally, had occurred since 1982.

against its adoption in 2007 (along with Australia, Canada, and the United States of America), however, endorsed the UNDRIP in 2010. The UNDRIP,

‘...establishes a universal framework of minimum standards for the survival, dignity and well-being of the indigenous peoples of the world and it elaborates on existing human rights standards and fundamental freedoms as they apply to the specific situation of indigenous peoples’.⁵⁶²

In addition to setting out a universal framework of minimum standards, the UNDRIP addresses indigenous rights at both an individual level, and at a collective level.

The UN Committees specifically look at how well indigenous rights for Māori are protected in Aotearoa/New Zealand during UN reporting processes. There are also three expert bodies that focus on indigenous rights. These include: the Special Rapporteur on the rights of Indigenous peoples; the United Nations Permanent Forum on Indigenous Issues; and the Expert Mechanism on the Rights of Indigenous Peoples.

The Special Rapporteur on the rights of Indigenous peoples, as part of the special procedures mandate, was established in 2001.⁵⁶³ Their mandate is to: promote good practices regarding implementation of international standards in relation to rights for Indigenous peoples; report on the human rights situations of Indigenous peoples in states; address violations of human rights;⁵⁶⁴ conduct thematic studies around topics of particular

⁵⁶² United Nations – Indigenous Peoples, Department of Economic and Social Affairs, “United Nations Declaration on the Rights of Indigenous Peoples”: <https://www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html>, Accessed 1 February 2019.

⁵⁶³ The Office of the High Commissioner for Human Rights (UN Human Rights), “Special Rapporteur on the rights of indigenous peoples.”, <https://www.ohchr.org/EN/Issues/IPeoples/SRIIndigenousPeoples/Pages/SRIPeoplesIndex.aspx>, Accessed 1 February 2019.

⁵⁶⁴ This occurs through communications with governments and other bodies.

importance relating to the promotion and protection of rights for Indigenous peoples; and report annually to the UN Human Rights Council⁵⁶⁵ (the Human Rights Council).

Established in 2000, the UN Permanent Forum on Indigenous Issues (the Permanent Forum) is an advisory body to the UN Economic and Social Council (the Economic and Social Council).⁵⁶⁶ The Permanent Forum has the mandate to address, and provide expert advice and recommendations on indigenous issues, to the Economic and Social Council, and to other bodies and agencies of the UN. Sessions are held annually, and, in addition to addressing the six mandated areas,⁵⁶⁷ each of the sessions have a thematic focus on certain issues.

The Expert Mechanism on the Rights of Indigenous Peoples (the Expert Mechanism) is a subsidiary body of the Human Rights Council, and was established in 2007. Comprised of seven independent experts, the Expert Mechanism provides expertise and advice on indigenous rights (as set out in the UNDRIP) to the Human Rights Council. Sessions are held by the Expert Mechanism annually.

Implementation of the UNDRIP in Aotearoa/New Zealand is overseen by Te Puni Kōkiri. The Māori Development Minister, Hon Nanaia Mahuta announced in late March 2019 that the Government would develop an action plan for the implementation of the UNDRIP in Aotearoa/New Zealand, stating,

⁵⁶⁵ The United Nations Human Rights Council is the main inter-governmental body within the United Nations system responsible for addressing situations of human rights violations.

⁵⁶⁶ United Nations – Indigenous Peoples, “Permanent Forum, Department of Economic and Social Affairs.” <https://www.un.org/development/desa/indigenouspeoples/unpfii-sessions-2.html>, Accessed 1 February 2019.

⁵⁶⁷ The six mandated areas are: economic and social development; culture; the environment; education; health; and human rights.

‘This Government is committed to leadership and building closer partnerships with Māori. The Declaration plan will identify specific actions that can make real progress on the aspirations of Māori as the tangata whenua of Aotearoa’.⁵⁶⁸

In April 2019, Members of the Expert Mechanism visited Aotearoa/New Zealand to provide advice on implementation of the UNDRIP, and specifically, advice on developing a national strategy or action plan for the UNDRIP.

MONITORING MECHANISM FOR THE UNDRIP IN AOTEAROA/NEW ZEALAND

The Monitoring Mechanism for the United Nations Declaration on the Rights of Indigenous Peoples in Aotearoa/New Zealand (the Monitoring Mechanism) is a working group created by Māori in 2015, and is independent of the government.⁵⁶⁹ The members of the Monitoring Mechanism are stated to have been selected by their Iwi, and are endorsed by the Iwi Chairs Forum.⁵⁷⁰ The stated objective of the Monitoring Mechanism is to promote and monitor the implementation of the UNDRIP in Aotearoa/New Zealand, and they have reported annually to the Expert Mechanism since their establishment. Reports of the Monitoring Mechanism have outlined six priority areas. These include:

⁵⁶⁸ Hon Nanaia Mahuta. 2019. Government moves on UN Rights Declaration. <https://www.beehive.govt.nz/release/government-moves-un-rights-declaration>.

⁵⁶⁹ In their second annual monitoring report to the United Nations Human Rights Council Expert Mechanism on the Rights of Indigenous Peoples, the Monitoring Mechanism state, ‘...[i]n preparing this report, the Monitoring Mechanism sought to engage with the New Zealand government. Despite numerous attempts to arrange face to face meetings, neither government civil servants nor Ministers were prepared to engage with the Monitoring Mechanism’. Monitoring Mechanism for the UN Declaration on the Rights of Indigenous Peoples in Aotearoa/New Zealand, *Report of the Monitoring Mechanism regarding the implementation of the UN Declaration on the Rights of Indigenous Peoples in Aotearoa/New Zealand A/HRC/EMRIP/2016/CRP.4*, (United Nations: New York, 2016), https://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=En&CountryID=124.

⁵⁷⁰ The Iwi Chairs Forum is the national collective of Iwi chairpersons representing Hapū and Iwi.

1. an overarching priority of constitutional transformation
2. self-determination, underpinned by participation in decision-making and free, prior and informed consent
3. lands, territories and resources
4. cultural rights
5. equality and non-discrimination, and
6. practical implementation of the UNDRIP and technical assistance.

The Monitoring Mechanism in their 2017 report to the United Nations conclude overall that,

‘...self-determination is not fully recognised or protected, law and policy processes don’t guarantee Māori participation in decision-making, a fundamental shift in approach is needed to ensure that tikanga (Māori law and culture) is properly valued and is reflected in law and policy, and urgent action is required to address the persistent and severe inequalities experienced by Māori’.⁵⁷¹

⁵⁷¹ Appendix 1 of Monitoring Mechanism for the UN Declaration on the Rights of Indigenous Peoples in Aotearoa/New Zealand, *Report of the Independent Monitoring Mechanism regarding the implementation of the UN Declaration on the Rights of Indigenous Peoples in Aotearoa New Zealand Intervention to the Committee on Economic, Social and Cultural Rights: Information for the Committee’s 63rd Session, March 2018 – Review of New Zealand*, United Nations (New York, 2018), <http://www.converge.org.nz/pma/cescr63-imm.pdf>

MĀORI WITH LIVED EXPERIENCE OF DISABILITY AND INTERNATIONAL HUMAN RIGHTS INSTRUMENTS

In 2006 the UNCRPD was adopted. The only mention of Indigenous peoples in the UNCRPD is found in the preamble, which refers to the concerns of State Parties regarding,

‘...the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, gender, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status...’⁵⁷²

Conversely, the UNDRIP, drafted throughout the development of the UNCRPD, only mentions disability in Article 21 (2), which directs States to,

‘...take effective measures and, where appropriate, special measures to ensure continuing improvement of their economic and social conditions. Particular attention shall be paid to the rights and special needs of indigenous elders, women, youth, children and persons with disabilities’.⁵⁷³

A decade on from the adoption of the UNCRPD, the Special Rapporteur on the rights of persons with disabilities and the Special Rapporteur on the rights of Indigenous peoples, in 2016, co-organised an expert meeting. The purpose of the meeting was to make certain that the existing international human rights mechanisms relating to Indigenous peoples, or people with lived experience of disability fully include the rights of Indigenous peoples with lived experience of disability. The experts expressed sentiment for the rights of Indigenous peoples with lived experience of disability, stating,

⁵⁷² Refer to ‘Preamble’ of UN General Assembly, “Convention on the Rights of Persons with Disabilities.” (New York: United Nations, 2006).

⁵⁷³ UN General Assembly, “United Nations Declaration on the Rights of Indigenous Peoples.” Washington: United Nations, 2007)., Art.21 (2).

‘Indigenous persons with disabilities face exclusion, marginalization and multiple layers of discrimination based on their disability, their ethnic origin and their gender...’⁵⁷⁴

During the meeting, the ‘potential tensions’ between the UNCRPD’s focus on individual rights versus the collective rights focus of the UNDRIP were highlighted and discussed. However,

‘...experts cautioned against seeing them as a dichotomy, and rather argued for understanding individual and collective rights as two aspects of the same body of entitlements.’⁵⁷⁵

Experts identified key challenges for Indigenous peoples with lived experience of disability. These included considerable knowledge gaps where many Indigenous peoples with lived experience of disability were not aware of their human rights. They also discussed that member states’ approaches to the delivery of services risked cultural and social assimilation of Indigenous peoples. The role of language in influencing social perceptions of disability among Indigenous communities was highlighted as a key issue where although language can play a positive role in promoting inclusion, at other times, language used to describe disability could contribute to stigma, discrimination, and exclusion. The situation of Indigenous women and girls with lived experience of disability was considered critical where gender was highlighted as factor in terms of exclusion, discrimination, and widespread marginalisation. The lack of access to support and services across a number of areas such as health, education, justice and political participation of Indigenous peoples with lived experience of disability was also important. The scarcity of statistical information, and the requirement to invest in disaggregated data was discussed. Appropriate data was

⁵⁷⁴ UN Special Rapporteur on the Rights of Indigenous Peoples and the UN Special Rapporteur on the Rights of Persons with Disabilities, *Expert Group Meeting on Indigenous Persons with Disabilities*, (Geneva: United Nations, 2016), <https://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/IPDisabilities.aspx>.

⁵⁷⁵ UN Special Rapporteur on the Rights of Indigenous Peoples and the UN Special Rapporteur on the Rights of Persons with Disabilities, *Expert Group Meeting on Indigenous Persons with Disabilities.*, pp.3–4.

identified as a key requirement, however, mechanisms to produce data also required the direct participation of, and respect for the rights of, Indigenous peoples with lived experience of disability.

The recommendations resulting from the expert meeting looked at ways to improve those international frameworks pertaining to the rights of Indigenous peoples with lived experience of disability. However, the experts also identified community-based approaches as the most suitable framework for the overall inclusion of Indigenous peoples with lived experience of disability, and for the provision of support services. Community-based approaches were viewed as representing,

‘...a point of convergence between both instruments, due to their collective and individual rights-based dimensions. Experts agreed that these approaches for the delivery of support services are key to promote the inclusion of indigenous persons with disabilities, while preventing cultural assimilation and subsequent loss of identity’.⁵⁷⁶

Expert members included members of the Expert Mechanism on the rights of Indigenous peoples, the Committee on the rights of persons with disabilities, Indigenous peoples with lived experience of disability, and academics. A number of Member States were represented, however, there were no named participants representing Aotearoa/New Zealand. Thus, it is difficult to discern the extent to which one can conclude that the assertions made apply to Māori with lived experience of disability in Aotearoa/New Zealand.

⁵⁷⁶ UN Special Rapporteur on the Rights of Indigenous Peoples and the UN Special Rapporteur on the Rights of Persons with Disabilities, *Expert Group Meeting on Indigenous Persons with Disabilities.*, pp.3–4.

Summary

In general, the Crown takes two approaches to meet the health and well-being needs of people with lived experience of disability: 1) provision as part of general health services and other system-wide supports to achieve improved health outcomes (provided, for example, by organisations such as the 20 DHBs); and 2) specific disability support services for those who meet 'eligibility criteria'.

The health and disability sector includes a range of organisations that all have different roles to play when it comes to meeting the health and disability needs of Māori with lived experience of disability, including the Ministry for Children and the Department of Corrections. The Ministry of Health has a purchasing role when it comes to disability support service funding (worth around \$1.2 billion per year) which is generally for those aged under 65 years. District health boards provide most health services throughout Aotearoa/New Zealand, and are required, under Ministry of Health guidance, to implement initiatives to reduce inequities of service access and provision for Māori with lived experience of disability.⁵⁷⁷ However, the devolution of disability to support services to DHBs in the early 2000s, with no follow-through on full devolution to DHBs, nor evaluation of the impacts of such policy on Māori with lived experience of disability, is likely to have contributed to the inequities demonstrated for Māori with lived experience of disability. Additionally, there is no clear evidence that considerations of the equity implications for Māori of an age-related split in DSS planning and funding were duly undertaken.

In addition to being guided by the New Zealand Public Health and Disability Act 2000 and other legislation, the health and disability sector is directed by high-level strategies (in particular the New Zealand Health Strategy and the New Zealand Disability Strategy). Both

⁵⁷⁷ For more discussion on the ways district health boards and other organisations respond to these obligations, refer to Chapter V.

of these note guidance from Treaty of Waitangi principles (adopting principles of participation, partnership and protection), but corresponding requirements or structures that ensure Māori with lived experience of disability are involved in health and disability sector decision making are rare. As a case study, the recent Ministry of Health restructure, which included the reintroduction of a Māori health unit and a Disability directorate, does not appear to have explicitly considered Māori with lived experience of disability, nor involved consultation with Te Ao Mārama, the Māori disability advisory group.

When it comes to Ministry of Health funded disability support services (which generally do not cover supports for personal health conditions, mental health conditions, conditions more commonly associated with aging or those caused by accident or injury), these are predominantly provided by non-Māori organisations. Only 33 Māori-owned and governed providers (or 3.4 per cent of the approximately 980 DSS providers) are contracted by the Ministry of Health.

The Government is prototyping a different model for disability support in the MidCentral DHB region called Mana Whaikaha. The prototype began operations at the end of 2018. As at 24 January 2019, around 17 per cent of people in the 'uptake' for the disability transformation prototype identified as Māori. One in five people in MidCentral identify as Māori.

Aotearoa/New Zealand is a party to a number of international human rights instruments and the monitoring of these have recently raised issues on Crown activity when it comes to Māori with lived experience of disability. The extent however, to which Māori with lived experience of disability have had the opportunity to participate in these international human rights discussions, is unclear.

Chapter IV – Data Review Part 1

Introduction

This chapter presents Part 1 of the data review of the information provided by a selection of Crown organisations under the Official Information Act 1982 (Part 2 of the data review is discussed in Chapter 5).⁵⁷⁸ Findings from the strategic literature review are discussed where relevant to provide contextual information. An overview of health and disability information the Crown holds for Māori with lived experience of disability, and Crown use of this information to inform strategy and policy is provided. This is followed by a presentation of data that examines experiences of Māori, and Māori with lived experience of disability (wherever data is available) within health and disability services (not already addressed by the Crown for Stage II of Wai 2575).⁵⁷⁹ For example: use of seclusion on Māori; experiences of health and disability services for Māori imprisoned by the Crown; and Māori children and young people in the Ministry for Children’s care and protection, and youth justice residences. All data presented in the tables and figures within this chapter is sourced from Crown data supplied to the researcher. Additionally, other than basic descriptive analyses undertaken by the researcher (indicated in the footnotes where applicable), the majority of the data in this chapter is derived from data analyses provided by Crown organisations. A summary of the key issues is then presented at the end of the chapter.

⁵⁷⁸ Also refer to Chapter I for further discussion of the research methods.

⁵⁷⁹ Refer to Chapter I for further information about the research project scope.

Information the Crown holds for Māori with lived experience of disability

Ratima et al., highlight that, ‘...[p]urposeful, consistent and culturally safe information collection based upon confidentiality and guardianship should be emphasised in every disability support service. The collection of ethnic, cultural, disability and circumstances data should be emphasised’.⁵⁸⁰

Ratima and Ratima also state that,

‘...[d]ata quality issues continue to undermine disability support service planning, purchasing, development and delivery for Māori. There are definitional and data collection problems which include inconsistencies in definitions of ethnicity, variable collection methods, and a limited range of data being collected. Further, while conventional measures of impairment and functioning will continue to be useful there are other indicators that may be equally important in understanding Māori impairment and disability, such as outcome measures that capture positive functioning and culturally specific measures.’⁵⁸¹

Both Utiku Potaka et al.,⁵⁸² and Ratima and Ratima emphasise that,

⁵⁸⁰ Mihi M Ratima, Mason H Durie, GR Allan, PS Morrison, A Gillies, and John A Waldon, *He Anga Whakamana: A Framework for the Delivery of Disability Support Services for Māori*. (Palmerston North: Te Pūmanawa Hauora, Massey University, 1995).
<http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/37D7A973746694CF4C2565D700185D8B?opendocument>, p.37.

⁵⁸¹ Ratima and Ratima, “Māori Experience of Disability and Disability Support Services.” *In Hauora: Māori Standards of Health IV. A study of the years 2000–2005*, p.190.

⁵⁸² Utiku K Potaka, Mason H Durie, Mihi Ratima, and John Waldon, *The MDI Framework: Māori Information Management Guidelines for Disability Support Services*. (Palmerston North: Massey University, 1994).
[http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/40DEAFB47CC023B94C2566AF0071E950/\\$file/MDI%20framework.pdf](http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/40DEAFB47CC023B94C2566AF0071E950/$file/MDI%20framework.pdf).

‘...Māori-specific data collection should include not only ethnic data but also cultural data such as hapū and iwi affiliation, access to Māori networks, whānau support, and other information related to those factors that strengthen Māori identity and may reflect positive functioning within Māori cultural contexts. Information about Māori understandings of disability and support service preferences could also be collected. This broader cultural data would inform the development of disability support services tailored to the specific needs of Māori’.⁵⁸³

Databases

An overview of information the Crown holds for Māori, including Māori with lived experience of disability, and Crown use of this information to inform strategy and policy is provided in the following tables. Table 9 presents a summary of the data that the Ministry of Health (MoH) holds for Māori with lived experience of disability by national database and highlights how disability is identified. In addition, Table 9 indicates potential data within each database of relevance to Māori, though there is no indication that the specified data is currently used by the MoH for Māori with lived experience of disability. Table 10 discusses the data that the MoH primarily uses for monitoring the performance of the health and disability system in relation to Māori with lived experience of disability, whilst Table 11 outlines the data the MoH states it primarily uses for the purposes of health and disability policy.

There are a number of available national databases that could be used to provide information that supports addressing the health aspirations and needs of Māori with lived experience of disability. However, only a few data sources appear to be used to inform monitoring of the quality of health and disability services for Māori with lived experience of disability, or to inform health and disability policy advice. These have a somewhat narrow

⁵⁸³ Ratima and Ratima, “Māori Experience of Disability and Disability Support Services.” *In Hauora: Māori Standards of Health IV. A study of the years 2000–2005*, p.190.

focus, specifically pertaining to mental health services (PRIMHD database), and disability support services (Socrates database). In the case of the Socrates database (relating to disability support services), the data only relates to people who meet 'eligibility criteria' for disability support services. The data is thus service-centric and does not necessarily cover the health and well-being aspirations, or support needs of Māori with lived experience of disability.

Disability is not able to be identified in the majority of the national health surveys, however, the Washington Group Short Set (WGSS) has been added to the 2018/19 *New Zealand Health Survey* for adults and children. The WGSS questions are not designed to measure prevalence of disability. Rather, they are used as a categorical variable (for example, by ethnic group or sex) to allow for comparison of outcomes by different population sub-groups. Additionally, the WGSS questions are informed by a Western model, and have not been designed for Indigenous peoples.⁵⁸⁴

Regarding the improvement of data coverage and quality for Māori with lived experience of disability, Action 9E of the *Disability Action Plan 2014–18* 'Implement the work programme of the Disability Data and Evidence Working Group (the Working Group), including a focus on Māori and Pasifika' was not completed. With the release of the *New Zealand Disability Strategy* in 2016, the Working Group's focus shifted from completing Action 9E to supporting the development of the *New Zealand Disability Strategy Outcomes Framework*.

On statistics and data collection generally, Statistics New Zealand (Stats NZ) has indicated that participation in the most recent Census in 2018 is significantly less than in previous years. While administrative data has been used to compensate for incomplete Census data age, sex, ethnicity, and Māori descent, Stats NZ has stated that,

⁵⁸⁴ Statistics New Zealand, *Improving New Zealand disability data*, (Wellington: Statistics New Zealand, 2017). <https://www.stats.govt.nz/assets/Reports/Improving-New-Zealand-disability-data/improving-new-zealand-disability-data.pdf>.

‘...some Census data may not be judged of sufficient quality for release as official statistics...Stats NZ will not release official statistical counts of iwi, because of the level of missing iwi affiliation data, and the lack of alternative government data sources to fill the gaps.’⁵⁸⁵

Poor data coverage and quality for Māori with lived experience of disability will thus be compounded by the disproportionate impacts that the poorly run 2018 Census has on Māori. This is because Census data are used for distribution of resources (for example, district health board funding), monitoring of the Crown’s actions, and in the case of Iwi and Hapū affiliation in particular, used by Māori to support their own aspirations.⁵⁸⁶

⁵⁸⁵ Statistics New Zealand, “2018 Census – real data about real people.” 29 April 2019. <https://www.stats.govt.nz/news/2018-census-real-data-about-real-people>.

⁵⁸⁶ Tahu Kukutai and Donna Cormack, “Census 2018 and Implications for Māori.” *New Zealand Population Review*. 2018. 44: 131–151. https://population.org.nz/app/uploads/2019/02/NZPR-Vol-44_Kukutai-and-Cormack.pdf.

Table 9: Data the Ministry of Health holds for Māori with lived experience of disability

Ministry of Health database	Database purpose	How is disability identified?	What data held could relate to Māori
Disability – Socrates national database	Used by 15 Needs Assessment and Service Coordination (NASC) organisations across Aotearoa/New Zealand, which assess the disability needs and allocate services for, people eligible for MoH disability support services (DSS).	According to the MoH, DSS eligible clients are people who have been identified as having a physical, intellectual or sensory disability (or a combination of these) which is likely to continue for a minimum of six months and result in the reduction of independent function to the extent that ongoing support is required.	<ul style="list-style-type: none"> • Client Demographic Data (eg Name, Gender, Date of Birth and, where applicable, Date of Death, Ethnicity, including Iwi and Hapū where applicable, Disability). • Referral (eg Date of the Referral, Outcome of the Referral, Eligibility Assessment (where applicable)). • Legal status (eg legislation and section under which each care order is made). • Needs Assessment (eg Functional Support Needs, Clients Goals) • Service Coordination (eg DSS funded Service Allocation and Coordination, Non-DSS funded Service Allocation, Unmet Needs)

Ministry of Health database	Database purpose	How is disability identified?	What data held could relate to Māori
Mental Health – Programme for the Integration of Mental Health Data (PRIMHD) Dataset	PRIMHD is a single national mental health and addiction information collection of service activity and outcomes data for people who access specialist mental health or addiction services. It is used to report on what services are being provided, who is providing the services and what outcomes are being achieved for across Aotearoa/New Zealand’s mental health sector.	The PRIMHD national data collection does not contain information about whether an individual is disabled. The MoH states that it does not have an agreed definition of what might be considered a ‘Psychiatric Disability’. However, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) defines the term disability to include mental illness. Seclusion in a mental health facility, for example, can only occur under the Mental Health (Compulsory Assessment and Treatment) Act, therefore the MoH states that anyone who is secluded could be considered as having a disability as per the UNCRPD.	<ul style="list-style-type: none"> • Referrals (from 1 July 2008 onwards) • Activities (services from 1 July 2008 onwards) • Legal Statuses (from 1 July 2008 onwards) • Outcomes (result of services; from 1 July 2008 onwards) • Demography information (from 1 July 2008 onwards)
Client Claims Processing System (CCPS)	Makes and records payments to health providers – both MoH and district health board (DHB) funded – payments to Rest Homes, Respite Care, Carer Support, and National Travel Assistance.	Disability information is required as this determines the funder. This is based on the Needs Assessment information that is provided by Socrates (Ministry DSS Clients). DHB’s Needs Assessor and Service Coordination’s submit completed form with the disability.	<ul style="list-style-type: none"> • As for NASC above, and also Invoice data (eg Provider details, Contract specific for the payment, Service to be billed for, Start Date and End Date of the Service Periods, Invoice Period).

Ministry of Health database	Database purpose	How is disability identified?	What data held could relate to Māori
Contract Management System (CMS)	Administers the Health Contracts for both the MoH and DHB Providers. CMS system information supports the other payment systems that the Ministry has. CMS system feeds information into other systems such as Proclaim, Oracle Financials and so on.	CMS contains data on the providers of the health and disability services that they provide to the sector.	<ul style="list-style-type: none"> • Contract Names • Contract Descriptions • Health Provider Contact Details • Funder • Financial Information • Budget Allocation
National Minimum Dataset (NMDS)	A national collection of public and private hospital discharge information including coded clinical data. It is used by the MoH, DHBs, primary health organisations, clinicians, researchers and members of the public for statistical information, clinical benchmarking, and planning and funding on both a national and provider basis.	Disabilities are classified using ICD-10-AM codes when they are responsible for the hospitalisation or are coexisting during an episode of admitted patient care. The National Health Index (NHI) number does not record Disability Status.	<ul style="list-style-type: none"> • Diagnoses • External causes of injury • Procedures • Cost weight • Diagnosis Related Groups (DRGs) • Purchase unit codes • Health specialty codes • Demographic information • Name of agency and facility • Admission and discharge dates • NHI number

Ministry of Health database	Database purpose	How is disability identified?	What data held could relate to Māori
National Non-Admitted Patient Collection (NNPAC)	Provides nationally consistent data on non-admitted patient (outpatient and emergency department) activity. Its main purposes are to monitor non-admitted patient attendances, analyse and calculate Inter District Flows (IDFs) and inform decisions on funding allocations and policy.	Purchase unit codes can be used to identify the type of service the patient attended eg if a DSS1022 (services child disability) purchase unit code was recorded then one could infer that the patient has a disability. Health specialty codes reflect the nature of the healthcare provided eg D40 Physical disability, A, T & R sub-series.	<ul style="list-style-type: none"> • Purchase unit codes • Health specialty codes • Demographic information • Date of service • Name of agency and facility • NHI number
New Zealand Health Survey		<p>Identification of disability is currently not possible in the New Zealand Health Survey. This makes it difficult to identify whether some Māori have a disability within the Ministry's datasets.</p> <p>The 2018/19 and 2019/20 Health Survey measure disability status using the Washington Group Short Set (WGSS). The MoH states that it plans to publish the 2018/19 Health Survey Data Explorer statistics for disabled/not disabled adult sub-populations at the end of this year but not dis-aggregated by Māori. The WGSS is not used to estimate disability prevalence.</p>	<ul style="list-style-type: none"> • Data may be pooled for the 2018/19 and 2019/20 surveys to compare Māori disabled and Māori non-disabled adults on many indicators.

Source: Ministry of Health⁵⁸⁷

⁵⁸⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1b MoH response 2 appendix.

Table 10: Ministry of Health’s main data used for monitoring performance of the health and disability system in relation to Māori with lived experience of disability

Māori data and information	Monitoring applications
<p>Disability Support Services (DSS)</p> <p>Equipment and modifications services (EMs)</p> <p>Learning/intellectual disability</p> <p>System transformation</p>	<ul style="list-style-type: none"> • Used to monitor implementation of <i>Whāia Te Ao Mārama 2018–2022: The Māori Disability Action Plan</i>. • Used for the administration of funding, planning and monitoring of national disability support services, national equipment and modifications, the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, and System Transformation/Mana Whaikaha funded services. • Supports monitoring compliance with domestic obligations (eg New Zealand Human Rights national Plan of Action) and international obligations (eg Convention on the Rights of Persons with Disabilities).
<p>Mental health</p>	<ul style="list-style-type: none"> • Used for planning, funding and monitoring purposes. • Used for statutory annual reporting (eg annual reports by the Office of the Director of Mental Health). • Used for Māori-specific performance monitoring. For example, the MoH has a measure that monitors the rate of Māori under Mental Health Act community treatment orders, though there is no target. In its most recent annual report by the Office of the Director of Mental Health (released early 2019), the MoH states, ‘this is a specific action outlined in <i>Rising to the Challenge</i>. In addition, the number of Māori subject to section 29 of the Mental Health Act is now an indicator in the Māori health plans that the Ministry requires every DHB to produce’.⁵⁸⁸ <p>However, requirements for the Māori health plans were removed by the MoH in 2016.</p> <ul style="list-style-type: none"> • Supports monitoring compliance with domestic obligations and international obligations.

Source: Ministry of Health⁵⁸⁹

⁵⁸⁸ Ministry of Health, Office of the Director of Mental Health Annual Report 2017, Ministry of Health (Wellington, 2019), <https://www.health.govt.nz/system/files/documents/publications/office-of-the-director-of-mental-health-and-addiction-services-annual-report-2017-v2.pdf>, p31.

⁵⁸⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1b MoH response 2 appendix.

Table 11: The Ministry of Health’s main disability data used for Māori for health and disability policy purposes

Māori data and information	Health and disability policy applications
Disability via Socrates	<ul style="list-style-type: none"> • Informs disability advice to Minister and Associate Ministers of Health. • Provides public with demographic and service utilisation data on the Māori disability client group. • Supports strategic and business planning for <i>Whāia Te Ao Mārama 2018–2022: The Māori Disability Action Plan</i>. • Used in funding, planning and monitoring of national disability support services, system transformation/Mana Whaikaha prototype. • Supports data compliance in international obligations eg UNCRPD
Learning/Intellectual Disability – seclusion data via PRIMHD	<ul style="list-style-type: none"> • The MoH states that the data in PRIMHD on learning/intellectual disability is not accurate. • The MoH for the first time has separated the data on seclusion for care recipients under the Intellectual Disability Compulsory Care and Rehabilitation Act 2003 from data on patients under the Mental Health (Compulsory Assessment and Treatment) Act 1992 and reported on this in the <i>Office of the Director of Mental Health and Addiction Services Annual Report 2017</i> (published early 2019) to allow for understanding of the use of seclusion for each group.
Mental health via PRIMHD	<ul style="list-style-type: none"> • Informs mental health policy advice to the Minister of Health. • Helps the MoH manage the national mental health system and improve the provision of mental health services. • Supports the implementation of government policy through collaborative efforts with district health boards, and for the administration of mental health legislation. • Supports MoH responsibilities in the Disability Action Plan,⁵⁹⁰ the New Zealand Human Rights National Plan of Action, and for international obligations with United Nations instruments such as the UNCRPD and the United Nations Convention Against Torture.

Source: Ministry of Health⁵⁹¹

⁵⁹⁰ Refer to Chapter III regarding the update of the Disability Action Plan.

⁵⁹¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1b MoH response 2 appendix.

Health and disability research

With regard to the contribution of high quality research towards the provision of information for addressing health and well-being of Māori with lived experience of disability, the Health Research Council is the Crown entity responsible for promoting and funding health research under the Health Research Council Act 1990.⁵⁹² The Health Research Council Act itself, makes no mention of disability. It defines health research as,

‘...research that has or may have relevance to human health; and includes biomedical research and public health research...biomedical research [includes] research in the biomedical sciences relevant to human health; and research into the causes, consequences, diagnosis, and treatment of human illness, [and] public health research means research into factors that influence the health of a population; and includes—research into health systems and health services; and research into the environmental, socio-economic, cultural, and behavioural factors that determine health status’.⁵⁹³

The Health Research Council states that it has ‘...funding mechanisms dedicated to advancing Māori health research...Though these funds are not ring-fenced for research operating at the intersection of health and disability services, they are designed to be leveraged by community groups to finance research that is self-determined and best fits the needs of the community’.⁵⁹⁴

Table 12(a) outlines the Health Research Council’s total funding for Māori and non-Māori separated by funding output type, per year, for the five-year timeframe 2014 to 2018.

⁵⁹² Health Research Council Act 1990.

⁵⁹³ Health Research Council Act 1990, s.2.

⁵⁹⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 6 HRC response.

Table 12(b) shows the proportion of funding for Māori and non-Māori separated by funding output type, per year, for the five-year timeframe 2014 to 2018.⁵⁹⁵

Both tables show that the proportion of funding for health research has decreased for Māori, whilst increased for non-Māori over the five-year period from 2014 to 2018. The proportion of funding for Māori was 12.14 per cent (compared with 87.87 per cent for non-Māori) in 2014, decreasing to 10.68 per cent (compared with 89.32 per cent for non-Māori) in 2018.⁵⁹⁶

Both tables also demonstrate that Māori are more likely to receive funding for earlier career development, for example, career development awards, rather than for substantive health research contracts where the relative proportion of funding received for Māori is lower (33.9 per cent compared with 7.71 per cent in 2018). This was the opposite for non-Māori who, 2018 were more likely to receive funding for substantive health research contracts (92.29 per cent) compared with earlier career development (66.1 per cent).⁵⁹⁷

As the Health Research Council does not ring-fence funding for Māori health research pertaining to disability, this places Māori with lived experience of disability in the position of applying for contested funding, along with all other applicants (Māori and non-Māori). It is difficult to discern how this situation could support the advancement of Māori health and disability research that meets the aspirations and needs of Māori with lived experience of disability, their whānau and communities. It is particularly so for an area where capacity and capability building in health and disability research by, and for, Māori with lived experience of disability is urgently required.

⁵⁹⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 6 HRC response.

⁵⁹⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 6 HRC response. Original analysis undertaken by researcher.

⁵⁹⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 6 HRC response. Original analysis undertaken by researcher.

Table 12a: Total funding for Māori and non-Māori separated by funding output type, per year, for the five-year timeframe 2014 to 2018 (All figures in NZ dollars \$)

Output type	Māori	non-Māori	Grand total
2014	\$14 406 146	\$104 328 162	\$118 734 308
Career development award	1 992 089	5 212 004	7 204 093
Co-funding agreement	0	5 096 962	5 096 962
Health research contract	12 414 057	94 019 196	106 433 253
2015	\$8 789 575	\$63 573 333	\$72 362 908
Career development award	2 016 793	4 054 534	6 071 327
Co-funding agreement	0	1 789 411	1 789 411
Health research contract	8 610 680	90 838 835	99 449 514
2016	\$16 472 854	\$96 595 048	\$113 067 902
Career development award	1 772 714	7 235 069	9 007 783
Co-funding agreement	0	1 789 411	1 789 411
Health research contract	14 700 140	87 570 568	102 270 708
2017	\$14 700 157	\$104 136 156	\$118 836 313
Career development award	2 923 893	6 075 213	8 999 106
Co-funding agreement	3 165 584	7 222 109	10 387 693
Health research contract	14 700 140	87 570 568	102 270 708
2018	\$11 731 201	\$98 116 596	\$109 847 797
Career development award	2 297 362	4 478 547	6 775 909
Co-funding agreement	1 865 879	3 020 264	4 886 143
Health research contract	7 567 960	90 617 785	98 185 745
Total funding 2014–2018	\$66 099 933	\$466 749 295	\$532 849 228

Source: Health Research Council of New Zealand

Table 12b: Proportion (%) of funding for Māori and non-Māori separated by funding output type, per year, for the five-year timeframe 2014 to 2018

Output type	Māori	non-Māori
2014	12.13%	87.87%
Career development award	27.65%	72.35%
Co-funding agreement	0.00%	100.00%
Health research contract	11.66%	88.34%
2015	12.15%	87.85%
Career development award	33.22%	66.78%
Co-funding agreement	0.00%	100.00%
Health research contract	10.49%	89.51%
2016	14.57%	85.43%
Career development award	19.68%	80.32%
Co-funding agreement	0.00%	100.00%
Health research contract	14.37%	85.63%
2017	12.37%	87.63%
Career development award	32.49%	67.51%
Co-funding agreement	30.47%	69.53%
Health research contract	8.66%	91.34%
2018	10.68%	89.32%
Career development award	33.90%	66.10%
Co-funding agreement	38.19%	61.81%
Health research contract	7.71%	92.29%
Total funding % 2014–2018	12.40%	87.60%

Source: Health Research Council of New Zealand

Seclusion and restraint of Māori with lived experience of disability

The following section focuses on the use of seclusion and restraint on Māori with lived experience of disability in health and disability services. All of the data presented in the tables and figures within the following sections has been prepared from Crown data sources. Additionally, other than some basic descriptive analyses by the researcher (indicated within the body of the text where applicable), the majority of the data has been prepared from the data analyses provided by the Crown.

Why is the use of seclusion and restraint important to examine?

In November 2017, the Independent Monitoring Mechanism (IMM) made a submission to the Committee on the Rights of Persons with Disabilities (the Committee) with suggestions to the Committee's *List of issues prior to submission of the combined second and third periodic reports of New Zealand*. Addressing overuse of seclusion and restraint (including for people in detention) was one of the key priority areas in the IMM submission,⁵⁹⁸ and was subsequently included by the Committee.⁵⁹⁹

Sharon Shalev, an international expert in the field of solitary confinement and seclusion, completed an independent review of seclusion and restraint practices in a number of Aotearoa/New Zealand detention settings in 2016. The review report, *Thinking outside the box? A review of seclusion and restraint practices in New Zealand*, states,

⁵⁹⁸ Refer to Chapter III for further discussion.

⁵⁹⁹ Committee on the Rights of Persons with Disabilities, *List of issues prior to submission of the combined second and third periodic reports of New Zealand*. CRPD/C/NZL/QPR/2-3. (New York: United Nations, 2018).
https://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=En&CountryID=124.

‘Overall, data collected by the Ministry of Health and the Department of Corrections on the use of seclusion and restraint in New Zealand revealed a high use. The data also clearly showed that ethnic minority groups, in particular Māori, were overrepresented in seclusion and segregation units. This was very concerning and needs to be investigated further. Some of the restraints which were used included forms of mechanical restraint which several jurisdictions, including England and Wales, no longer use’.⁶⁰⁰

Action 9(d) of the *Disability Action Plan 2014–2018* was to, ‘...explore how the Mental Health (Compulsory Assessment and Treatment) Act 1992 relates to the New Zealand Bill of Rights Act 1990 and the CRPD [Convention on the Rights of Persons with Disabilities]’.⁶⁰¹

‘Action 9(d) was completed and the findings were reported back to Ministers in July 2017. The key issues and concerns raised as a result of Action 9(d) [included]...greater priority given to reducing and eliminating seclusion and restraint’.⁶⁰²

The elimination of seclusion in Aotearoa/New Zealand is important for Māori who are more likely to experience seclusion than any other ethnic groups in Aotearoa/New Zealand. Inequities in the use of seclusion for Māori compared with non-Māori have been documented over the last 17 years,⁶⁰³ yet continue to persist within health and disability

⁶⁰⁰ Sharon Shalev, *Thinking Outside The Box? A Review of Seclusion and Restraint Practices in New Zealand*, (Wellington: Human Rights Commission, 2017), <https://www.seclusionandrestraint.co.nz/>, p.26.

⁶⁰¹ Office for Disability Issues, *Disability Action Plan 2014-2018* (Wellington: Office for Disability Issues, 2014), <https://www.odi.govt.nz/nz-disability-strategy/disability-action-plan/disability-action-plan-2014-2018/>.

⁶⁰² Ministry of Health, *Office of the Director of Mental Health Annual Report 2017*, (Wellington: Ministry of Health, 2019), <https://www.health.govt.nz/system/files/documents/publications/office-of-the-director-of-mental-health-and-addiction-services-annual-report-2017-v2.pdf>.p16.

⁶⁰³ Ministry of Health, *Office of the Director of Mental Health Annual Report 2017*; Ministry of Health, *Office of the Director of Mental Health Annual Report 2016*, (Wellington: Ministry of Health, 2017), <https://www.health.govt.nz/publication/office-director-mental-health-annual-report-2016>.; Mental Health Commission, *Seclusion in New Zealand Mental Health Services*, (Wellington: Mental Health Commission, 2004); Melissa McLeod, Paula T King, James Stanley, Cameron Lacey, Ruth Cunningham, and Shirley Simmonds, *The use of seclusion for Māori in adult inpatient mental health services in New Zealand*, (Wellington: Te Pou o Te Whakaaro Nui, 2013), <https://www.tepou.co.nz/uploads/files/resource->

services in Aotearoa/New Zealand. The most recent report, *Office of the Director of Mental Health and Addiction Services: Annual Report 2017*, highlights,

‘Māori were more likely than non-Māori to have been secluded, have greater numbers per 100,000 population of seclusion events, and of greater average duration’.⁶⁰⁴

The report, *Thinking outside the box? A review of seclusion and restraint practices in New Zealand*, states,

‘The apparent overrepresentation of ethnic minorities, in particular Māori in seclusion and segregation units in prisons and health and disability units should be investigated further as a matter of urgency’.⁶⁰⁵

The use of seclusion in health and disability services is provided for under section 71 of the Mental Health (Compulsory Assessment and Treatment) Act 1993 (MH(CAT) Act) and section 60 of the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (ID(CC&R) Act).^{606,607} Standards New Zealand defines seclusion as a situation whereby, ‘...a

assets/the-use-of-seclusion-for-Maori-in-adult-inpatient-mental-health-services-in-New-Zealand.pdf.; Melissa McLeod, Paula T King, James Stanley, Cameron Lacey and Ruth Cunningham, “Ethnic disparities in the use of seclusion for adult psychiatric inpatients in New Zealand,” *The New Zealand Medical Journal* 130, no. 1454 (2017), <https://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2017/vol-130-no-1454-28-april-2017/7225>.; Selim M El-Badri and Graham Mellsop, “A study of the use of seclusion in an acute psychiatric service”, *Australian and New Zealand Journal of Psychiatry* 36, no. 3 (2002), <https://journals.sagepub.com/doi/abs/10.1046/j.1440-1614.2002.01003.x>.

⁶⁰⁴ Ministry of Health, *Office of the Director of Mental Health Annual Report 2017*., p.41.

⁶⁰⁵ Shalev, *Thinking Outside The Box? A Review of Seclusion and Restraint Practices in New Zealand*., p.58

⁶⁰⁶ Mental Health (Compulsory Assessment and Treatment) Act 1993, s.71; Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, s.60.

⁶⁰⁷ Ministry of Health, *Seclusion under the Mental Health (Compulsory Assessment and Treatment) Act 1992*, (Wellington: Ministry of Health, 2010), <https://www.health.govt.nz/publication/seclusion-under-mental-health-compulsory-assessment-and-treatment-act-1992>., p.44; Ministry of Health, *A Guide to the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003*, (Wellington: Ministry of Health, 2004), <https://www.health.govt.nz/system/files/documents/publications/idccrguidelines-intellectualdisability.pdf>.

consumer is placed alone in a room or area, at any time and for any duration, from which they cannot freely exit'.⁶⁰⁸ Section 60(1) of the ID(CC&R) Act defines seclusion as the,

'...placing [of] the care recipient without others in a room or other area that provides a safe environment for the care recipient throughout the care recipient's stay in the room or area; but does not allow the care recipient to leave without help'.⁶⁰⁹

The MH(CAT) Act does not contain specific provisions for the use of restraint. However, section 122B sanctions the use of such force in certain emergency situations, '...as may be reasonably necessary in the circumstances'.⁶¹⁰ Under section 61(1) of the ID(CC&R) Act, a 'care recipient' may be restrained if,

'...necessary to prevent the care recipient from doing 1 or more of the following:
(a) endangering the health or safety of the care recipient or of others; (b) seriously damaging property; [and] (c) seriously compromising the care and well-being of the care recipient or of other care recipients'.⁶¹¹

The Ministry of Health (MoH) states that the use of seclusion, '...should be an uncommon event, and services should use it only when there is an imminent risk of danger to the individual or others and no other safe and effective alternative is possible'.⁶¹² Jennifer Lai et.al., point out however, that, '...current literature and best practice frameworks widely recognize the negative impact of seclusion on people's individual freedom and well-

⁶⁰⁸ Standards New Zealand, *Health and Disability Services (General) Standard*, (Wellington: Standards Council, 2008), p.30.

⁶⁰⁹ Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, s.60(1).

⁶¹⁰ Mental Health (Compulsory Assessment and Treatment) Act 1993, s.122B.

⁶¹¹ Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, s.61(1).

⁶¹² Ministry of Health, *Office of the Director of Mental Health Annual Report 2017.*, p.40.

being'.⁶¹³ The report, *Thinking outside the box? A review of seclusion and restraint practices in New Zealand*, also states,

'While the Ministry of Health and the DHBs' high-level commitment to the reduction and eventual elimination of seclusion was clear, the necessary change of mindset was not always evident on the ground, with some patients (or 'clients') spending much of their time in seclusion and/or restraint...

...we were told that placements...were "usually driven by perceived dangerousness; actual assault on staff; overstimulation; risk of escape and overcrowding". Overcrowding is not a justifiable reason for locking up a patient in a small, barren room with no personal belongings for days on end, nor is it provided for under the Mental Health (Compulsory Assessment and Treatment) Act 1992...

In all units visited, seclusion rooms resembled prison segregation cells, and were mostly barren other than a mattress and bedding'.⁶¹⁴

The report also criticises the lack of appropriate monitoring regarding the use of restraint in health and disability services, stating,

'The statistical data for restraint incidents did not record the reason for use of restraints. Furthermore, incidents involving the use of restraint were not collated and analysed nationally'.⁶¹⁵

In addition to the known significant inequities in the use of seclusion on Māori compared with non-Māori, there is also significant variation in seclusion rates between the district

⁶¹³ Jennifer Lai, Angela Jury, Jenny Long, David Fergusson, Mark Smith, Sarah Baxendine, and Angela Gruar, "Variation in seclusion rates across New Zealand's specialist mental health services: Are sociodemo-graphic and clinical factors influencing this?", *International Journal of Mental Health Nursing* 28 (2019), <https://doi.org/10.1111/inm.12532>, p.289.

⁶¹⁴ Shalev, *Thinking Outside The Box? A Review of Seclusion and Restraint Practices in New Zealand.*, pp.36-37.

⁶¹⁵ Shalev, *Thinking Outside The Box? A Review of Seclusion and Restraint Practices in New Zealand.*, p.38

health boards (DHBs) across Aotearoa/New Zealand.⁶¹⁶ Lai et. al., investigated the extent to which this variation could be explained by differences in sociodemographic and clinical factors of populations admitted to adult mental health services. They report that,

‘...variation in seclusion rates between DHB adult mental health inpatient services cannot be attributed to the sociodemographic or clinical characteristics of people admitted to these services. Instead, variation between DHB seclusion rates is more likely to be related to other factors, such as the organizational culture of the unit and factors related to clinical practice’.⁶¹⁷

The MoH reports a decrease in the total number of people secluded, and the total number of seclusion hours in adult inpatient services since 2007, and following the introduction of the national seclusion reduction policy in 2009 (but also reports that decreasing seclusion trends have steadied).⁶¹⁸

‘Between 2009, when the seclusion reduction policy was introduced, and 2017, the total number of people secluded in adult inpatient services nationally decreased by 28 per cent. The total number of seclusion hours for people in adult inpatient services nationally decreased by 59 per cent’.⁶¹⁹

‘Between 2016 and 2017, while the total number of people who were secluded decreased by 3 percent, the number of events increased by 6 percent and the hours spent in seclusion increased by 8 percent’.⁶²⁰

⁶¹⁶ Lai et al., “Variation in seclusion rates across New Zealand’s specialist mental health services: Are sociodemo-graphic and clinical factors influencing this?.”; Ministry of Health, *Office of the Director of Mental Health Annual Report 2016.*; Ministry of Health, *Office of the Director of Mental Health Annual Report 2017.*

⁶¹⁷ Lai et al., “Variation in seclusion rates across New Zealand’s specialist mental health services: Are sociodemo-graphic and clinical factors influencing this?.”, p.294.

⁶¹⁸ Ministry of Health, *Office of the Director of Mental Health Annual Report 2017.*

⁶¹⁹ Ministry of Health, *Office of the Director of Mental Health Annual Report 2017.*, p.42.

⁶²⁰ Ministry of Health, *Office of the Director of Mental Health Annual Report 2017.*, p.42.

The report also states that, for the number of Māori and non-Māori aged 20–64 years secluded in adult inpatient services from 2007 to 2017,

‘Nationally over this time, the [total] number of people secluded decreased by 32 percent. The number of people secluded who identified as Māori decreased by 17 percent over the same time’.⁶²¹

Whether or not the reduction in seclusion use over time has occurred for all Māori who are admitted to inpatient services in Aotearoa/New Zealand remains unclear. The MoH only reports on trends over time in the use of seclusion in the adult inpatient services. It does not report on use for all inpatient services over time, for example forensic (adult or youth), learning/intellectual disability, and youth services.

The MoH does report, however, on selected seclusion indicators annually for some inpatient services. For example, for care recipients with a legal status under the ID(CC&R) Act⁶²² or for forensic mental health services. However, these are not disaggregated by Māori compared with non-Māori.⁶²³

Trends in seclusion use over time in health and disability services

The following section provides additional information to that which has been published by the MoH to date on the use of seclusion both on Māori as a population group, and on Māori with lived experience of disability in Aotearoa/New Zealand. Note that data on the use of restraint has never been collated nor reported by the MoH, and therefore, was not

⁶²¹ Ministry of Health, *Office of the Director of Mental Health Annual Report 2017.*, p.48.

⁶²² Seclusion reported under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 is reported by statute only and not by the service. Thus, people may be secluded under the Mental Health (Compulsory Assessment and Treatment) Act 1993 whilst being treated within a Regional Intellectual Disability Secure Service as there is overlap in seclusion data between legal status and service. Refer to Ministry of Health, *Office of the Director of Mental Health Annual Report 2017.*

⁶²³ Ministry of Health, *Office of the Director of Mental Health Annual Report 2017.*

able to be examined for Māori for the Tribunal judiciary process. With regard to the monitoring of the use of restraint, although the MoH states,

‘DHBs are required to report restraint events in accordance with the *Health and Disability Services (Restraint Minimisation and Safe Practice Standard) 2008* at a local level. There has never been a requirement for DHBs to report restraint events to PRIMHD although the Ministry is currently developing guidelines for the use and reporting of restraint so that consistent data can be collected at a national level – the intention is for this to be collected initially by manual reporting mechanisms with the goal of restraint data being collected via PRIMHD in the future’.⁶²⁴

The data presented in the following figures and tables is sourced from the MoH Programme for the Integration of Mental Health Data (PRIMHD) dataset.⁶²⁵ Of note, the tables and figures presented below do not match the Office of the Director of Mental Health (ODMH) annual reports secondary to different data extraction dates by the MoH. Also, the ODMH includes some manual data for some of the DHBs whereas this analyses only includes data from PRIMHD only.⁶²⁶

With regard to monitoring the use of seclusion on people with lived experience of disability in health and disability services, and providing disaggregation by impairment type (for example, by physical or sensory impairment), the MoH states,

⁶²⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1zc Ministry of Health Clarifying question on Restraint reporting to PRIMHD.

⁶²⁵ PRIMHD is the Ministry of Health’s national collection for mental health and addiction service and outcome data. It became obligatory for district health boards to report to PRIMHD in 2008. Non-governmental organisations also report to the PRIMHD database with 204 NGOs were reporting to PRIMHD as at December 2017. Refer to Ministry of Health, *Office of the Director of Mental Health Annual Report 2017*.

⁶²⁶ It also includes eight clients not reported to PRIMHD, and excludes one outlier client. Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health Request 1.

‘The PRIMHD national data collection does not contain information about whether an individual is disabled. However, the [United Nations Convention on the Rights of Persons with Disabilities] UNCRPD defines the term disability to include mental illness. Seclusion in a mental health facility can only occur under the Mental Health Act, therefore anyone who is secluded could be considered as having a disability as per the CRPD’.⁶²⁷

The MoH thus includes all people who are secluded under the MH(CAT) Act as having disability, stating,

‘In interpreting the mental health seclusion data, we would suggest that the people secluded under the Mental Health Act, including Māori, are considered as having a disability as per the [United Nations Convention on the Rights of Persons with Disabilities] UNCRPD’.⁶²⁸

The following three figures show the total rates of Māori secluded under the MH(CAT) Act compared with non-Māori, the rates of Māori secluded compared with non-Māori for adult inpatient services, and the rates of Māori secluded compared with non-Māori in forensic inpatient services, per year, for the 10-year period 2008 to 2017 (Figures 2–4).⁶²⁹

Figure 2 shows the show the total rates of Māori secluded compared with non-Māori per year, for the 10-year period 2008 to 2017.⁶³⁰ In 2009, when the seclusion reduction policy

⁶²⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health Request 1.

⁶²⁸ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g MoH Response 3 main appendix.

⁶²⁹ Inpatient services examined included: adult; forensic; and youth services, though people may be secluded under the Mental Health (Compulsory Assessment and Treatment) Act 1993 whilst being treated within a Regional Intellectual Disability Secure Service as there is overlap in seclusion data between legal status and service. Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health Request 1.

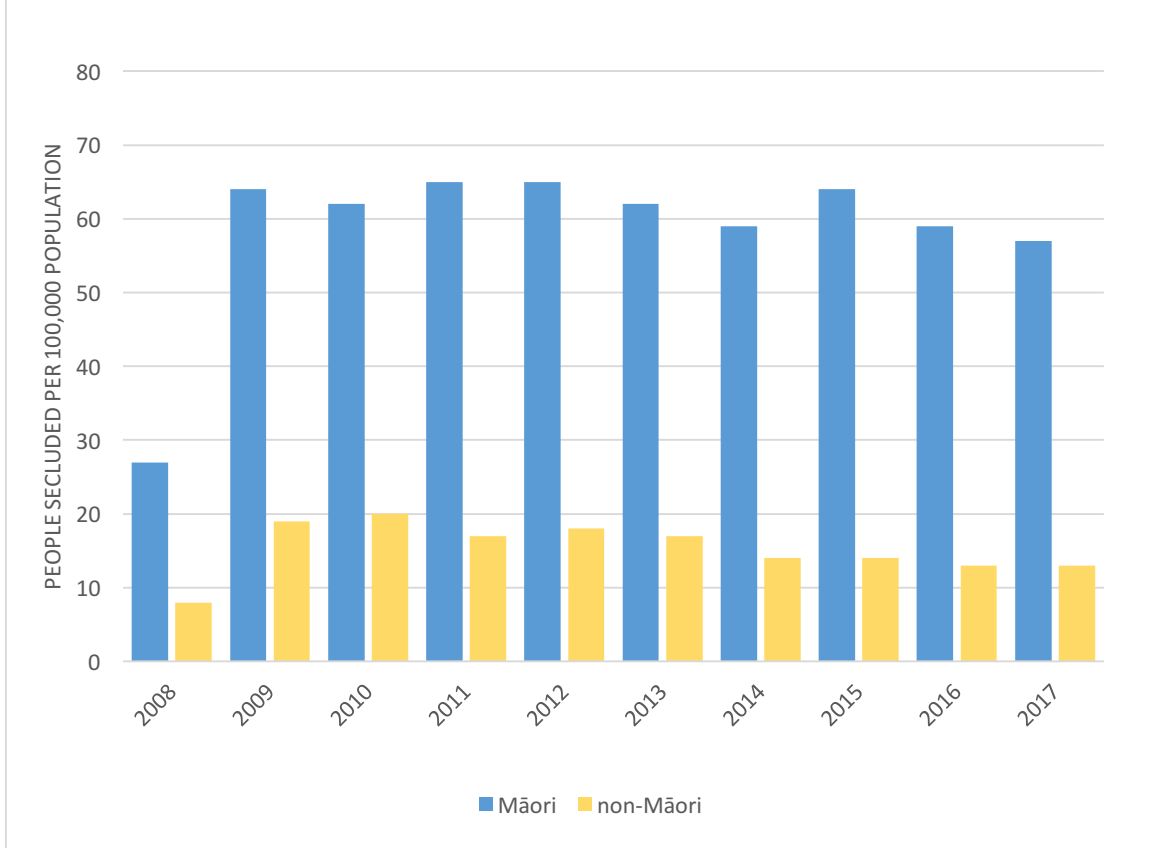
⁶³⁰ Note that the increase in rates for both Māori and non-Māori between 2008 to 2009 is likely due to increased reporting of data to the PRIMHD database as the implementation of mandatory reporting for district health boards commenced from 2008 onwards.

was introduced, the rate for Māori was 64 per 100,000 population compared with 19 per 100,000 population for non-Māori. In 2017, the rate for Māori was 57 per 100,000 population compared with 13 per 100,000 population for non-Māori.

Figure 3 shows the rate of Māori secluded compared with non-Māori in adult inpatient services per year, for the 10-year period 2008 to 2017. In 2009, when the seclusion reduction policy was introduced, the rate for Māori was 89 per 100,000 population compared with 25 per 100,000 population for non-Māori. In 2017, the rate for Māori was 84 per 100,000 population compared with 18 per 100,000 population for non-Māori.

Figure 4 shows the rate of secluded Māori compared with non-Māori in forensic inpatient services per year, for the 10-year period 2008 to 2017. In 2009, the rate for Māori was 21 per 100,000 population compared with 3 per 100,000 population for non-Māori. In 2017, the rate for Māori was 13 per 100,000 population compared with 1 per 100,000 population for non-Māori.

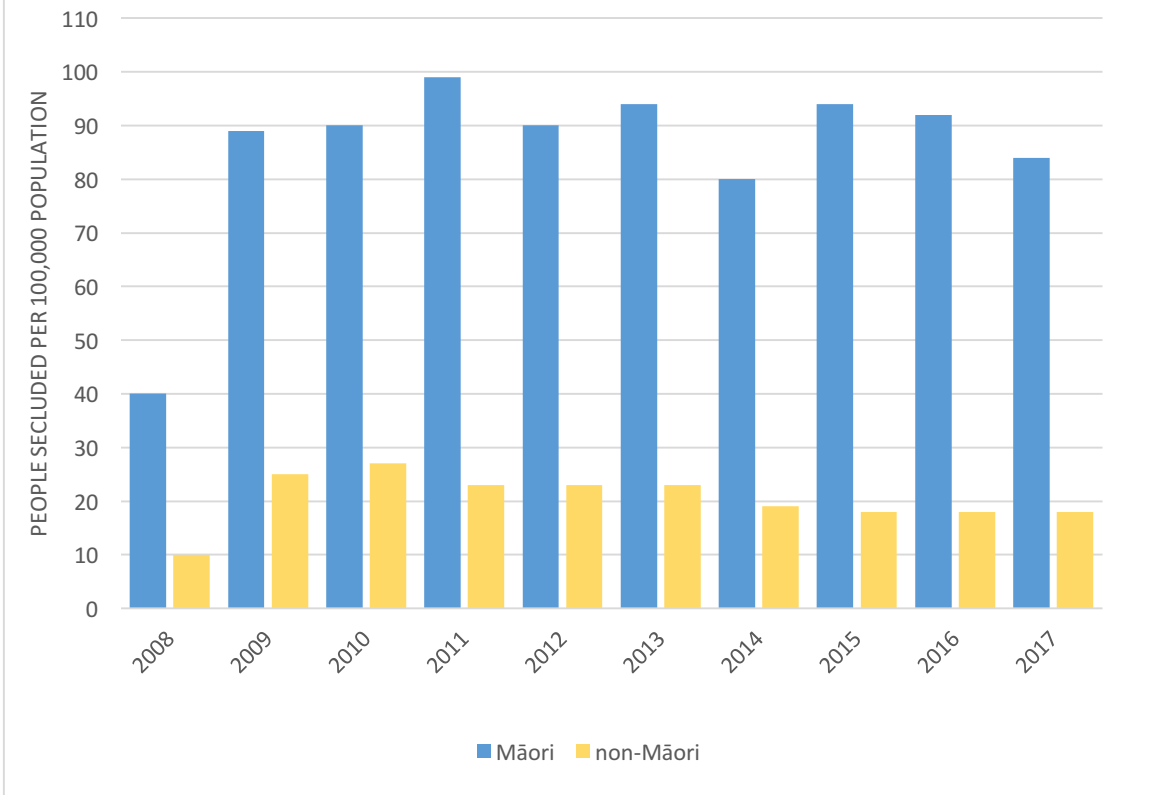
Figure 2: Total rate of secluded Māori and non-Māori per 100,000 population per year for the 10-year period 2008 to 2017



Source: Ministry of Health PRIMHD Dataset ⁶³¹

⁶³¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health Request 1. Note that the original data analysis has been performed by the Crown.

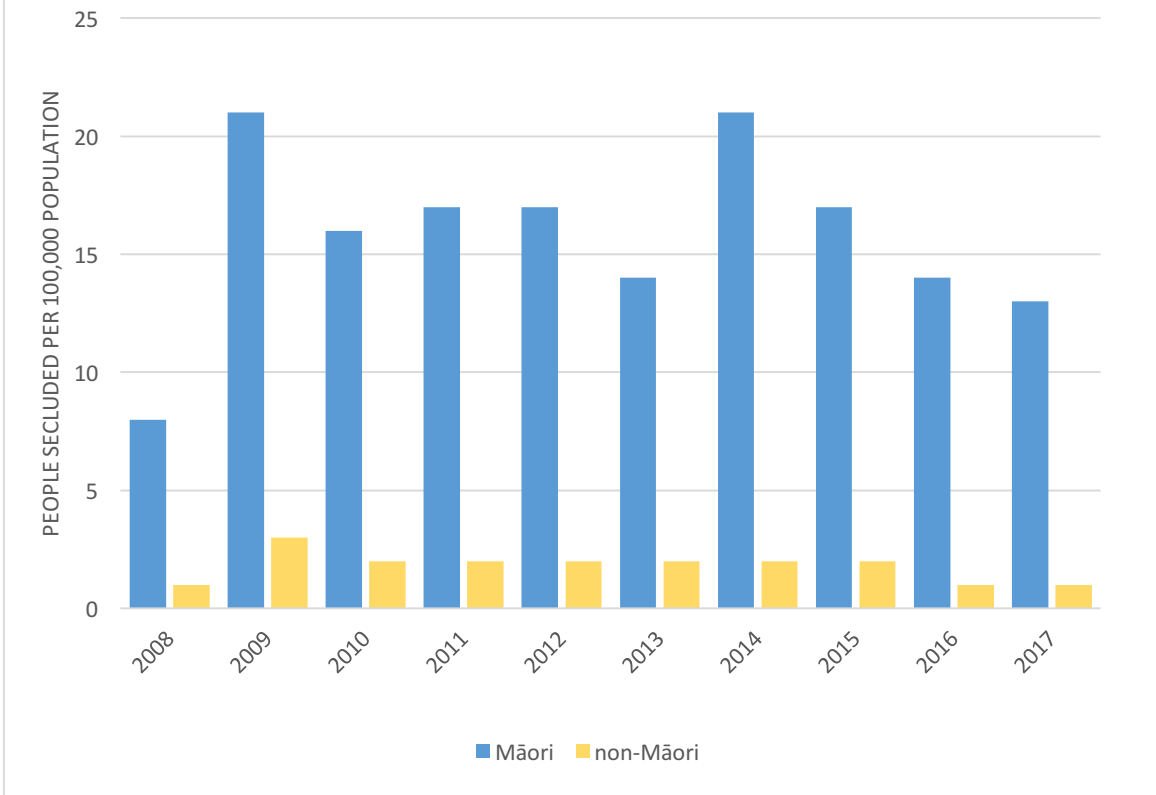
Figure 3: Rate of secluded Māori and non-Māori in adult inpatient services per 100,000 population per year for the 10-year period 2008 to 2017



Source: Ministry of Health PRIMHD Dataset ⁶³²

⁶³² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health Request 1. Note that the original data analysis has been performed by the Crown.

Figure 4: Rate of secluded Māori and non-Māori in adult forensic inpatient services per 100,000 population per year for the 10-year period 2008 to 2017



Source: Ministry of Health PRIMHD Dataset ⁶³³

⁶³³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health Request 1. Note that the original data analysis has been performed by the Crown.

Table 13 shows the rate ratios (RR)⁶³⁴ with 95% confidence intervals (CI) of Māori secluded compared with non-Māori, for total, adult,⁶³⁵ adult forensic, youth forensic⁶³⁶ and youth⁶³⁷ inpatient services, per year, for the 10-year period 2008 to 2017.⁶³⁸ Secluded Māori compared with non-Māori (Māori: non-Māori) RRs have increased across all of the services for the 10-year period, indicating that the inequities in the rates of secluded Māori compared with non-Māori have increased over the 10-year period examined.

The total secluded Māori: non-Māori RR increased from 3.4 (95% CI 2.9–4.2) in 2008 to 4.5 (95% CI 3.9–5.1) in 2017. For adult inpatient services, the secluded Māori: non-Māori RR increased from 3.9 (95% CI 3.2–4.9) in 2008 to 4.8 (95% CI 4.1–5.5) in 2017, and for youth inpatient services, the secluded Māori: non-Māori RR increased from 2.1 (95% CI 1.2–3.7) in 2008 to 3.6 (95% CI 2.3–5.5) in 2017.

For adult forensic services, the secluded Māori: non-Māori RR increased from 6.7 (95% CI 3.9–11.3) in 2008 to 9.0 (95% CI 5.9–13.6) in 2017, and for youth forensic services, the secluded Māori: non-Māori RR increased from 1.6 (95% CI 1.2–3.7) in 2008 to 20.4 (95% CI 2.5–165.7)⁶³⁹ in 2017.⁶⁴⁰

⁶³⁴ The rate ratios (RR) have not been age-standardised, thus represent the crude RRs.

⁶³⁵ The Ministry of Health defines adult services as clients aged 20–64 years. Refer to Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1z MoH OIA Mental Health Seclusion Report Wai 2575 Māori Disability Research.

⁶³⁶ There were no youth forensic seclusion clients for 2013. Refer to Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1z MoH OIA Mental Health Seclusion Report Wai 2575 Māori Disability Research.

⁶³⁷ The Ministry of Health defines youth services as clients aged 0–19 years. Refer to Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1z MoH OIA Mental Health Seclusion Report Wai 2575 Māori Disability Research.

⁶³⁸ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1z MoH OIA Mental Health Seclusion Report Wai 2575 Māori Disability Research.

⁶³⁹ The wide 95% confidence interval is due to one non-Māori youth forensic client in 2017. Refer to Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1z MoH OIA Mental Health Seclusion Report Wai 2575 Māori Disability Research.

⁶⁴⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1z MoH OIA Mental Health Seclusion Report Wai 2575 Māori Disability Research.

Table 13: Secluded Māori: non-Māori rate ratios (95% Confidence Interval – CI) by inpatient services for the years 2008 to 2017

Year	Total		Adult – excl. forensic		Adult – Forensic		Youth – Forensic		Youth – excl. forensic	
	Rate ratio	95% CI	Rate ratio	95% CI	Rate ratio	95% CI	Rate ratio	95% CI	Rate ratio	95% CI
2008	3.4	2.9–4.2	3.9	3.2–4.9	6.7	3.9–11.3	1.6	0.1–17.5	2.1	1.2–3.7
2009	3.4	3.0–3.8	3.5	3.0–4.0	7.1	5.1–10.0	3.1	1.1–9.0	2.9	2.0–4.3
2010	3.1	2.7–3.5	3.3	2.9–3.8	5.4	3.7–7.9	3.1	1.2–8.3	3.1	2.2–4.4
2011	3.7	3.3–4.2	4.2	3.7–4.8	5.9	4.1–8.5	4.6	1.3–16.4	2.6	1.8–3.9
2012	3.5	3.1–4.0	3.8	3.3–4.3	5.7	4.0–8.1	5.4	1.6–18.3	3.1	2.2–4.4
2013	3.8	3.3–4.2	4.2	3.6–4.8	7.7	5.2–11.4	–	–	2.6	1.8–3.7
2014	4.2	3.7–4.7	4.3	3.7–4.9	9.2	6.5–13.0	7.0	1.8–26.9	3.6	2.5–5.3
2015	4.6	4.1–5.2	5.3	4.6–6.1	6.1	4.2–8.7	9.8	2.7–35.7	2.8	1.9–4.1
2016	4.6	4.0–5.2	5.2	4.5–6.0	8.4	5.5–12.6	4.4	1.2–15.6	2.5	1.6–3.7
2017	4.5	3.9–5.1	4.8	4.1–5.5	9.0	5.9–13.6	20.4	2.5–165.7	3.6	2.3–5.5

Source: Ministry of Health PRIMHD Dataset⁶⁴¹

Table 14 shows the RRs (with 95% CIs) of seclusion events for Māori compared with non-Māori, for total, adult, forensic,⁶⁴² and youth inpatient services.⁶⁴³ The total Māori: non-Māori RR for seclusion events decreased from 3.9 (95% CI 3.6–4.2) in 2008 to 3.5 (95% CI 3.3–3.8) in 2017. This also occurred for adult inpatient services, where the Māori: non-

⁶⁴¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1z MoH OIA Mental Health Seclusion Report Wai 2575 Māori Disability Research. Note that the original data analysis has been performed by the Crown.

⁶⁴² Adult forensic and youth forensic have been merged for seclusion events. Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1z MoH OIA Mental Health Seclusion Report Wai 2575 Māori Disability Research.

⁶⁴³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1z MoH OIA Mental Health Seclusion Report Wai 2575 Māori Disability Research. Note that the original data analysis has been performed by the Crown.

Māori RR for seclusion events decreased from 3.7 (95% CI 3.2–4.2) in 2008 to 2.8 (95% CI 2.5–3.0) in 2017.

Table 14: Seclusion events Māori: non-Māori rate ratio (95% Confidence Interval – CI) by inpatient services for the years 2008 to 2017

Year	Total		Adult – excl. forensic		Adult + Youth – forensic		Youth – excl. forensic	
	Rate ratio	95% CI	Rate ratio	95% CI	Rate ratio	95% CI	Rate ratio	95% CI
2008	3.9	3.6–4.2	3.7	3.2–4.2	4.4	4.0–4.9	1.2	0.8–1.8
2009	3.4	3.2–3.5	3.6	3.4–3.9	3.1	3.0–3.3	2.6	2.1–3.2
2010	3.2	3.1–3.4	3.8	3.5–4.1	2.7	2.5–3.0	2.9	2.4–3.5
2011	3.3	3.2–3.5	4.7	4.3–5.0	2.6	2.4–2.7	4.6	3.7–5.7
2012	3.1	2.9–3.2	3.1	2.9–3.4	2.8	2.6–2.9	3.5	2.9–4.2
2013	4.0	3.8–4.2	4.3	4.0–4.7	3.6	3.3–3.8	3.6	3.0–4.4
2014	5.6	5.4–5.9	3.7	3.4–4.1	6.2	5.8–6.5	3.0	2.4–3.7
2015	6.0	5.7–6.3	5.3	4.9–5.8	6.5	6.0–6.9	2.7	2.1–3.4
2016	5.5	5.1–5.9	4.9	4.4–5.4	8.1	7.2–9.2	1.9	1.5–2.4
2017	3.5	3.3–3.8	2.8	2.5–3.0	7.4	6.5–8.5	3.3	2.5–4.2

Source: Ministry of Health PRIMHD Dataset⁶⁴⁴

⁶⁴⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1z MoH OIA Mental Health Seclusion Report Wai 2575 Māori Disability Research. Note that the original data analysis has been performed by the Crown.

For youth inpatient services however, the Māori: non-Māori RR for seclusion events increased from 1.2 (95% CI 0.8–1.8) in 2008 to 3.3 (95% CI 2.5–4.2) in 2017. For forensic inpatient services, the Māori: non-Māori RR also increased from 4.4 (95% CI 4.0–4.9) in 2008 to 7.4 (95% CI 6.5–8.5) in 2017.

Overall, the figures and tables indicate that the significant inequities in rates of secluded Māori compared with non-Māori have increased over the 10-year period examined and this occurred across all of the inpatient services examined. This occurred following the time that the seclusion reduction policy was implemented (from 2009 onwards). However, the inequity in the rates of seclusion events for total Māori compared with non-Māori have decreased over the 10-year period. This decrease has been driven by a decrease in the rates of seclusion events for Māori compared with non-Māori in adult inpatient services over the 10-year period, but this trend has not occurred elsewhere in the other inpatient services examined.

In other words, the significant inequities in the rates of secluded Māori compared with non-Māori have increased over time, and this has continued following implementation of the seclusion reduction policy. But once secluded, the inequity in the number of seclusion events for Māori compared with non-Māori has reduced over the 10-year period but only for Māori admitted to adult inpatient services. Inequities in the rates of seclusion events for Māori compared with non-Māori were admitted to both youth and forensic inpatient services have actually increased over this same 10-year period examined.

SECLUSION OF MĀORI WITH LIVED EXPERIENCE OF LEARNING/ INTELLECTUAL DISABILITY

There are five DHBs which provide for specialist inpatient forensic services,⁶⁴⁵ including for people under the ID(CC&R) Act. The MoH reports on seclusion data for care recipients with a legal status under the ID(CC&R) Act, separately to people secluded under the MH(CAT)

⁶⁴⁵ These district health boards (DHB) are Canterbury, Capital & Coast, Southern, Waikato and Waitemata DHBs. There is also a smaller inpatient forensic service at Whanganui DHB.

Act which includes people those who have a legal status under the MH(CAT) Act, but are admitted to the Regional Intellectual Disability Secure Services (RIDSS). The RIDSS provide for,

‘...specialist secure intellectual disability forensic services...RIDSS provide secure beds for people subject to compulsory care orders under the IDCC&R Act, or other appropriate legal mandates. RIDSS services vary in bed configuration and numbers. Some beds are provided within existing forensic mental health infrastructure; others are provided in purpose-built facilities. Some RIDSS also have “step-down” facilities, which are medium secure “cottages” intended to provide a more home-like environment as care recipients move towards a transition to the community...

The numbers of beds across RIDSS services around the country vary greatly. A small group of care recipients currently in secure care have not made significant rehabilitative gains towards transitioning to community placement. These clients have intellectual disabilities and/or mental health conditions of such severity that they have already been subject to long-term hospital-level care (10.5 years on average, with a range from 6 to 20 years), and it is highly likely they will continue to require long-term secure care and more restrictive practices’.⁶⁴⁶

Care recipients under the ID(CC&R) Act are also subject to seclusion,⁶⁴⁷ however, as they may be secluded in the inpatient forensic services, seclusion data is reported via PRIMHD and is,

‘...indistinguishable from forensic mental health service user seclusion data. The [MoH] is actively working with Disability Support Services and DHBs to report

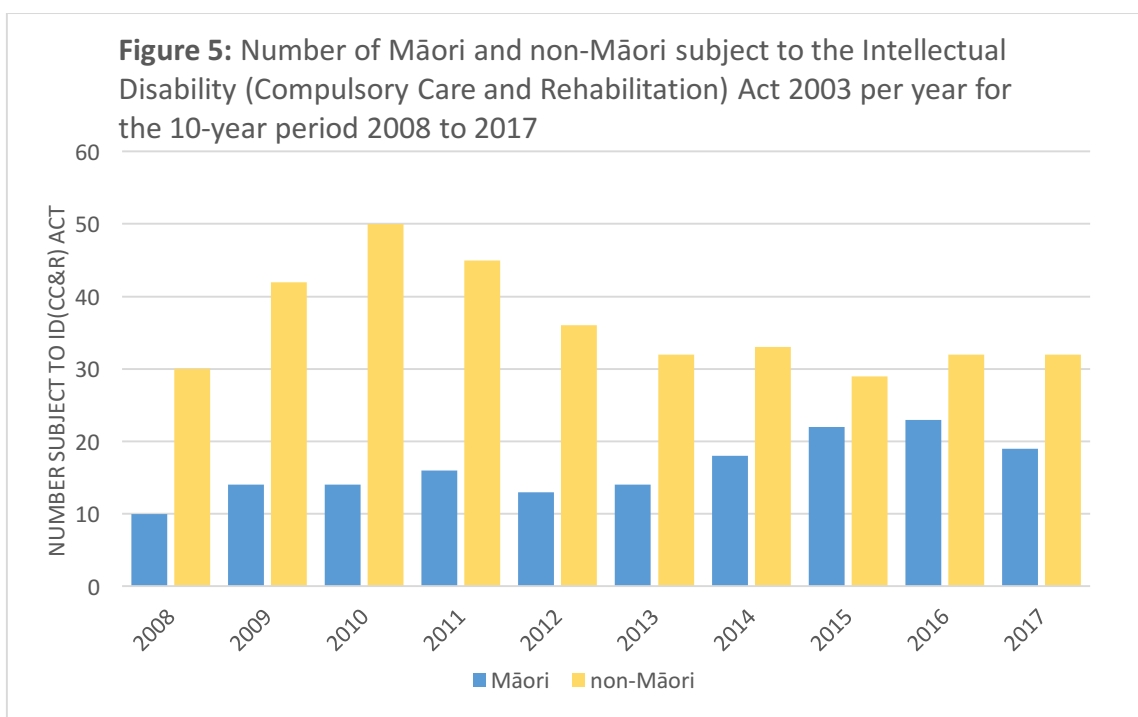
⁶⁴⁶ Ministry of Health, *Office of the Director of Mental Health Annual Report 2017*, p.49.

⁶⁴⁷ Ministry of Health, *Seclusion under the Mental Health (Compulsory Assessment and Treatment) Act 1992*.

IDCC&R Act seclusion data separately from forensic mental health data in PRIMHD'.⁶⁴⁸

The MoH states that, although development work is underway on the reporting of seclusion on people under the ID(CC&R) Act, data is only available for the 2017 year.

To provide context for the use of seclusion on Māori who are subject to the ID(CC&R) Act, Figures 5 and 6 present the numbers and proportions of Māori and non-Māori subject to the ID(CC&R) Act, per year, for the 10-year period 2008 to 2017. The figures show that both the number and proportion of Māori subject to the ID(CC&R) Act have increased over time, whilst the proportion of non-Māori decreased over the 10-year period.⁶⁴⁹

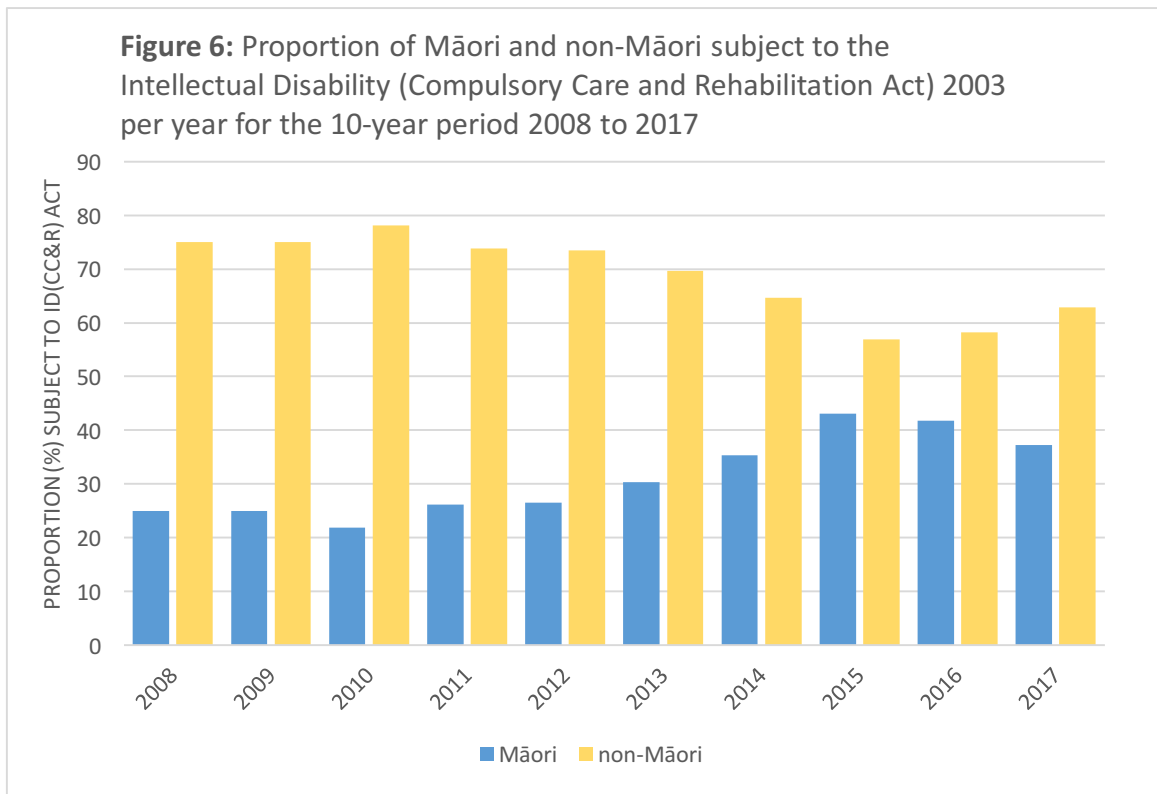


Source: Ministry of Health⁶⁵⁰

⁶⁴⁸ Ministry of Health, *Office of the Director of Mental Health Annual Report 2017*, p.49.

⁶⁴⁹ The numbers for non-Māori have fluctuated over time, but have remained stable since 2013.

⁶⁵⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health Request 1.



Source: Ministry of Health⁶⁵¹

*HIGH AND COMPLEX FRAMEWORK – MINISTRY OF HEALTH RESPONSE
STRATEGY ON HOSPITAL LEVEL SECURE BED PROVISION*

The MoH describes the High and Complex Framework (HCF) as a,

‘...framework of supports for individuals with an intellectual disability who present significant risk to themselves and/or others and have been engaged with the criminal justice system...The HCF has a vision of significantly improving the lives of this highly vulnerable but small number of individuals whose needs cannot be met under the mainstream services. The goal of the HCF is to provide the right

⁶⁵¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health Request 1. Original data analysis performed by researcher.

supports to ensure that these people can live their lives free from offending. The focus is on supporting people subject to orders under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003'.⁶⁵²

In 2008, 25 per cent (n. = 10) of people subject to the ID(CC&R) Act were Māori compared with 75 per cent (n. = 30) of non-Māori. In 2017, 37 per cent (n. = 19) of people subject to the ID(CC&R) Act were Māori compared with 63 per cent (n. = 32) of non-Māori. The MoH has a statutory responsibility to provide all people subject to orders under the ID(CC&R) Act with appropriate residential placement, and contracts with non-governmental organisations and the five DHBs (previously discussed).⁶⁵³

Figure 7 shows the numbers of Māori and non-Māori admitted to hospital level secure beds under the ID(CC&R) Act, per year, for the 10-year period 2008 to 2017. The numbers of Māori admitted to the hospital level secure beds over the 10-year period have ranged from two to 10, compared with four to 19 for non-Māori.

The MoH states that,

'...although there have been occasional bed pressures since the [ID(CC&R)] Act was operationalised in 2004, the capacity limitations became acute in 2018 for the first time. The increase in acute bed pressure has at times led to a temporary lack of capacity to provide the necessary hospital level beds for people under the HCF referred from courts.

There are many reasons contributing to the increasing bed pressure. This includes the lack of bed capacity to meet regional demand, increasing need for secure care services, lack of capacity to respond to the increasing needs of youth, issues

⁶⁵² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g MoH Response 3 main appendix.

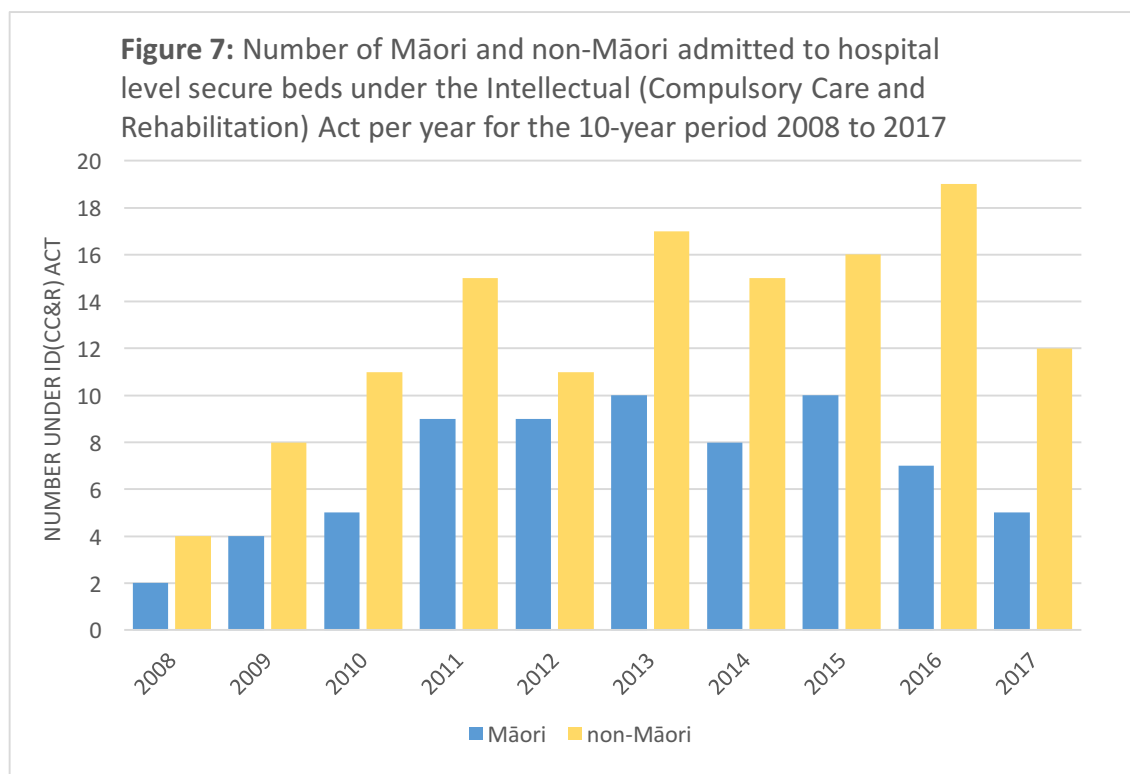
⁶⁵³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g MoH Response 3 main appendix.

related to gender and age, and the need for specialised care solutions for a diverse client group, including those with autism.

To date, the demand for hospital level secure beds has been closely managed at the acute level through careful referral management and the movement of individuals around the beds available at a national level. This has been possible due to regional variations in the level of acuity and capacity. However, due to the increase in the numbers of individuals required to be managed at the hospital level, all regions are now operating at capacity.

To address the sector's concerns, the Ministry has been meeting with the Chief Executives and representatives of DHBs to discuss pressures across the HCF from both a regional and national perspective and consider more sustainable options that will address the bed pressure issues in the long term'.⁶⁵⁴

⁶⁵⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g MoH Response 3 main appendix.



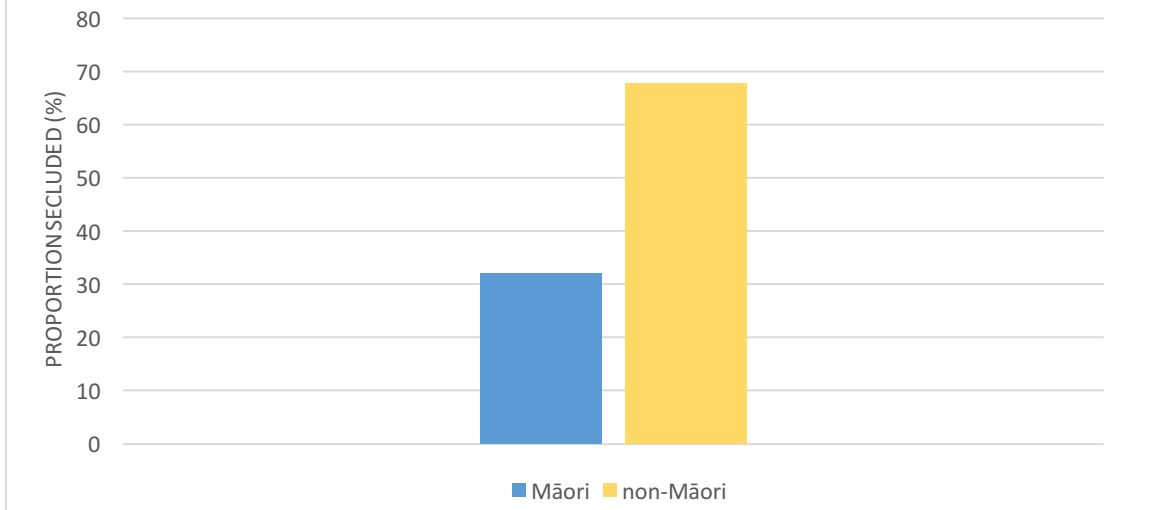
Source: Ministry of Health⁶⁵⁵

Figure 8 shows the proportion of Māori and non-Māori under the ID(CC&R) Act who were secluded for the year 2017. The proportion of secluded Māori was 32 per cent (n. = 9) compared with 68 per cent (n. = 19) for non-Māori. The proportion of secluded Māori is similar to the proportion of Māori subject to the ID(CC&R) Act for 2017. This was 37 per cent (Figure 6).⁶⁵⁶

⁶⁵⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1g MoH Response 3 main appendix.

⁶⁵⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health Request 1.

Figure 8: Proportion of Māori and non-Māori secluded under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 for the year 2017

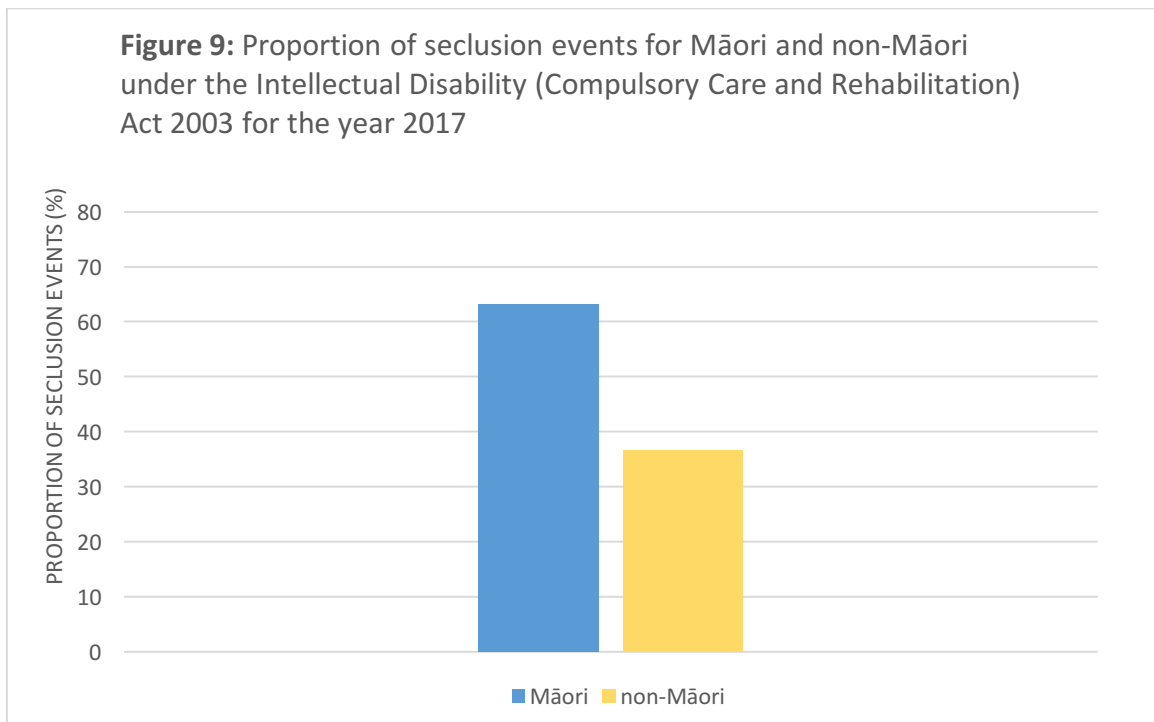


Source: Ministry of Health⁶⁵⁷

Figure 9 shows the proportion of seclusion events for Māori and non-Māori under the ID(CC&R) Act for the year 2017. Although the proportion of secluded Māori was 32 per cent compared with 68 per cent for non-Māori, the proportion of seclusion events for Māori show a reverse pattern. This was 63 per cent (n. = 322) for Māori compared with 37 per cent (n. = 187) for non-Māori.⁶⁵⁸

⁶⁵⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health Request 1. Original data analysis performed by researcher.

⁶⁵⁸ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health Request 1.



Source: Ministry of Health⁶⁵⁹

Māori were 1.7 times more likely than non-Māori to be secluded multiple times.⁶⁶⁰

According to the available data collated by the MoH, on average, the nine Māori with lived experience of learning/intellectual disability who were secluded whilst under the ID(CC&R) Act, would have each been secluded up to 36 times during the 2017 year.⁶⁶¹ This compares with MoH figures from 2017 which report that, on average, people in adult inpatient services are secluded twice.⁶⁶²

⁶⁵⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health Request 1. Original data analysis performed by researcher.

⁶⁶⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health Request 1. Original data analysis performed by researcher.

⁶⁶¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health Request 1. Original data analysis performed by researcher.

⁶⁶² Ministry of Health, *Office of the Director of Mental Health Annual Report 2017*.

The Crown's plan to address seclusion use in health and disability services

Shalev has highlighted a number of concerns regarding use of seclusion and restraint in health and disability services. Some of these included,

'...health and disability units across the country [that] housed individuals who were subjected to very long periods in seclusion and/or restraint. Not only were solitary confinement and restraint not reserved as last resort short-term options in these cases, but they appeared to have become the default position and were applied for prolonged times with no clear end in sight.

Examples include a man who had been held in isolative, segregated conditions in a long-term health and disability unit for over six years [and] two men at another health and disability unit, both also kept in similar conditions for over six years and one of whom was also restrained in a body belt...For the individuals concerned, prolonged seclusion and /or restraint (and often both) had thus become a chronic state rather than an emergency short term response to an acute situation...I was concerned to note that discussions of what the future held for these individuals appeared to focus on how to 'do' the seclusion/ restraint better, or differently – build a better seclusion area, a new living quarter, or design a new restraint belt. But there appeared to be very little by way of thinking about an entirely different solution to the perceived challenges that these individuals presented (for example that they self-harm or that they are unpredictable). In this context, it should also be noted that this would appear to

violate principles established by the Committee on the Rights of Persons with Disabilities'.^{663,664}

In response to the concerns around seclusion in health and disability services, the MoH states the, '...reduction (and eventual elimination) of seclusion will require strong local leadership and resourcing, evidence-based seclusion reduction initiatives, ongoing workforce development and significant organisational commitment',⁶⁶⁵ and goes on to highlight actions taken to reduce seclusion. For example, '...reducing and eventually eliminating the use of seclusion for Māori is a priority action in *Rising to the Challenge* supported by Te Pou'.⁶⁶⁶

Rising to the Challenge is the mental health and addiction service development plan 2012–2017,⁶⁶⁷ though the plan has not been updated since 2012 when it was first published. Te Pou o te Whakaaro Nui (Te Pou) is a national centre of workforce development for the mental health, addiction and disability sectors in Aotearoa/New Zealand and is funded by the MoH in relation to seclusion reduction. Te Pou states that it,

'...works closely alongside district health boards...providing advice and consultation to support change and ongoing practice development in reducing

⁶⁶³ Shalev, *Thinking Outside The Box? A Review of Seclusion and Restraint Practices in New Zealand*, pp.42-43.

⁶⁶⁴ The guidelines state that 'throughout all the reviews of State party reports, the Committee has established that it is contrary to article 14 to allow for the detention of persons with disabilities based on the perceived danger of persons to themselves or to others. The involuntary detention of persons with disabilities based on risk or dangerousness, alleged need of care or treatment or other reasons tied to impairment or health diagnosis is contrary to the right to liberty, and amounts to arbitrary deprivation of liberty'. Refer to Committee on the Rights of Persons with Disabilities, Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities: The right to liberty and security of persons with disabilities. Adopted during the Committee's 14th session, held in September 2015. Geneva: September 2015.

⁶⁶⁵ Ministry of Health, *Office of the Director of Mental Health Annual Report 2017*, p.42.

⁶⁶⁶ Ministry of Health, *Office of the Director of Mental Health Annual Report 2017*, p.47.

⁶⁶⁷ Ministry of Health, *Rising to the Challenge: The Mental Health and Addiction Service Development Plan 2012–2017*, (Wellington: Ministry of Health, 2012), <https://www.health.govt.nz/publication/rising-challenge-mental-health-and-addiction-service-development-plan-2012-2017>.

the use of seclusion and restraint. The use of data is a key focus of this work. The Te Pou Information team collate and analyse the seclusion data collected nationally, and work with DHBs to encourage active use of this data to inform and improve practice change'.⁶⁶⁸

Te Pou has also produced a range of evidence-based resources on seclusion reduction including the two reports, *Reducing Māori seclusion: A summary report with recommendations for managers and leaders of mental health services*,⁶⁶⁹ and, *Supporting seclusion reduction for Māori “Taiheretia tātou kia puta te hua”*.⁶⁷⁰

In February 2018, the MoH published transitional guidelines for mental health services to eliminate the use of night safety procedures by December 2022.⁶⁷¹ Additionally, in March 2018, the Health Quality & Safety Commission (HQSC) and Te Pou launched a national project called 'Pathways to Eliminate Seclusion by 2020'.⁶⁷² Leading up to the launch of the programme, the HQSC, in December 2017, announced,

⁶⁶⁸ Te Pou o te Whakaaro Nui, “Reducing Seclusion and Restraint.” <https://www.tepou.co.nz/initiatives/reducing-seclusion-and-restraint/102.>, Accessed 21 June 2019.

⁶⁶⁹ Te Pou o te Whakaaro Nui. *Reducing Māori seclusion: A summary report with recommendations for managers and leaders of mental health services*, (Auckland: Te Pou o te Whakaaro Nui, 2013). <https://www.tepou.co.nz/resources/reducing-maori-seclusion-a-summary-report-with-recommendations-for-managers-and-leaders-of-mental-health-services/472.>

⁶⁷⁰ Te Pou o te Whakaaro Nui. *Supporting seclusion reduction for Māori “Taiheretia tātou kia puta te hua”*, (Auckland: Te Pou o te Whakaaro Nui, 2014). <https://www.tepou.co.nz/uploads/files/resource-assets/supporting-seclusion-reduction-for-maori-taiheretia.pdf>.

⁶⁷¹ This transitional guideline is to help those working in mental health and secure disability services who use night safety procedures work towards eliminating the procedure. Night safety procedures is the practice of locking a patient in their bedroom overnight for safety reasons. There is no therapeutic value. Refer to Ministry of Health, *Night Safety Procedures: Transitional Guideline*. Wellington: Ministry of Health, 2019)., <https://www.health.govt.nz/publication/night-safety-procedures-transitional-guideline.>, Accessed 23 April 2019.

⁶⁷² Ministry of Health, *Office of the Director of Mental Health Annual Report 2017*.

‘We appreciate that zero seclusion by 2020 is an ambitious goal, yet our collective aim is to have a consistent national approach, over the next two years, that will help us to achieve as close as we can to zero seclusion by that time’.⁶⁷³

The HQSC, however, clarified a few months later (in December 2018) that elimination of seclusion by 2020 was an ‘aspirational goal’ rather than a target. The HQSC highlights the negative consequences of seclusion, for example, acknowledging that seclusion causes, ‘...physical and psychological harm to those who experience it...Seclusion contravenes basic human rights and does not align with modern, evidence-based, high-quality care’.⁶⁷⁴ However, they then go on to state,

‘For us, eliminating seclusion by 2020 is an aspirational goal, rather than a target. Some people have asked us why we are taking this approach...To set a target and hold someone to account for something they cannot fully control can lead to unhelpful responses...After all, when you say to someone “We want to get to zero”, people have a right to say “Actually, I’m not sure I can do that”...’⁶⁷⁵

In contrast, the MoH discusses the same programme as being based on evidenced strategies to eliminate seclusion, with no sense that health professionals can actually opt out of ‘achieving zero seclusion’. For example, the MoH states,

‘...the zero seclusion project [which] takes a recovery approach that encompasses a strong focus on the role of consumers, families, and whānau. The project uses

⁶⁷³ Health Quality & Safety Commission, “Mental health and addiction quality improvement programme New projects announcement 1 December 2017 Q&A:”, https://www.hqsc.govt.nz/assets/Mental-Health-Addiction/NEMR_files/QA_on_new_MHAQI_projects_announced_Dec_1_2017_v7_final.pdf, Accessed 23 April 2019.

⁶⁷⁴ Janice Wilson, Richard Hamblin, and Shaun McNeil, “Why eliminating seclusion by 2020 is an aspirational goal”. <https://www.hqsc.govt.nz/blog/why-eliminating-seclusion-by-2020-is-an-aspirational-goal/>, Accessed 23 April 2019.

⁶⁷⁵ Wilson, Hamblin, and McNeil, “Why eliminating seclusion by 2020 is an aspirational goal”. <https://www.hqsc.govt.nz/blog/why-eliminating-seclusion-by-2020-is-an-aspirational-goal/>, Accessed 23 April 2019.

quality improvement methods to test and implement evidence-based strategies to reduce and eliminate the use of seclusion'.⁶⁷⁶

The Government, in their response to the Committee on the Rights of Persons with Disabilities' *List of issues* published in March 2019 also appears to contradict the HQSC position, stating,

'...the programme Zero Seclusion: towards eliminating seclusion by 2020 was launched in March 2018. The implementation was informed by a co-design phase, and there is a strong focus on the role of consumers, families and whānau in supporting long-term change'.⁶⁷⁷

This does highlight a disconnect between a stated need by the Crown to eliminate seclusion versus Crown inaction to eliminate seclusion. For example, there is a stark disconnect with regard to intent behind the statement, 'eliminating seclusion by 2020' (as stated by the New Zealand Government to the United Nations)⁶⁷⁸ versus that of, 'eliminating seclusion by 2020 is an aspirational goal not a target' (as stated by the HQSC to the New Zealand health and disability sector).⁶⁷⁹ Whilst one works to achieve zero seclusion as the target, has an implementation plan, and accountability mechanisms for not achieving zero seclusion, the other does not. In the case of the Crown's use of seclusion on people within its health and disability services, it is Māori who bear the disproportionate impact of this disconnect, experiencing persistent and significant inequities that have been reported on within the health and disability sector for at least 17 years.

⁶⁷⁶ Ministry of Health, *Office of the Director of Mental Health Annual Report 2017*, p.40.

⁶⁷⁷ New Zealand Government, *The New Zealand Government's response to 'the list of issues prior to submission of the combined second and third periodic review of New Zealand'*, p.40.

⁶⁷⁸ New Zealand Government, *The New Zealand Government's response to 'the list of issues prior to submission of the combined second and third periodic review of New Zealand'*.

⁶⁷⁹ Wilson, Hamblin, and McNeil, "Why eliminating seclusion by 2020 is an aspirational goal."

Monitoring of health and well-being, and health and disability support services in prisons

Primary healthcare services for people in Aotearoa/New Zealand prisons are provided in prison health centres by registered medical staff. The Department of Corrections (Corrections) states that each person on arrival to the prison,

‘...has their health needs assessed...and ongoing care and treatment is given if required. This assessment includes whether [they are] at risk to themselves or others...All [persons] aged over 18 are screened as part of the arrival process to assess if they have a mental health need. If they have a mild to moderate mental health need they can be referred to the prison doctor or receive counselling, including if eligible, cognitive behavioural therapy. All [persons] with serious mental health needs are managed in partnership with their local Regional Forensic Mental Health Services. In acute cases [they] may be transferred to a secure forensic mental health facility...managed by District Health Boards’.⁶⁸⁰

As previously outlined in Chapter III, the MoH and ACC are responsible for the funding and delivery of secondary and tertiary healthcare (specialist and hospital) services to people in prison. Corrections state that in the case of, ‘...disabled Māori prisoners, it is important to address and be responsive to all of their needs, both from a cultural and a health perspective, in order to achieve our goal of reducing reoffending’.⁶⁸¹ However, Corrections does not provide any further information about how they are addressing or being responsive to the needs of Māori with lived experience of disability in prison.

⁶⁸⁰ Department of Corrections, “Health care.”, https://www.corrections.govt.nz/homepage_redev_2019/popular_links/prison_sentences/being_in_prison/health_care.html, Accessed 20 April 2019.

⁶⁸¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response.

Regarding any training that Corrections provides to develop staff skills and expertise to deliver appropriate health and disability support services to Māori, for example, cultural safety and disability responsiveness training, Corrections states they do not,

‘...offer particular medical training, however all registered health professionals (including those employed by Corrections) are expected to maintain their own professional capability and engage in professional development as necessary...From a cultural competence perspective, Corrections offers Ara Tika, foundational introductory training...This is designed to help staff understand who they are working with and where those people come from...Ara Tika gives a lot of attention to identity, and some of the factors that contribute to an individual’s identity formation. Disability and health status are explored in this part of the session as it is discussed within the context of the Whare Tapa Wha framework’.⁶⁸²

Ethnicity

Ethnicity information is self-reported by a person upon their processing at reception at the prison. Multiple ethnicities can be self-reported, with a ‘primary identified’ ethnicity indicated.⁶⁸³ Corrections states they, ‘do not attempt to verify or confirm prisoners’ ethnicity’.⁶⁸⁴

⁶⁸² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response.

⁶⁸³ For example, in the information provided by the Department of Corrections, the ‘Māori’ category includes all of those who have recorded their ‘primary identified ethnicity’ as Māori and the ‘non-Māori’ category includes all of those who have recorded their ‘primary identified ethnicity’ as anything other than Māori, or have not specified an ethnic group.

⁶⁸⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response.

Numbers of Māori and non-Māori in prison

There are 15 men's prisons⁶⁸⁵ and three women's prisons⁶⁸⁶ in Aotearoa/New Zealand. To provide context regarding the health and well-being of Māori with lived experience of disability in prison, and the delivery of health and disability support services in prisons, the numbers of imprisoned Māori and non-Māori are presented in the following tables. Tables 15a and 15b show the total numbers in men's and women's prisons per year, for the 10-year timeframe 2008 to 2017.

There has been an increase in numbers over the 10-year period examined for both Māori and non-Māori for both the men's and women's prisons. However, there are significant inequities in the proportion of Māori imprisoned by the Crown compared with the proportion of non-Māori. For the year 2017, Māori made up 50.7 per cent (n. = 5145) of the total prison population (n. = 10150). This compares with Māori comprising only 14.9 per cent of the resident population.⁶⁸⁷

⁶⁸⁵ These are: Auckland Prison; Auckland South Corrections Facility; Christchurch Men's Prison; Hawke's Bay Regional Prison; Invercargill Prison; Manawatu Prison; Mount Eden Corrections Facility; Northland Region Corrections Facility; Otago Corrections Facility; Rimutaka Prison; Rolleston Prison; Spring Hill Corrections Facility; Tongariro Prison; Waikeria Prison; and Whanganui Prison.

⁶⁸⁶ These are: Arohata Prison; Auckland Region Women's Corrections Facility; and Christchurch Women's Prison.

⁶⁸⁷ Based on the 2013 Census resident population.

Table 15a: Numbers of Māori and non-Māori in men’s prisons in Aotearoa / New Zealand per year for the years 2008 to 2017

	Māori	Non-Māori	Total in men’s’ prisons
2008	3643	3765	7408
2009	3909	3898	7807
2010	4114	4029	8143
2011	4038	3917	7955
2012	4053	3952	8005
2013	4022	4016	8038
2014	4047	3948	7995
2015	4123	4061	8184
2016	4485	4287	8772
2017	4731	4680	9411

Source: Department of Corrections⁶⁸⁸

Additionally, the numbers of Māori imprisoned by the Crown have increased over time. For the 2017 year, the number of Māori in the men’s prisons was 4731 compared to 3643 in the 2008 year, an increase of 23 per cent point increase of 1088, a 23 per cent point increase. For the 2017 year, the number of Māori in the women’s prisons was 414 compared with 250 in the 2008 year, an increase of 164.

⁶⁸⁸ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response Appendices.

Table 15b: Numbers of Māori and non-Māori in women’s prisons in Aotearoa/ New Zealand per year for the years 2008 to 2017

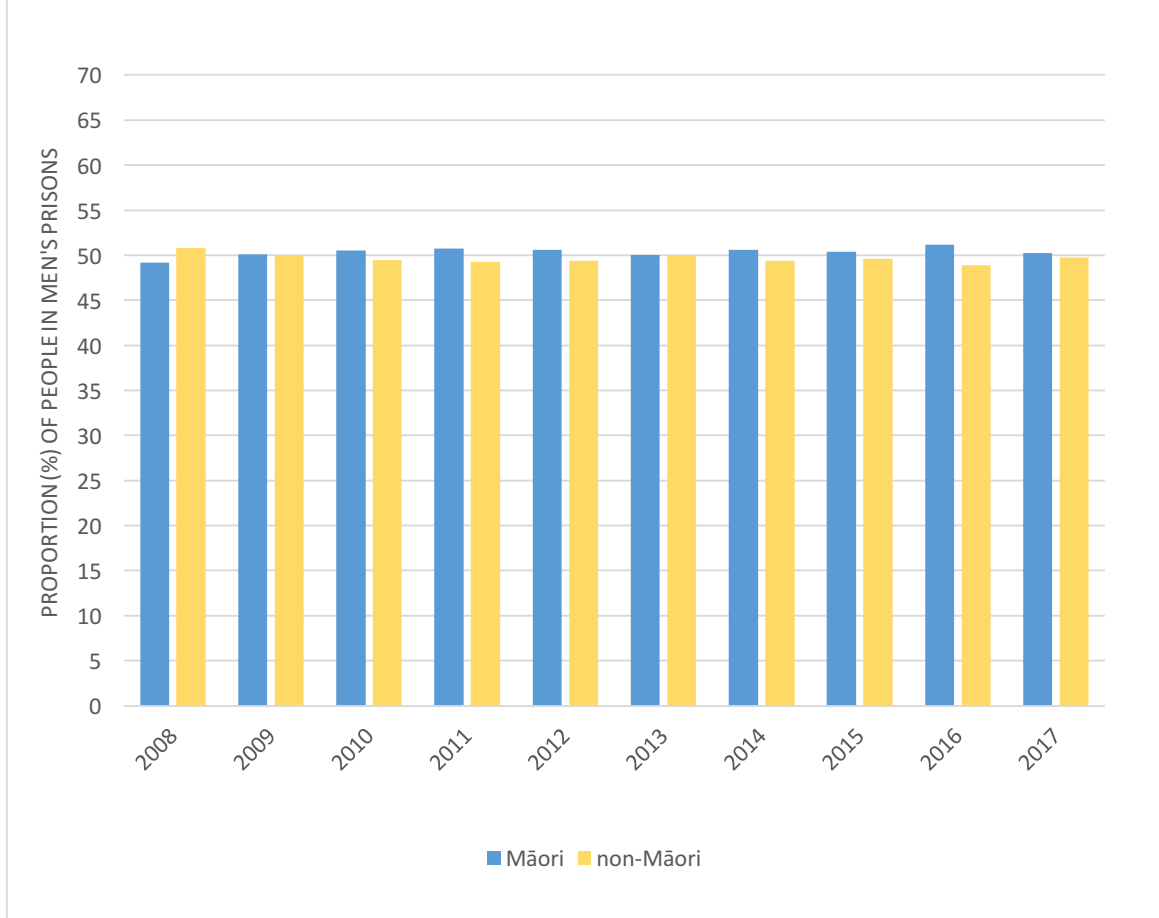
	Māori	Non-Māori	Total number in women’s prisons
2008	250	184	434
2009	279	213	492
2010	321	219	540
2011	306	227	533
2012	299	211	510
2013	307	187	494
2014	313	212	525
2015	292	258	550
2016	371	278	649
2017	414	325	739

Source: Department of Corrections⁶⁸⁹

Figure 10 shows the proportion of Māori and non-Māori in the men’s prisons per year for the 10-year period 2008 to 2017. The proportion of Māori and non-Māori have not changed significantly over the 10-year period. In 2017, Māori made up 50 per cent of the men’s prisons, compared with 49.7 per cent for non-Māori.

⁶⁸⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response Appendices. Original data analysis undertaken by researcher.

Figure 10: Proportion of Māori and non-Māori in Aotearoa/ New Zealand in men's prisons per year for the 10-year period 2008 to 2017

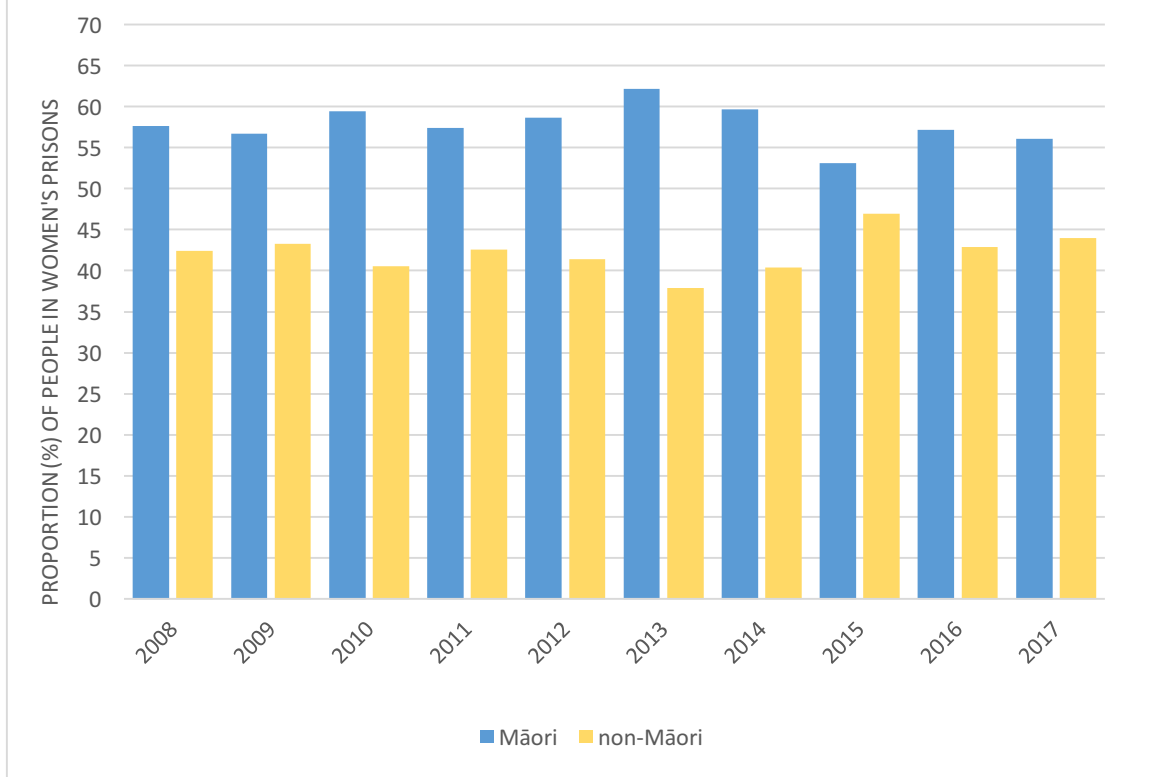


Source: Department of Corrections ⁶⁹⁰

Figure 11 shows the proportion of Māori and non-Māori in the women's prisons per year for the 10-year period 2008 to 2017. The proportion of Māori has fluctuated over time but the trend has stayed consistent, in other words, neither upwards or downwards. In 2017, Māori made up 56 per cent of the women's prisons, compared with 44 per cent for non-Māori.

⁶⁹⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response Appendices. Original data analysis undertaken by researcher.

Figure 11: Proportion of Māori and non-Māori in Aotearoa/ New Zealand women's prisons per year for the 10-year period 2008 to 2017



Source: Department of Corrections ⁶⁹¹

Thus, despite representing only 14.9 per cent of the population, Māori are significantly over-represented in the proportion of people imprisoned per year by the Crown. This occurs for Māori across both the men's and women's prisons in Aotearoa/New Zealand, and the trend for both has not significantly changed over the time-frame analysed.

⁶⁹¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response Appendices. Original data analysis undertaken by researcher.

Monitoring of access to health and disability support services in prisons

Regarding the monitoring of health and well-being as well as access to health and disability support services of Māori with lived experience of disability in prisons, the Government states,

‘The Government does not have data which can tell us whether a prisoner has a disability and a mental health issue. All prisoners are entitled to support, treatment, and care for any conditions or disabilities they have’.⁶⁹²

Corrections also states that information about health and disability services is not monitored because it is,

‘...stored in a separate database to that of other offender information. These two databases do not overlap and we do not, at present, have the ability to cross-reference the information in them. Furthermore, health information is not generally stored in centralised format but rather is held on individual offender files. For these reasons, information about the intersection between ethnicity and health or disability status is not held in a way that is readily retrievable...’.⁶⁹³

MĀORI WITH LIVED EXPERIENCE OF DISABILITY IN PRISON

Although Corrections state that they do not hold health and disability information in a centralised format, they have undertaken some work collating numbers of people in prisons who Corrections categorise as having visual impairment and hearing impairment,

⁶⁹² New Zealand Government, *The New Zealand Government’s response to ‘the list of issues prior to submission of the combined second and third periodic review of New Zealand’*, p.41

⁶⁹³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response.

over a six-month period.^{694,695} However, they have not collated information on other types of impairment, for example, physical impairment.

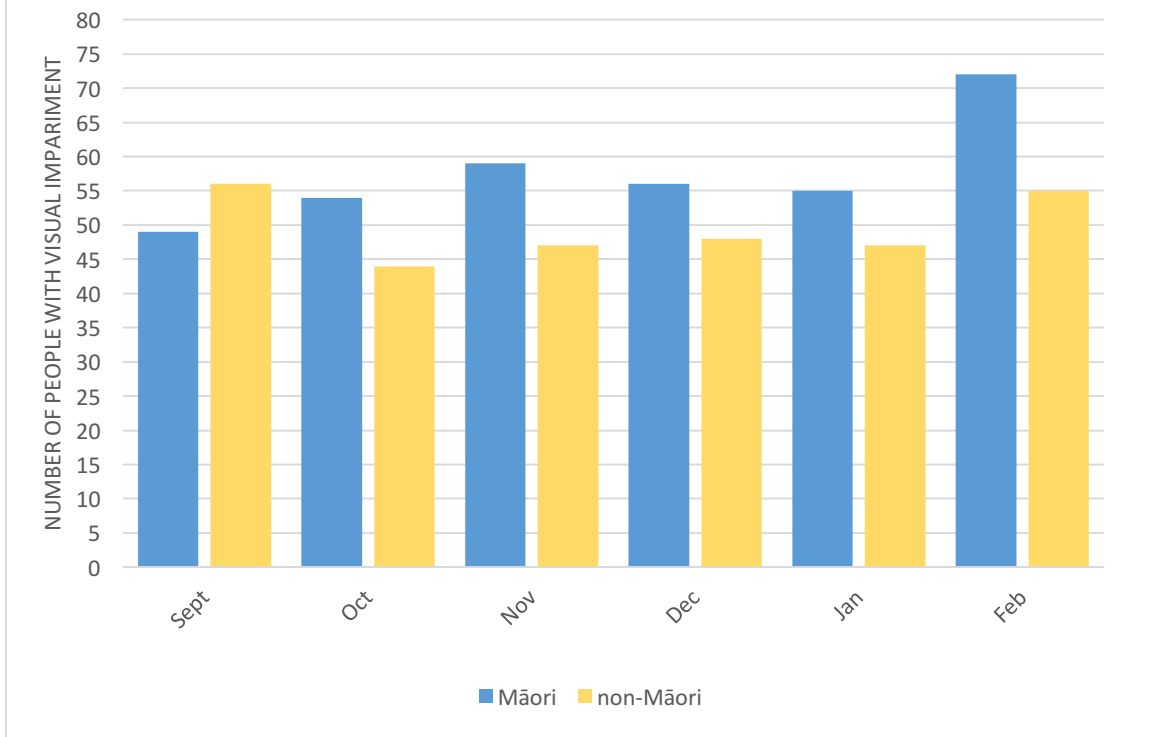
Figure 12 shows the number of Māori and non-Māori with visual impairment for the total prisons in Aotearoa/New Zealand, per month, over the six-month period from September 2018 to February 2019. The numbers represent a 'snapshot' of Māori and non-Māori with visual impairment as at the end of each month. Accordingly, some people may be counted across multiple months.

The range for Māori with visual impairment in prison varies from 49 to 72 Māori over the six-month period, compared with 44 to 56 for non-Māori. The most recent numbers from February 2019 shows that there were 72 Māori with visual impairment compared with 55 non-Māori with visual impairment in prison.

⁶⁹⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response.

⁶⁹⁵ Corrections do not provide a definition for how they categorise 'visual impairment' or 'hearing impairment'.

Figure 12: Number of Māori and non-Māori with visual impairment in Aotearoa/New Zealand total prisons per month for the six-month period September 2018 to February 2019

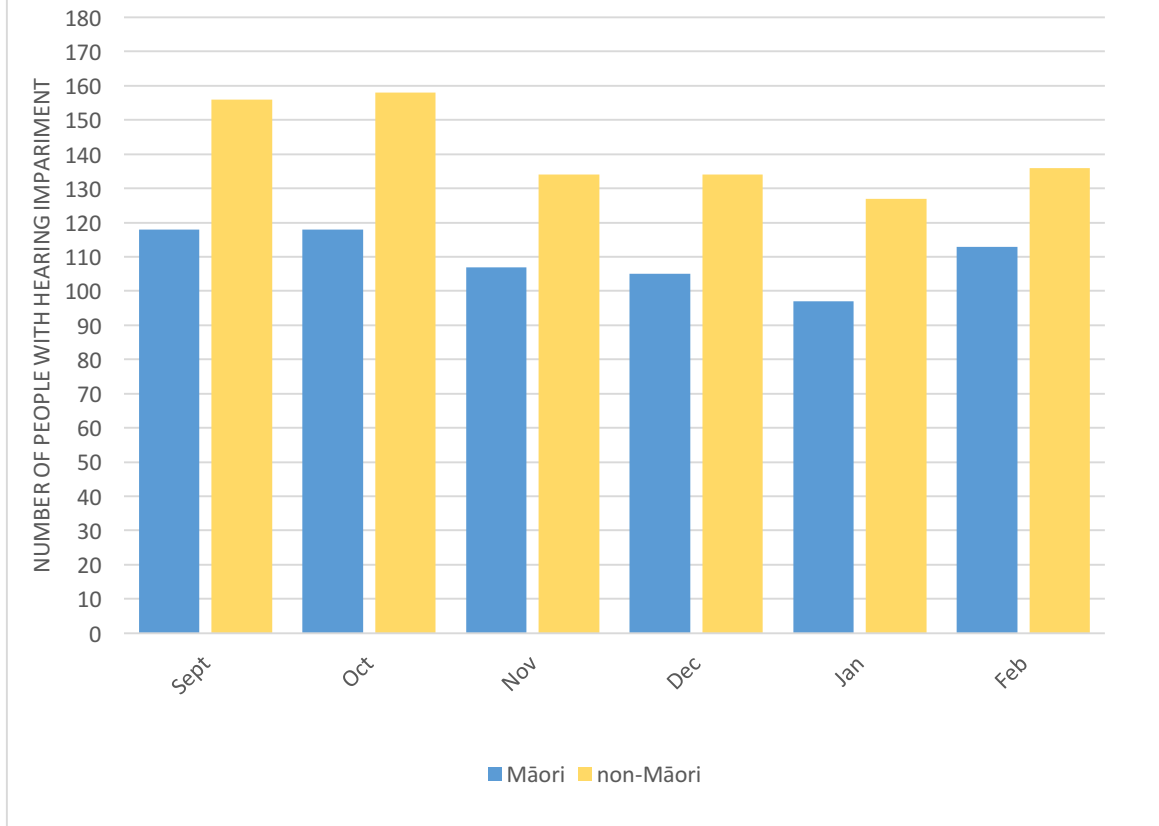


Source: Department of Corrections⁶⁹⁶

Figure 13 shows the number of Māori and non-Māori with hearing impairment for the total prisons in Aotearoa/New Zealand, per month, over the six-month period from September 2018 to February 2019. The numbers represent a ‘snapshot’ of Māori and non-Māori with hearing impairment as at the end of each month. Accordingly, some people may be counted across multiple months.

⁶⁹⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response.

Figure 13: Numbers of Māori and non-Māori with hearing impairment in Aotearoa/New Zealand total prisons per month for the six-month period September 2018 to February 2019



Source: Department of Corrections⁶⁹⁷

The range for Māori with hearing impairment in prison varies from 97 to 118 Māori over the six-month period, compared with 127 to 158 non-Māori. The most recent numbers from February 2019 shows that there were 113 Māori with hearing impairment compared with 136 non-Māori in prison.

With regard to Correction’s collation and provision of monitoring data on the access of Māori with lived experience of disability to the following: primary healthcare services,

⁶⁹⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response.

disability support services; secondary and tertiary healthcare services; regional forensic services; and dental care services, Corrections states,

‘Corrections does not hold this information in a readily retrievable format. In order to identify this type of information, we would be required to manually review a large number of files. Accordingly this part of your request is declined...the information cannot be made available without substantial collation or research’.⁶⁹⁸

As the Crown does not monitor information on access to health and disability support services, and has refused to collate and provide such information to the researcher despite it being clear it was for research to support the Waitangi Tribunal’s Inquiry, access to health and disability support services for Māori with lived experience of disability imprisoned in Aotearoa/New Zealand is largely unknown. However, what this does signify is that the Crown does not collate and analyse nationally the access to health and disability support services of imprisoned Māori, and imprisoned Māori with lived experience of disability. In other words, the Crown does not have the appropriate mechanisms in place for monitoring access to health and disability support services for Māori, and Māori with lived experience of disability whom the Crown imprisons within Aotearoa/New Zealand.

At-Risk Units

Corrections states that At-Risk Units (ARUs)⁶⁹⁹ are,

‘...established in New Zealand prisons to provide a safe environment to accommodate prisoners who are at risk of self-harm...Prisoners are placed in ARUs for various reasons, including: significant mental health or behavioural

⁶⁹⁸ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response.

⁶⁹⁹ Department of Corrections, “M.05.03 Observing and managing at-risk prisoners.” https://corrections.govt.nz/resources/policy_and_legislation/Prison-Operations-Manual/Movement/M.05-Prisoners-at-risk-of-self-harm/M.05-3.html, Accessed 1 February 2019.

disturbance; active self-harm; alcohol or drug detoxification; anxiety related to first time in prison; medical observation; hunger strike; inability to complete reception assessment due to language barriers or disability'.⁷⁰⁰

The report, *Thinking outside the box? A review of seclusion and restraint practices in New Zealand* states,

'The most concerning aspect of prison segregation practices were the At Risk units (ARUs), where those deemed to be the most vulnerable in the prison were housed, sometimes for long periods of time. ARUs appeared to be very similar to other segregation units (by whichever name) both in terms of the material conditions, and in terms of the impoverished regimes.

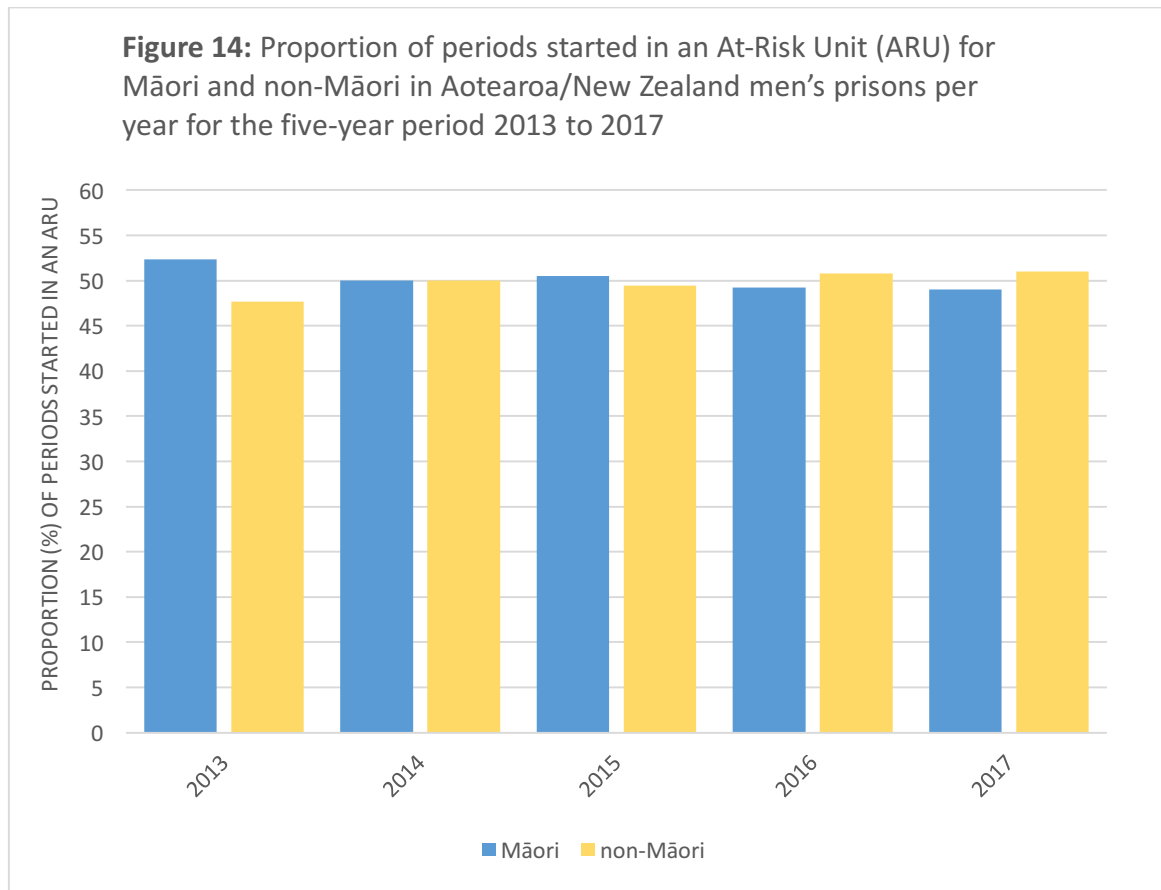
But ARUs also had the added disadvantage of potentially degrading practices such as requiring all prisoners housed in them to wear anti-tear gowns ('strip gowns') and use special bedding, or housing vulnerable individuals in glass-fronted cells with nothing in them. Key decisions were undertaken by custodial staff with limited clinical input into the identification of a prisoner as being at risk of self-harm, and their management thereafter (for example, setting the frequency of their observation by staff).

The key focus in At Risk units appeared to be on having as little as possible inside the cell so to minimise prisoners' access to materials which they could use to harm themselves with. These 'situational controls' were not accompanied by the necessary accompanying work with the individual on addressing the underlying issues which led to their placement there. Furthermore, in a number of the At Risk units, some of the few in-cell fixtures were not ligature resistant or tamper proof, meaning that they could be used for self-harm, making these cells unsafe. This was extremely concerning and defeats the sole stated purpose of At Risk

⁷⁰⁰ Department of Corrections, "Transforming intervention and support for at-risk prisoners." https://www.corrections.govt.nz/resources/research_and_statistics/journal/volume_5_issue_2_november_2017/transforming_intervention_and_support_for_at-risk_prisoners.html, Accessed 1 February 2019.

units – to provide a safe environment for individuals who were at high risk of self-harm’.⁷⁰¹

Figure 14 shows the proportion of periods started in an At-Risk Unit (ARU) for Māori and non-Māori in men’s prisons per year for the five-year period 2013 to 2017.



Source: Department of Corrections⁷⁰²

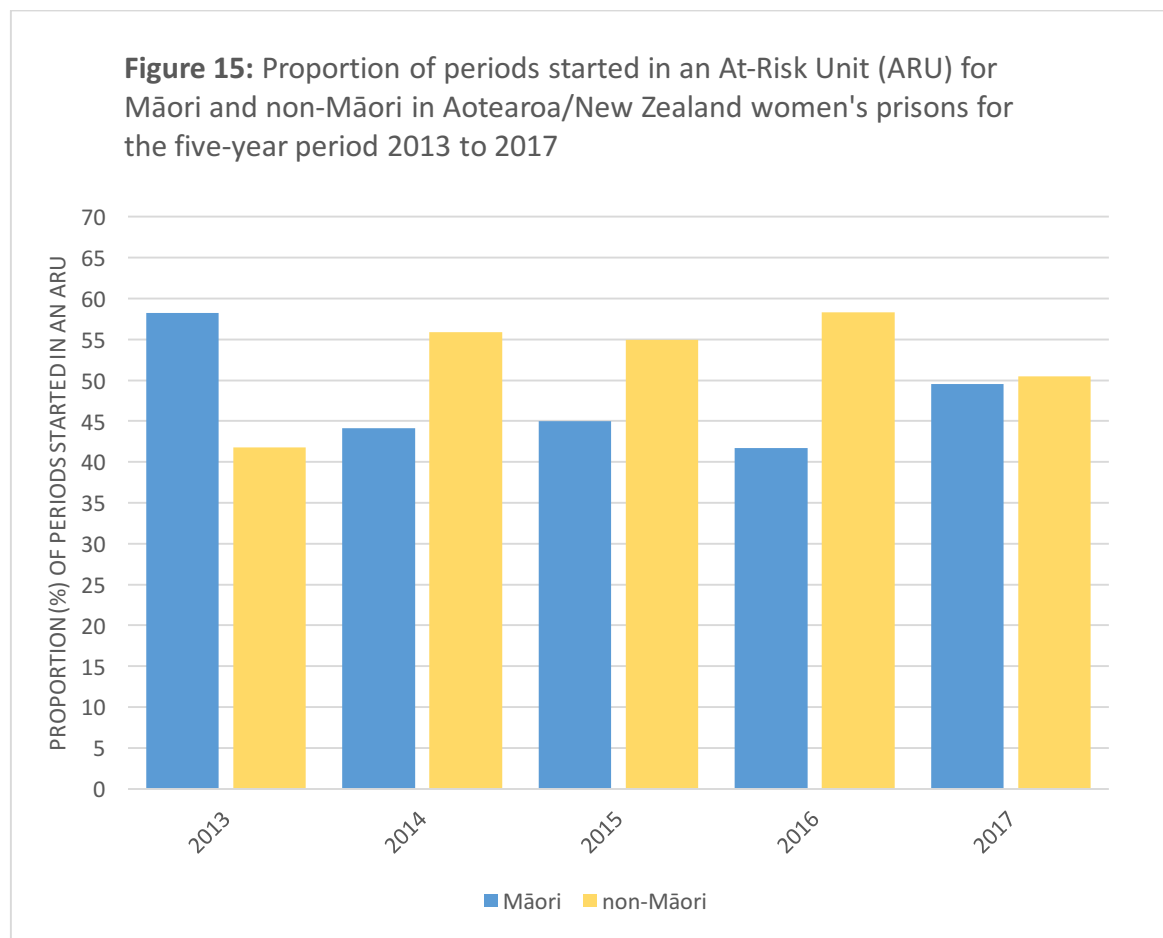
The proportion of periods started in an ARU for Māori and non-Māori have not changed significantly over the five-year period examined. For example, in 2013, the proportion of periods started in an ARU for Māori was 52.3 percent compared with 47.7 per cent for non-

⁷⁰¹ Shalev, *Thinking Outside The Box? A Review of Seclusion and Restraint Practices in New Zealand*, pp.33–34.

⁷⁰² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response. Original data analysis undertaken by researcher.

Māori. For 2017, the proportion of periods started in an ARU for Māori was 49 per cent compared with 51 per cent for non-Māori.⁷⁰³

Figure 15 shows the proportion of periods started in an At-Risk Unit (ARU) for Māori and non-Māori in women’s prisons per year for the five-year period 2013 to 2017.



Source: Department of Corrections⁷⁰⁴

The proportion of periods started in an ARU for both Māori and non-Māori have fluctuated over the five-year period examined. Overall the trend is downwards for Māori, and upwards for non-Māori. For example, in 2013, the proportion of periods started in an ARU

⁷⁰³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response. Original data analysis undertaken by researcher.

⁷⁰⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response. Original data analysis undertaken by researcher.

for Māori was 58.2 per cent compared with 41.8 per cent for non-Māori. For 2017, the proportion of periods started in an ARU for Māori was 49.5 per cent compared with 50.5 per cent for non-Māori.⁷⁰⁵

Regarding the collation and provision of monitoring data on numbers of Māori with lived experience of disability that are placed within the ARUs in prisons, Corrections states,

‘Corrections does not hold this information in a readily retrievable format. In order to identify this type of information, we would be required to manually review a large number of files. Accordingly this part of your request is declined...the information cannot be made available without substantial collation or research’.⁷⁰⁶

As the Crown does not monitor periods started in an ARU by disability and has refused to collate and provide such information to the researcher despite it being clear it was for research to support the Waitangi Tribunal’s Inquiry, the numbers of Māori with lived experience of disability who are placed in ARUs in Aotearoa/New Zealand is largely unknown. However, what this does signify is that the Crown does not collate and analyse nationally its placement of Māori with lived experience of disability into the ARUs within prisons. In other words, the Crown does not have the appropriate mechanisms in place for monitoring its own use of ARUs on Māori with lived experience of disability whom the Crown imprisons within Aotearoa/New Zealand.

⁷⁰⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response. Original data analysis undertaken by researcher.

⁷⁰⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response.

Directed segregation

The Corrections Act 2004 states that, ‘...the opportunity of a prisoner to associate with other prisoners may be restricted or denied in accordance with sections 58 to 60 [these being]: segregation for purpose of security, good order, or safety; segregation for purpose of protective custody; [and] segregation for purpose of medical oversight’.⁷⁰⁷ Corrections also state that,

‘When the prison director is considering an application for segregation, they must decide and justify based on the facts, which section/subsection the prisoner is to be segregated under...The prisoner must not automatically be denied association; it must clearly state the reason(s) for directing either of the association status *(restricted/denied) and how the selected association status mitigates the risk(s) the prisoner presents. Segregation directions must be evidence-based’.^{708,709}

The report, *Thinking outside the box? A review of seclusion and restraint practices in New Zealand*, states,

‘Depending on the reason for their segregation, prisoners could be housed in the prison’s At Risk unit, in a Management Unit or in a punishment unit (sometimes called ‘separates’) or the ‘pound’ – an old fashioned term for a punishment block, essentially small, free standing, fenced and gated breeze block buildings, containing 3–6 cells and shower stalls. These punishment blocks contained no

⁷⁰⁷ Corrections Act 2004.

⁷⁰⁸ Department of Corrections, “M.07.01 Segregation directions.” https://corrections.govt.nz/resources/policy_and_legislation/Prison-Operations-Manual/Movement/M.07-Segregation-of-prisoners/M.07.html, Accessed 1 February 2019.

⁷⁰⁹ *‘Restricted association’ refers to a person be able to have limited ‘contact’ with other people in prison (usually with people in prison who are also under segregation direction). ‘Denied association’ refers to a person not be able to have ‘contact’ with any other people in prison. Refer to Department of Corrections. “M.07.01 Segregation directions”.

office or other space for staff, as staff were not stationed in them, and we were told that they were only used when no other segregation cells were available'.⁷¹⁰

Ti Lamusse's research into the use of solitary confinement in prisons in Aotearoa/New Zealand found that,

'The conditions in the management, separates and At-Risk Units, which make up sanctioned solitary confinement, are often bleak and degrading. People in these units, as well as the countless others in de facto solitary confinement, are locked in their cells for 22–24 hours per day with minimal human contact. Being denied this basic human dignity, people coming out of solitary are more damaged and more likely to hurt others'.⁷¹¹

Figure 16 shows the proportion of directed segregation events for Māori and non-Māori in men's prisons per year for the five-year period 2013 to 2017. There are significant inequities for Māori compared with non-Māori across the five-year period examined. For example, in 2017, Māori (64 per cent) were 1.7 times more likely to be segregated than non-Māori (36 per cent) in the men's prisons.⁷¹²

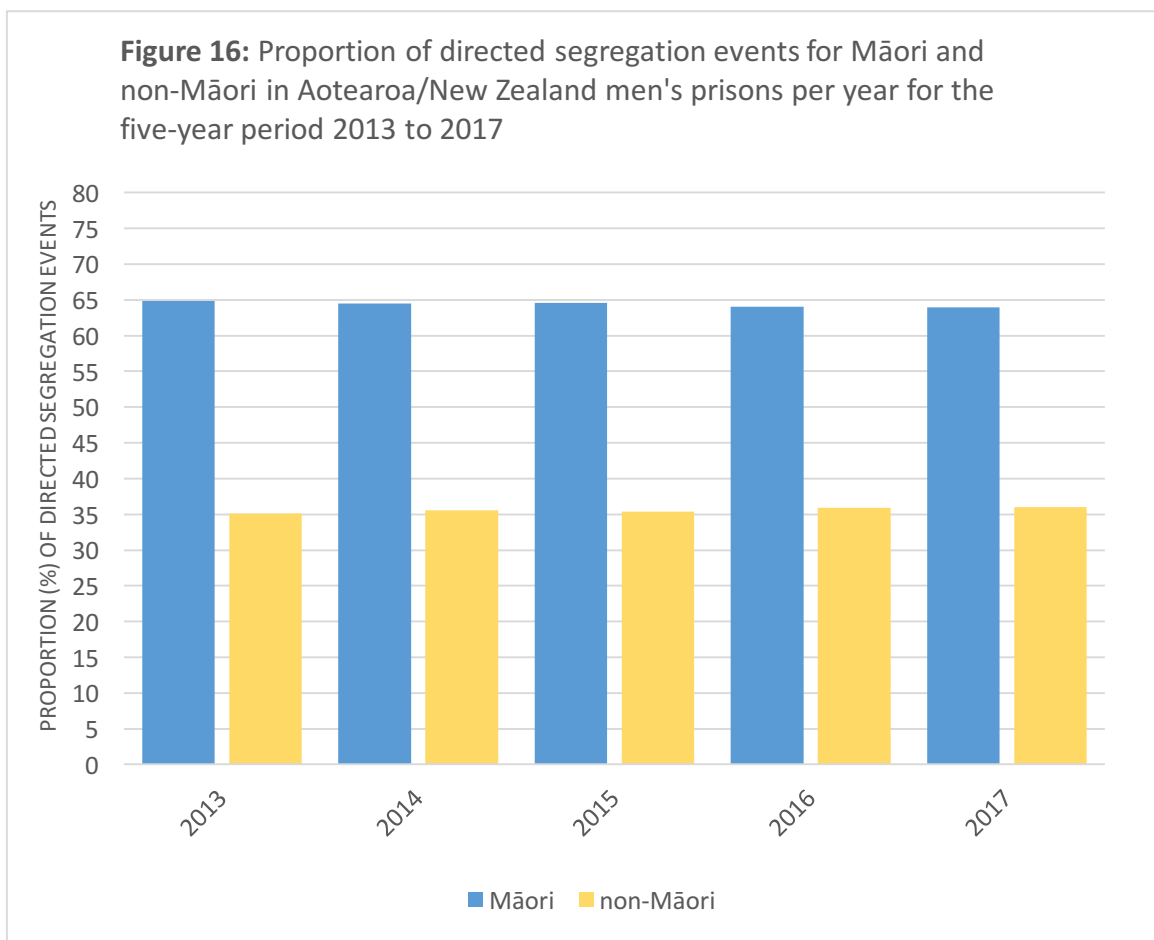
Figure 17 shows the proportion of directed segregation events for Māori and non-Māori in women's prisons per year for the five-year period 2013 to 2017. Though proportions for both Māori and non-Māori have fluctuated over time. However, there are significant inequities for Māori compared with non-Māori across the five-year period examined (and these were higher for Māori in the women's prisons compared with men's prisons). For example, in 2013, Māori (76.6 per cent) were 3.3 times more likely to be segregated than non-Māori (23.4 per cent) in the women's prisons. In 2017, Māori (65.9 per cent) were 1.9

⁷¹⁰ Shalev, *Thinking Outside The Box? A Review of Seclusion and Restraint Practices in New Zealand*, p.31

⁷¹¹ Ti Lamusse, "Solitary Confinement in New Zealand Prisons", *Economic and Social Research Aotearoa* (2018), <https://esra.nz/wp-content/uploads/2018/01/Solitary-Confinement-in-New-Zealand-Prisons.pdf>, p.23.

⁷¹² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response. Original data analysis undertaken by researcher.

times more likely to be segregated than non-Māori (34.1 per cent) in the women's prisons.⁷¹³

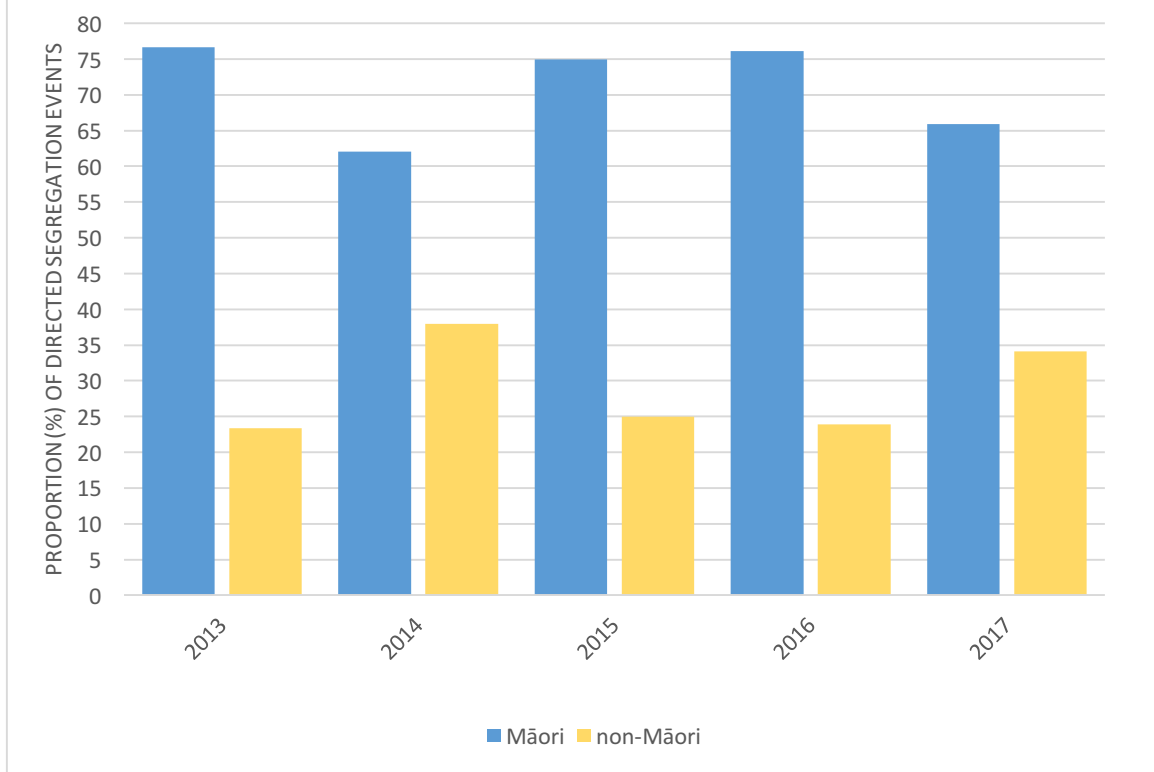


Source: Department of Corrections⁷¹⁴

⁷¹³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response. Original data analysis undertaken by researcher.

⁷¹⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response. Original data analysis undertaken by researcher.

Figure 17: Proportion of directed segregation events for Māori and non-Māori in Aotearoa/New Zealand women's prisons per year for the five-year period 2013 to 2017



Source: Department of Corrections⁷¹⁵

Regarding the collation and provision of monitoring data on numbers of Māori with lived experience of disability who have been segregated in prisons, Corrections states,

‘Corrections does not hold this information in a readily retrievable format. In order to identify this type of information, we would be required to manually review a large number of files. Accordingly this part of your request is declined...the information cannot be made available without substantial collation or research’.⁷¹⁶

⁷¹⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response. Original data analysis undertaken by researcher.

⁷¹⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response.

As the Crown does not monitor its own use of directed segregation events on Māori with lived experience of disability, and has refused to collate and provide such information to the researcher despite it being clear it was for research to support the Waitangi Tribunal's Inquiry, the numbers of Māori with lived experience of disability who the Crown uses directed segregation on, is largely unknown. However, what this does signify is that the Crown does not collate and analyse nationally its use of directed segregation on Māori with lived experience of disability within prisons. In other words, the Crown does not have the appropriate mechanisms in place for monitoring its own use of directed segregation on Māori with lived experience of disability whom the Crown imprisons within Aotearoa/New Zealand.

Mechanical restraint incidents

Although mechanical restraints are not permitted in Aotearoa/New Zealand healthcare services,⁷¹⁷ the Corrections Act 2004 allows for the use of specified mechanical restraints in prisons. Section 87 of the Corrections Act states,

‘A mechanical restraint—may not be used for any disciplinary purpose; must be used in a manner that minimises harm and discomfort to the prisoner. A prison manager may authorise the use of a mechanical restraint on a prisoner for more than 24 hours only if, in the opinion of a medical officer, continued restraint is necessary to protect the prisoner from self-harm’.⁷¹⁸

Under the Corrections Regulations 2005, mechanical restraints authorised for use by a staff member include:⁷¹⁹ handcuffs for general use; handcuffs for emergency use; waist

⁷¹⁷ Julia Carr and Paula King, “The use of ‘tie down’ in New Zealand prisons—what is the role of the health sector?”, *The New Zealand Medical Journal* 132, no. 1493 (2019), <https://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1493-12-april-2019/7858>.

⁷¹⁸ Corrections Act 2004, s.87.

⁷¹⁹ Corrections Regulations 2005, Schedule 5.

restraints used in conjunction with handcuffs; tie-down beds;⁷²⁰ wrist bed restraints; torso restraints; head protectors; and spit hoods.

Regarding the collation and provision of monitoring data on the use of mechanical restraints on Māori with lived experience of disability, Corrections state,

‘...information about mechanical restraint incidents is not recorded in a way that identifies the prisoner who has the mechanical restraints applied. Therefore we are unable to identify the ethnicity or disability status of the offenders involved...as the information requested is not held by Corrections, and we have no grounds for believing that it would be held for another agency’.⁷²¹

However, after further clarification was sought by the researcher regarding this response,⁷²² Corrections clarified that, although they do have a central database of mechanical restraints incidents,

‘...there is no record of the offender who had the mechanical restraints used on them...it is recorded on individual offender files...we would therefore be required to manually review a large number of files. While we acknowledge that it was incorrect for Corrections to decline this part of your request... we continue to do so...as the information requested cannot be made available without substantial collation and research’.⁷²³

⁷²⁰ In April 2019, the Department of Corrections abolished the use of tie-down beds in prisons. Refer to RNZ, “Corrections bans tie-down beds two years after critical report.” 11 April 2019, <https://www.radionz.co.nz/news/national/386859/corrections-bans-tie-down-beds-two-years-after-critical-report.>, Accessed 20 April 2019.

⁷²¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response.

⁷²² This was due to the Department of Corrections (Corrections) having released information under the Official Information Act 1982 on 22 December 2017 on use of mechanical restraints in prisons. The information provided evidence that Corrections had knowledge of whom mechanical restraints were used on in prison. Refer to Corrections OIA response C90080.

⁷²³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16a Corrections clarification response.

Additionally, with regard to the collation and provision of monitoring data on the use of mechanical restraints on Māori with lived experience of disability – detained in a regional forensic mental health service or a care facility for people with learning/intellectual disabilities, during their transport to and from court appointments or medical appointments.⁷²⁴ Corrections state,

‘Information on restraint incidents on transports...is not held centrally, or in a consistent format across regions...we would be required to manually review a large number of files. Therefore this part of your request is declined...as the information requested cannot be made available without substantial collation and research’.⁷²⁵

As the Crown does not monitor its use of mechanical restraints on Māori, or on Māori with lived experience of disability, and has refused to collate and provide such information to the researcher despite it being clear it was for research to support the Waitangi Tribunal’s Inquiry, the Crown’s use of mechanical restraints on Māori with lived experience of disability imprisoned in Aotearoa/New Zealand is largely unknown. Nor is this information known for Māori with lived experience of disability who are detained in a regional forensic mental health services or in care facilities for people with lived experience of learning/intellectual disability, and transported by Corrections to and from court appointments or medical appointments. However, what this does signify is that the Crown does not collate and analyse nationally its use of mechanical restraints on Māori, and Māori with lived experience of disability whom the Crown imprisons, nor on Māori with lived experience of disability whom the Crown detains in regional forensic mental health services or in care facilities, and are then transported. In other words, the Crown does not have the appropriate mechanisms in place for monitoring its own use of mechanical restraints on

⁷²⁴ Set out in Schedule 1 “Transports destinations and Patient and Care Recipient groups covered by this agreement” of the Memorandum of Understanding between the Ministry of Health and Department of Corrections 2011.

⁷²⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 16 Corrections Final Response.

Māori with lived experience of disability whom the Crown imprisons, nor on Māori with lived experience of disability being transported from regional forensic mental health services or care facilities.

Monitoring of health and disability services in the Ministry for Children’s care and protection and youth justice residences

The Ministry for Children’s care and protection and youth justice residences provide secure residential care to young people who are generally aged 12–17 years and deemed to require such care. Regarding the care and protection residences, the Ministry for Children states that,

‘...the objectives of practice for the care and protection population are to deliver high quality services for children and young people in the custody of the Chief Executive of Oranga Tamariki in a safe environment that is culturally appropriate. The ultimate goals to address their needs and make positive changes to the young people’s lives and relationships in order to assist with their reintegration into their family, whānau, hapū, iwi, and other groups responsible for their on-going wellbeing’.⁷²⁶

With regard to the main function of the youth justice residences, the Ministry for Children states that the residences,

‘...provide a safe and secure environment for a young person when a judge decides that it would be unsafe for the young person to live in the community. Secure residential care is a highly specialised environment at the most intensive

⁷²⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 17 Oranga Tamariki Response.

end of the continuum of services available to tamariki and rangatahi in need of Oranga Tamariki intervention. Alongside providing a secure and safe environment for young offenders, these residences support community safety, and, where practical, address drivers of offending behaviour. In addition, it is also necessary to address the underlying difficulties and needs of the young person'.⁷²⁷

Ethnicity

The Ministry for Children reports ethnicity for Māori, based self-identification of children and young people who self-identify in the ethnic categories of Māori, Pacific, or Other.⁷²⁸

Numbers of Māori children and young people in the residences

There are four care and protection⁷²⁹ and four youth justice residences⁷³⁰ in Aotearoa/New Zealand. To provide context with regard to the health and well-being of Māori children and young people with lived experience of disability in the care and protection and youth justice residences, the proportions and numbers of Māori and non-Māori children and young people are presented in the following figures.

Figure 18 shows the proportion of Māori and non-Māori children and young people in the Ministry for Children's care and protection and youth justice residences per year for the 10-year period from 2008 to 2017. There are significant inequities for Māori children and young people compared with non-Māori. The proportion of Māori has increased over the 10-year period examined from 59.6 per cent in 2008 to 81.2 per cent in 2017. In contrast, the proportion of non-Māori has decreased over the 10-year period from 40.4 per cent in

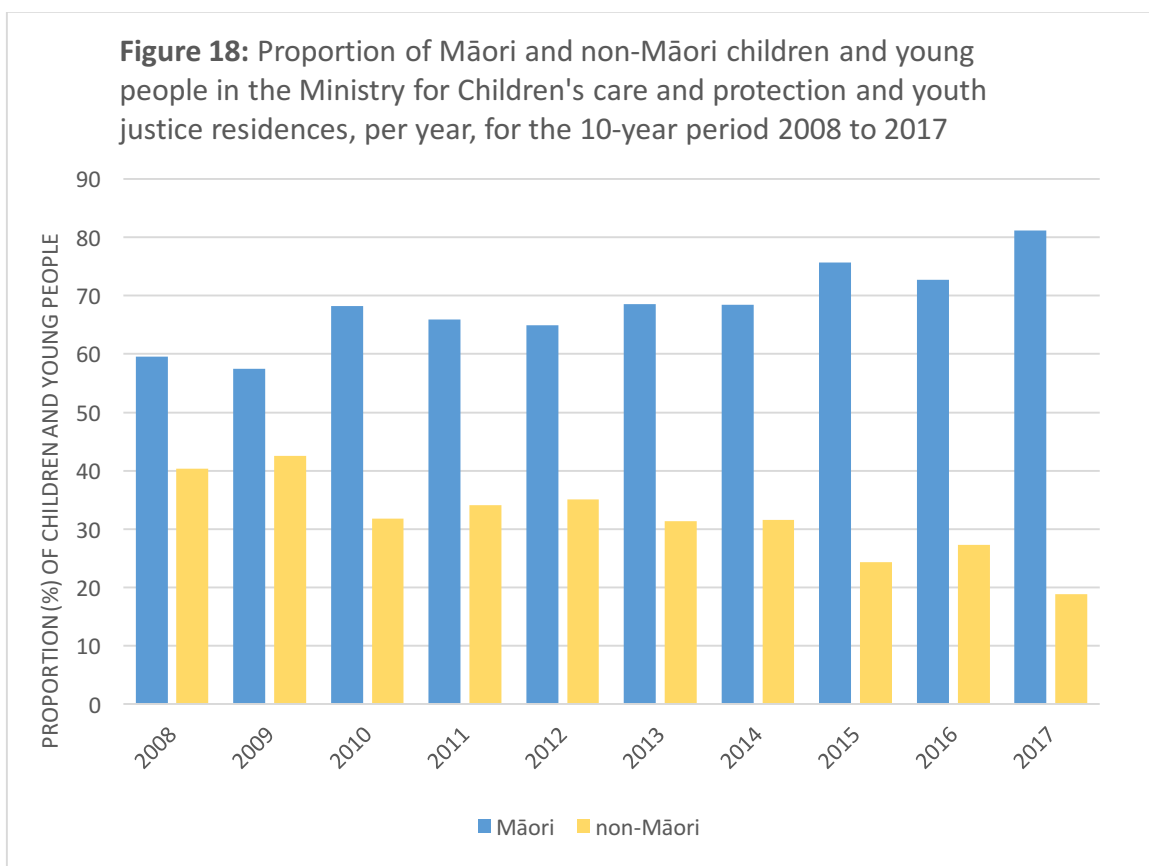
⁷²⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 17 Oranga Tamariki Response. Original data analysis undertaken by researcher.

⁷²⁸ Multiple ethnic categories can be self-identified, for example, 'Māori' and 'Pacific'.

⁷²⁹ These are: Whakatakapokai in South Auckland; Epuni in Lower Hutt; Te Oranga in Christchurch; and Puketai in Dunedin.

⁷³⁰ These are: Korowai Manaaki in South Auckland; Te Maioha o Parekarangi in Rotorua; Te Au rere a te Tonga in Palmerston North; and Te Puna Wai ō Tuhinapo in Christchurch.

2008 to 18.8 per cent in 2017.⁷³¹ For the 2017 year, Māori children and young people were 4.3 times more likely than non-Māori to be placed in a residence. The inequity has increased since 2008 when Māori children and young people were 1.5 times more likely than non-Māori to be placed in a residence. The increase in inequity is secondary to increasing numbers over time for Māori children and young people across both care and protection and youth justice residences, with decreasing numbers over time for non-Māori across both care and protection and youth justice residences (Figures 19 and 20).

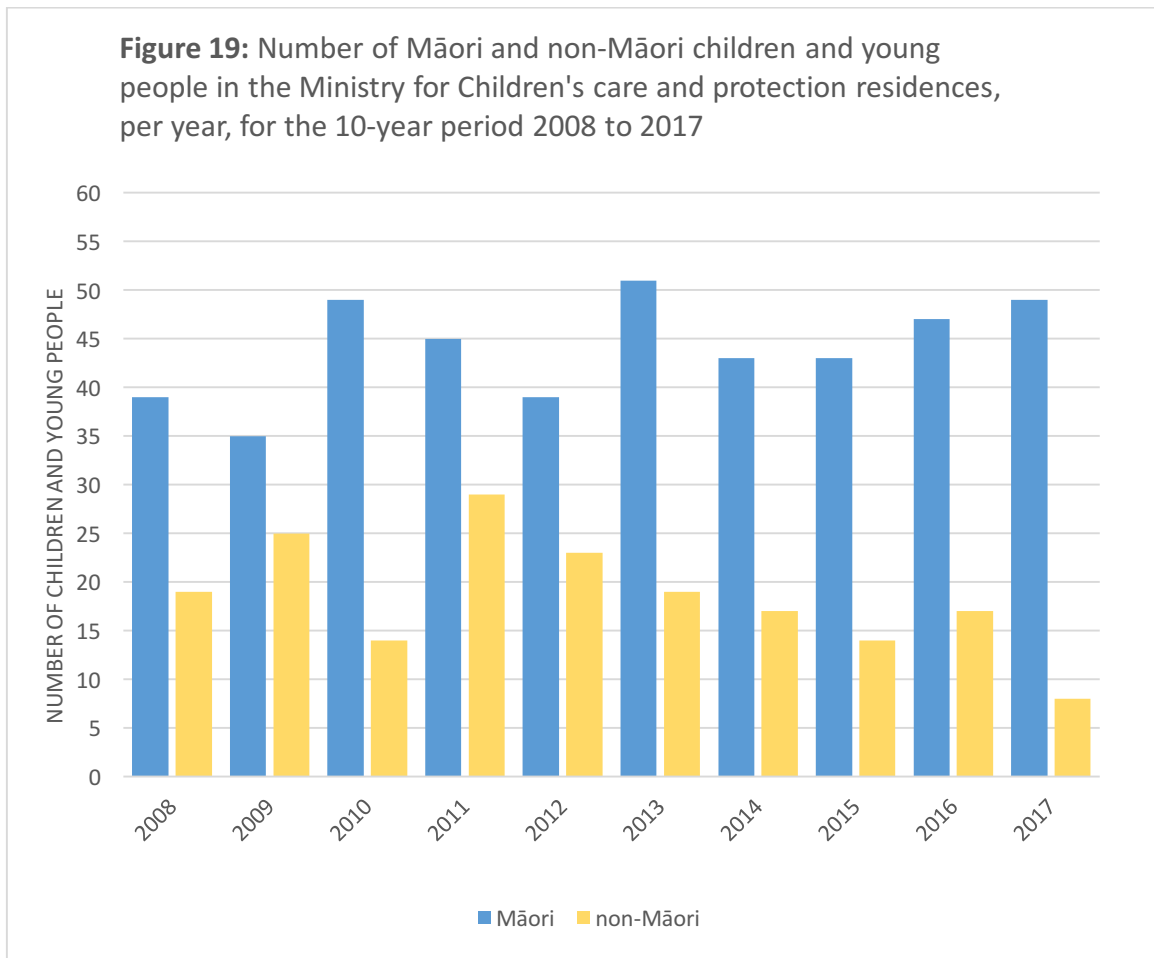


Source: Ministry for Children⁷³²

⁷³¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 17 Oranga Tamariki Response.

⁷³² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 17 Oranga Tamariki Response. Original data analysis undertaken by researcher.

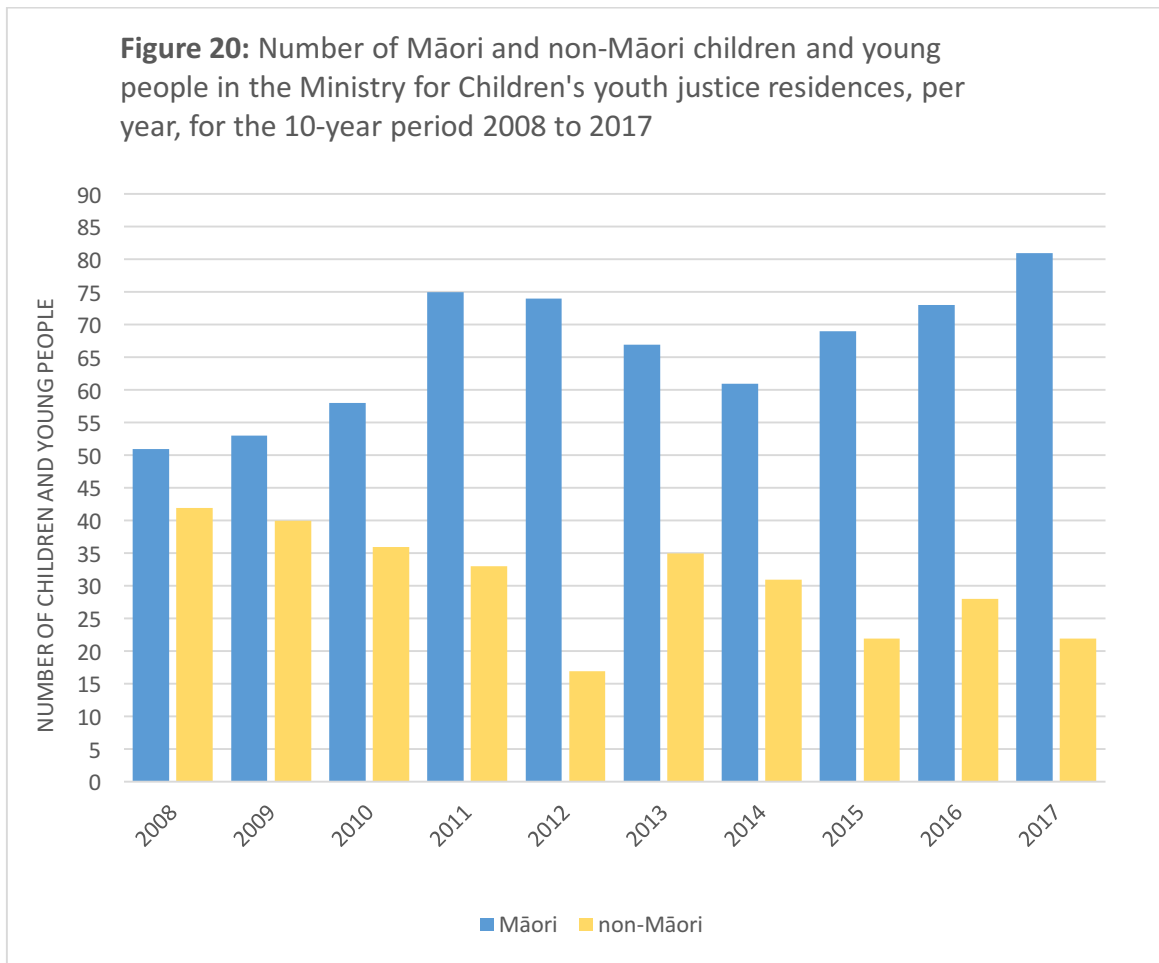
Figure 19 shows the number of Māori and non-Māori children and young people in the care and protection residences per year for the 10-year period from 2008 to 2017. The numbers for both Māori and non-Māori have fluctuated over the 10-year period examined, However, for Māori the trend has been upwards with numbers increasing over time from 39 in 2008, to 49 in 2017. For non-Māori, the trend has been downwards, the numbers decreasing over time from 19 in 2008, to 8 in 2017.



Source: Ministry for Children⁷³³

⁷³³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 17 Oranga Tamariki Response.

Figure 20 shows the number of Māori and non-Māori children and young people in the youth justice residences per year for the 10-year period from 2008 to 2017. The numbers for both Māori and non-Māori have fluctuated over the 10-year period examined, However, for Māori the trend has been upwards with numbers increasing over time from 51 in 2008, to 81 in 2017. For non-Māori, the trend has been downwards, the numbers decreasing over time from 42 in 2008, to 22 in 2017.



Source: Ministry for Children⁷³⁴

⁷³⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 17 Oranga Tamariki Response.

MĀORI CHILDREN AND YOUNG PEOPLE WITH LIVED EXPERIENCE OF DISABILITY

A Cabinet paper in 2017 stated that, ‘...children and young people with disabilities are over-represented among the children and young people engaged with the Ministry for Vulnerable Children and its services’,⁷³⁵ however relevant statistics were not provided. With regard to the collation and provision of monitoring data on the numbers of Māori children and young people with lived experience of disability in care and protection and youth justice residences, the Ministry for Children states,

‘The number of disabled Māori and non-Māori tamariki and rangatahi in from 2008 to 2017 is not centrally located. This information is contained in notes in individual files. Accordingly, in order to provide this information our staff would have to manually review a large number of files’.⁷³⁶

As the Crown does not monitor this information, and has refused to collate and provide such information to the researcher despite it being clear it was for research to support the Waitangi Tribunal’s Inquiry, the number of Māori children and young people with lived experience of disability in the care and protection and youth justice residences across Aotearoa/New Zealand is largely unknown. However, what this does signify is that the Crown does not collate and analyse nationally, the numbers of Māori children and young people with lived experience of disability within its care and protection and youth justice residences across Aotearoa/New Zealand. In other words, the Crown does not have the appropriate monitoring mechanisms in place to be able to ensure that the health and disability support needs for Māori children and young people with lived experience of disability within its care and protection and youth justice residences are being met.

⁷³⁵ Office of the Minister for Children, *Progress for implementing the new vulnerable children operating model* (Wellington, 2017), <https://www.orangatamariki.govt.nz/assets/Uploads/Our-progress-so-far/Cabinet-Paper-Progress-in-Implementing-the-New-Vulnerable-Children-Operating-Model.pdf>.

⁷³⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 17 Oranga Tamariki Response.

Monitoring of health and disability support services

There are six district health boards (DHBs) within the catchment area of the eight care and protection and youth justice residences. The DHBs contract with providers to deliver primary healthcare services to the residences.

Each child or young person who is admitted to the residence receives a triage health assessment with an on-site registered nurse within 24–48 hours of entry, to identify and prioritise their immediate health needs and appropriate action or treatment required. An examination by a registered medical practitioner occurs within one week of being admitted to the residence. This is indicated in regulation 14(2) of the *Oranga Tamariki Residential Care Regulations 1996*.

Primary healthcare services in the residences include: referrals for laboratory screening, diagnostic services and pharmacy series, sexual health screening and treatment, provision of, or referral to vision and hearing screening, dental services as required, alcohol and drug assessment and treatment, primary mental health assessment and treatment, immunisation services, and referrals to specialist services as needed. These services operate in conjunction with the medical and services coordination processes, and includes transition planning for when a child or young person leaves the residence.⁷³⁷

The Ministry for Children does not have a centralised system in its care and protection residences and youth justice residences for monitoring the delivery of healthcare and disability support services to Māori children and young people.⁷³⁸ With regard to the collation and provision of monitoring data on access to health and disability support

⁷³⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 17 Oranga Tamariki Response.

⁷³⁸ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 17 Oranga Tamariki Response.

services for Māori children and young people with lived experience of disability in care and protection and youth justice residences, the Ministry for Children states,

‘...[the] number of Māori and non-Māori tamariki and rangatahi accessing from 2013–2017 is not centrally located. This information is contained in notes in individual files. Accordingly in order to provide this information our staff would have to manually review a large number of files’.⁷³⁹

As the Crown does not monitor this information and has refused to collate and provide such information to the researcher despite it being clear it was for research to support the Waitangi Tribunal’s Inquiry, access to health and disability support services for Māori children and young people, and Māori children and young people with lived experience of disability, in the care and protection and youth justice residences across Aotearoa/New Zealand is largely unknown. However, what this does signify is that the Crown does not collate and analyse nationally, the access to health and disability support services for Māori children and young people, and Māori children and young people with lived experience of disability, within its own care and protection and youth justice residences across Aotearoa/New Zealand. In other words, the Crown does not have the appropriate mechanisms in place for monitoring access to health and disability support services to ensure that health and disability support needs are being met.

Secure care placement

With regard to the use of ‘secure care’⁷⁴⁰ on children and young people in their residences, the Ministry for Children states,

⁷³⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 17 Oranga Tamariki Response.

⁷⁴⁰ Mechanical restraints are reported as no longer in use in care and protection and youth justice residences. Refer to Shalev, *Thinking Outside The Box? A Review of Seclusion and Restraint Practices in New Zealand*.

‘Placing a young person in secure care is an option we have to prevent young people being a risk to themselves or others when there is no alternative to ensure safety. It is not a punishment. Where young people are placed in secure care, it is important that they are given a clear explanation as to the reason they have been placed in secure care...Before a decision is made to place a young person in secure care, a wide range of interventions must have already been used or considered and an assessment has to clearly show that the young person meets the legal grounds to be placed in secure care’.⁷⁴¹

The Oranga Tamariki Act 1989 and the *Oranga Tamariki (Residential Care) Regulations 1996* (the Regulations), contain provisions for ‘secure care’ placements of children and young people in residences.^{742,743} Section 368 of the Oranga Tamariki Act states,

(1) A child or young person may be placed in secure care in a residence if, and only if, such placement is necessary—

(a) to prevent the child or young person absconding from the residence where any 2 of the conditions specified in subsection (2) apply; or

(b) to prevent the child or young person from behaving in a manner likely to cause physical harm to that child or young person or to any other person.

(2) The conditions referred to in subsection (1) (a) are—

(a) the child or young person has, on 1 or more occasions within the preceding 6 months, absconded from a residence or from Police custody:

⁷⁴¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 17 Oranga Tamariki Response.

⁷⁴² Oranga Tamariki Act 1989, s.368.

⁷⁴³ Oranga Tamariki (Residential Care) Regulations 1996.

(b) there is a real likelihood that the child or young person will abscond from the residence:

(c) the physical, mental, or emotional well-being of the child or young person is likely to be harmed if the child or young person absconds from the residence.

The decision to place a child or young person in 'secure care' must have the approval of a team leader or a staff member on the senior duty roster. The child or young person's parent or guardian, or the person who cared for them prior to entering the residence, and their advocate/lawyer is notified as soon as possible after they are placed in 'secure care' and they are sent a follow up letter within 24 hours. This is set out in section 369 of the Oranga Tamariki Act.

Under section 370, there are time limits for placement in 'secure care', and each placement must be reviewed daily in accordance the Regulations.⁷⁴⁴ There are also legal limits imposed on the ability to confine a child or young person in 'secure care' to their bedroom under the Regulations.⁷⁴⁵

The Ministry for Children states that 'secure care' is a,

'...high-level intervention and is closely monitored. [They] must only remain in their bedroom for as long as is reasonably necessary to achieve the purpose of the confinement. A review of the grounds for confinement must be made frequently, for example every ten minutes, half hour or hourly. If they are confined between the hours of 8am and 8pm checks are undertaken every five minutes. Overnight checks are usually at least every 30 minutes...Every child or young person placed in secure care (including those confined in a bedroom under

⁷⁴⁴ Regulation 47 of the Oranga Tamariki (Residential Care) Regulations 1996.

⁷⁴⁵ Regulation 48 of the Oranga Tamariki (Residential Care) Regulations 1996.

Regulation 48) has access to a range of planned, purposeful and varied activities including where practicable cultural, recreational, social, sporting and educational activities. Regulation 48 of the Regulations only applies to young people in secure care and confinement is not permitted at any time in the other areas of our residences'.⁷⁴⁶

Shalev, in the report, *Thinking outside the box? A review of seclusion and restraint practices in New Zealand*, states,

'Children and young people in Care and Protection residences could be held in separation from their peers in 'Secure Care' units which were identical to prison segregation units. These were inappropriate'.⁷⁴⁷

The report also highlighted issues around lack of access to basic necessities such as drinking water for children and young people.

'Seclusion rooms/cells in several of the facilities visited did not have access to drinking water. Rooms in the Secure Care Unit in the children's care and protection residence had a basin, but we were told that the water was not suitable for drinking'.⁷⁴⁸

Of concern, similar to other issues highlighted with regard to the Crown's lack of monitoring of the health and well-being of Māori children and young people within their care and protection and youth justice residences, the Crown's use of secure unit placements on Māori children and young people, and those with lived experience of disability is not centrally located. Instead, the information is recorded in daily log books within each residence.

⁷⁴⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 17 Oranga Tamariki Response.

⁷⁴⁷ Shalev, *Thinking Outside The Box? A Review of Seclusion and Restraint Practices in New Zealand*, p.10

⁷⁴⁸ Shalev, *Thinking Outside The Box? A Review of Seclusion and Restraint Practices in New Zealand*, p.44

With regard to the collation and provision of monitoring data on the use of ‘secure care’ on Māori children and young people and those with lived experience of disability in care and protection and youth justice residences, the Ministry for Children states, ‘...[a]ccordingly, in order to provide this information our staff would have to manually review a large amount of daily log books’.⁷⁴⁹

As the Crown does not monitor this information, and has refused to collate and provide such information to the researcher despite it being clear it was for research to support the Waitangi Tribunal’s Inquiry, the Crown’s use of ‘secure care’ placements on Māori children and young people, and Māori children and young people with lived experience of disability within the care and protection and youth justice residences across Aotearoa/New Zealand is largely unknown. However, what this does signify is that the Crown does not collate and analyse nationally its use of ‘secure care’ placements on Māori children and young people, and Māori children and young people with lived experience of disability within the care and protection and youth justice residences. In other words, the Crown does not have the appropriate mechanisms in place for monitoring its own use of ‘secure care’ placements on Māori children and young people, and Māori children and young people with lived experience of disability within its care and protection and youth justice residences.

Summary

Current monitoring and data collection for identifying, and addressing inequities in services and outcomes for Māori with lived experience of disability is not effective. The Ministry of Health does hold several national databases that contain information on Māori with lived experience of disability. However, the health status of the total disability population in Aotearoa/New Zealand – including Māori with lived experience of disability – is not

⁷⁴⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 17 Oranga Tamariki Response.

measured, as disability is not able to be identified in the majority of the national health surveys.

Though the Ministry of Health does collect routine disability support services data, the usefulness of this data regarding addressing health and well-being for Māori with lived experience of disability is limited to the level of examining trends in service utilisation. Although the Washington Group Short Set (WGSS) has been added to the 2018/19 New Zealand Health Survey for adults and children, the WGSS questions are not designed to measure prevalence of disability. Rather, they are used as a categorical variable (for example, by ethnic group or sex) to allow for comparison of outcomes by different population sub-groups. Additionally, the WGSS questions are informed by a Western model, and have not been designed for Indigenous peoples. In which case, the assumption that the effectiveness of the use of the WGSS questions as a mechanism for the provision of meaningful information for Māori with lived experience of disability should be critiqued.

Regarding the improvement of data quality for Māori with lived experience of disability, Action 9E of the Disability Action Plan 2014–18 was never completed following the release of the *New Zealand Disability Strategy*. Poor data quality for Māori with lived experience of disability is also likely to be compounded by the disproportionate impacts that the poorly run 2018 Census will have on Māori. This is because Census data are used for distribution of resources (for example, district health board funding), monitoring of the Crown's actions, and in the case of Iwi and Hapū affiliation in particular, used by Māori to support their own aspirations.

Additionally, as the Health Research Council does not ring-fence funding for Māori health research on disability, it is difficult to discern how this situation could support the advancement of Māori health research that meets the aspirations and needs of Māori with lived experience of disability, their whānau, and communities.

There are significant gaps in the monitoring of, and data collection for, identifying and addressing inequities in the Crown's use of seclusion and restraint on Māori with lived

experience of disability. What data is available shows that the inequities in secluded Māori compared with non-Māori have actually increased over a 10-year period, and following the introduction of the seclusion reduction policy by the Crown in 2009.

The Crown's (over)use of seclusion on Māori with lived experience of learning/ intellectual disability is of considerable concern. According to data provided by the Crown for the year 2017, Māori with lived experience of learning/ intellectual disability, on average, are being secluded up to 36 times. This compares with Ministry of Health figures from 2017 which report that, on average, people in adult inpatient services are secluded twice.

There are significant gaps in the monitoring of, and data collection for, identifying and addressing inequities in health services and outcomes for Māori children and young people, and Māori children and young people with lived experience of disability in the Ministry for Children's care and protection and youth justice residences. Nor is there monitoring of the Crown's own use of 'secure care' placements on Māori children and young people, and Māori children and young people with lived experience of disability within these residences.

There are significant gaps in the monitoring of, and data collection for, identifying and addressing inequities in health services and outcomes for both Māori and Māori with lived experience of disability who are imprisoned by the Crown. Nor is there monitoring of the Crown's own use of directed segregation on Māori with lived experience of disability, or mechanical restraints on Māori, and Māori with lived experience of disability within prisons, nor for Māori with lived experience of disability detained in regional forensic services or in care facilities, and then transported.

What evidence there is, shows significant inequities for Māori compared with non-Māori in the use of directed segregation. For example, in 2017, Māori were 1.7 times more likely to be segregated than non-Māori in the men's prisons, and 1.9 times more likely to be segregated than non-Māori in the women's prisons.

The lack of systems in place to monitor the activity of Crown organisations regarding the Crown's own use of such practices as secure care placements, directed segregation, and use of mechanical restraints in those Crown institutions where Māori make up the greatest proportions of the population is of considerable concern.

Chapter V – Data Review Part 2

Introduction

This chapter presents Part 2 of the data review of the information that was provided by a selection of Crown organisations under the Official Information Act 1982 (Part 1 of the data review is discussed in Chapter IV).⁷⁵⁰ Summaries of the thematic analysis using a Treaty-principles framework,⁷⁵¹ are presented in a number of tables in the sections below.

Summary themes from the Ministry of Health (MoH) are discussed first, followed by the district health boards, Crown health organisations (excluding the MoH), and lastly, the Office for Disability Issues. A summary of the key issues overall, is presented at the end of the chapter.

The Ministry of Health

Table 16 presents the summary themes from the thematic analysis of information provided by the MoH using a Treaty-principles framework. This includes the following principles: partnership, participation, options, active protection, and equity.

⁷⁵⁰ Refer to Chapter I for further discussion of the research methods.

⁷⁵¹ Refer to Chapter I for discussion of the 'Treaty principles' framework used for the thematic analysis.

Partnership

It is not clear whom the MoH considers to be its partners when it comes to Māori health and disability issues. For example, the MoH has an 'achieving equity' programme, '...because it is a priority for government to deliver equitable outcomes for all New Zealanders'.⁷⁵² This includes, '...working with system partners...'.⁷⁵³ However, no detail for this is provided.

The MoH includes Māori with lived experience of disability in decision making through Te Ao Mārama, '...a group of external advisors that support the implementation of Whāia Te Ao Mārama: The Māori disability action plan'.⁷⁵⁴ However, a review of Te Ao Mārama's meeting minutes over a period of 18 months,⁷⁵⁵ shows limited engagement by the MoH with Te Ao Mārama (outside the direct implementation of the action plan, *Whāia Te Ao Mārama*), and no clarity about what happens with the advice that Te Ao Mārama provides as to whether or not it is actually incorporated.

The MoH Disability Directorate also, '...aims to have positive partnerships with its stakeholders, in particular disabled people, their family/whānau, carers and disability support providers'.⁷⁵⁶ In addition to Te Ao Mārama, the Disability Directorate engages with a consumer consortium. Its Māori membership includes a Māori disability provider collective and a Māori Needs Assessment and Service Coordination operations group. Engagement with Māori with lived experience of disability in other work across the MoH

⁷⁵² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁵³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁵⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁵⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1h, 1i, 1j, 1k, 1ka Ministry of Health.

⁷⁵⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

however, is ad hoc. For example, the MoH states, 'each business unit determines how it involves Māori with disabilities, seeking advice from the Disability Directorate'.⁷⁵⁷

Participation

Māori participation in committees appointed by the Minister of Health is common, but not universal, and participation in committees by Māori with lived experience of disability is unknown. The MoH states it, '...does not hold information on the number of appointed members with disabilities, as there is no specific reporting requirements for this information'.⁷⁵⁸ Māori with lived experience of disability are participants in the MoH-led disability transformation work in the MidCentral district. But the extent of this participation is unclear. The MoH provides information about Māori involvement in the 'co-design' team and indicates, for example, that Māori have been involved in discussions on service delivery which,

'...confirmed that a kaupapa Māori approach...can help tāngata whaikaha and whānau engage with disability support services. Participants emphasised that Māori values, concepts and practices should be fused within a transformed disability system in an authentic way, rather than attached as an afterthought or appendage'.⁷⁵⁹

No information is provided however, on how this feedback has been incorporated into system transformation or disability support service design. There are also examples where Māori are not involved in relevant projects. For example, action 9(c) of the Disability Action Plan is to, 'increase access to health services and improve health outcomes for disabled

⁷⁵⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁵⁸ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁵⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

people with a specific focus on people with learning/intellectual disabilities'.⁷⁶⁰ The MoH leads this work and established a Project Reference Group in 2015 with no apparent participation by Māori with lived experience of disability – the MoH stating that the Project Reference Group had, '...the vision...[to] ensure Māori disabled people were consulted with'.⁷⁶¹

In one instance, the MoH gives examples of engaging with other government agencies as a proxy for 'engaging with Māori'. For the funded family care legislation (in addition to targeted engagement including Māori with lived experience of disability), the MoH consulted with Te Tumu Whakarae (a network of district health board Māori health managers), and the Ministry of Social Development which has engaged with Māori stakeholders for the carers' strategy action plan.

The MoH does not set explicit standards for district health boards (DHB) when it comes to involving Māori with lived experience of disability in decision making. Instead, the MoH leaves it up to the DHBs whereby,

'...DHB accountability arrangements reflect expectations that in the service planning process DHBs use a framework for the consultation of different groups and communities, such as Māori and people with disability and [non-governmental organisation] NGO representing service users and communities'.⁷⁶²

There is also little information on the involvement of Māori with lived experience of disability in the health and disability workforce, as shown by material that was provided to Te Ao Mārama in October 2018. Despite this, MoH officials state to Te Ao Mārama, '...[t]he

⁷⁶⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁶¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1b Ministry of Health.

⁷⁶² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

Ministry consider Māori are well covered apart from leadership roles in governance...[thus the] area for focus is Māori leadership roles'.⁷⁶³

Options

The MoH does not routinely identify or monitor the number of Māori-owned and Māori-governed disability support service (DSS) providers and cannot provide information on MoH audits of Māori DSS providers. However, in response to the information request under the Official Information Act, the MoH undertook a manual review of providers contracted to deliver DSS and those who have received Māori Provider Development Scheme funding. Although there are caveats around the quality of the information, it does indicate that there are only a small number of Māori DSS providers (the review identified 33) operating in a large disability support service sector (total of 980 providers).⁷⁶⁴

Active protection

The MoH expects that members of its committees, '...are aware and responsive to the various cultural considerations required for Māori, as well as other community groups'.⁷⁶⁵

The MoH does indicate that it provides training and induction material for ministerial committees and new appointees when appropriate, but does not expand on what that means or whether it includes Māori and/or disability responsiveness training.

For MoH staff, the MoH provides tools to, '...support understanding and decision making when working collaboratively with Māori'.⁷⁶⁶ However, these were not supplied to the

⁷⁶³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1ka Ministry of Health.

⁷⁶⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1za Ministry of Health.

⁷⁶⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁶⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

researcher so it is not possible to tell if they are adequate. The MoH does not collect data on course completion but the Disability Directorate has a focus on cultural competence training and in the 2016/17 year, 90 per cent of staff (of the then DSS team) completed online cultural competency training. The MoH has work underway to support its diversity and inclusion strategy, but there is no mention specifically on disability responsiveness training for staff or strategies to recruit Māori with lived experience of disability.

The MoH dedicate considerable effort to ensuring funding is correctly administered to eligible clients. However, there is no effort demonstrated on ensuring spending is targeted toward Māori with lived experience of disability. The MoH states that it,

‘...is not able to estimate the proportion of Vote Health that is targeted for health services for disabled Māori. Any attempt to produce an estimate would not accurately represent the range of health services that Māori disabled may be receiving’.⁷⁶⁷

Equity

The MoH provides little detail on what is done specifically to ensure DHBs meet their obligations to Māori with lived experience of disability. While the MoH can provide examples of how its monitoring can identify inequities, there is no evidence that the MoH acts to address the health need of Māori with lived experience of disability when such inequities are identified.

Annual planning guidance sent by the MoH to DHBs reinforces, ‘obligations as Treaty partner’, and equity actions, such as monitoring and reporting by ethnicity where data allows. But there is nothing specific about Māori with lived experience of disability in general guidance.

⁷⁶⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1b Ministry of Health.

Quality data for Māori with lived experience of disability is very limited. The MoH states,

‘...identification of disability is currently not possible in some of the Ministry’s data collection, including the New Zealand Health Survey. This makes it difficult to identify whether some Māori have a disability within the Ministry datasets’.⁷⁶⁸

The lack of data also impacts on the ability of the MoH to monitor its contracted services to ensure that they are achieving equity for Māori with lived experience of disability.

‘While the Ministry’s National Screening Unit monitors access to services (and outcomes) by ethnicity its programmes are currently unable to identify participants by their disability status. Screening service providers are, however, expected to consider the needs of participants with disabilities’.⁷⁶⁹

Data on inequities for Māori is available, and has been for a number of years. For example, the MoH discusses how its monitoring can identify inequities in the number of Māori subject to community treatment orders under the Mental Health (Compulsory Assessment & Treatment) Act. However, there is no evidence of proportionate action to address said inequities (highlighting the difference between actions to address significant health inequities, compared with simply monitoring or tracking persistent inequities over time).

⁷⁶⁸ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁶⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

Table 16: Summary themes from information provided by the Ministry of Health analysed by Treaty principles

Principle	Themes
Partnership	<p>It is not clear who the Ministry of Health (the Ministry) considers its partners when it comes to Māori health and disability issues.</p> <p>For example, the Ministry has an achieving equity programme, ‘...because it is a priority for government to deliver equitable outcomes for all New Zealanders...’. This includes, ‘...working with system partners...’, but no detail is provided.⁷⁷⁰</p> <p>The Ministry includes Māori with lived experience of disability in decision making through Te Ao Mārama, ‘...a group of external advisors that support the implementation of <i>Whāia Te Ao Mārama: The Māori disability action plan</i>’.⁷⁷¹ The level of influence of the group is unclear.</p> <p>Te Ao Mārama is also able to provide advice to the Ministry on issues that affect Māori with disabilities. From the group’s meeting minutes there appears to be limited engagement with the group outside the direct implementation of <i>Whāia Te Ao Mārama</i> and no clarity about what happens with the group’s advice and whether it is incorporated. For example, in October 2018 the group were provided an update on the new structure for the Ministry of Health which included both the establishment of a Māori health directorate and a Disability Directorate.⁷⁷² The group were not given a chance for feedback, and it does not seem that its advice was sought from the Ministry at any stage.</p> <p>The Disability Directorate also, ‘...aims to have positive partnerships with its stakeholders, in particular disabled people, their family/whānau, carers and disability support providers.’⁷⁷³ In addition to Te Ao Mārama, the Directorate engages with a consumer consortium. Its Māori membership includes a Māori disability provider collective and a Māori Needs Assessment and Service Coordination operations group.</p> <p>Engagement with Māori with lived experience of disability in other work across the Ministry is, however, ad hoc where,</p> <p>‘Each business unit determines how it involves Māori with disabilities, seeking advice from the Disability Directorate.’⁷⁷⁴</p>

⁷⁷⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁷¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁷² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1ka Ministry of Health.

⁷⁷³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁷⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

Principle	Themes
Participation	<p>Across Ministry committees, Māori participation in committees appointed by the Minister of Health is common but not universal.</p> <p><i>Refer to Table 27: 14 out of 42 committees have no identified/recorded Māori membership.</i></p> <p>Participation in committees by Māori with lived experience of disability is unknown.</p> <p>The Ministry states that it, ‘...does not hold information on the number of appointed members with disabilities, as there is no specific reporting requirements for this information’.⁷⁷⁵</p> <p>Māori with lived experience of disability are participants in the Ministry-led disability transformation work in the MidCentral district. But the extent of the participation is unclear.</p> <p>The Ministry provides information about Māori involvement in the co-design team and indicates, for example, that Māori have been involved in discussions on service delivery and, ‘...confirmed that a kaupapa Māori approach (ie a Māori way of doing things) can help tāngata whaikaha and whānau engage with disability support services. Participants emphasised that Māori values, concepts and practices should be fused within a transformed disability system in an authentic way, rather than attached as an afterthought or appendage’.⁷⁷⁶ No information is provided on how this feedback has been incorporated into system transformation or disability support service design.</p> <p>As at 24 January 2019, around 17% of people in the ‘uptake’ for the disability transformation prototype identified as Māori. One in five people in MidCentral identify as Māori.⁷⁷⁷</p> <p>For Ministry-led work focused on disability issues, consultation with Māori – by including Māori with lived experience of disability in targeted engagement – is common.</p> <p>Consultation with Māori usually takes the form of Māori participating in workshops or focus groups, completing surveys and sometimes Te Ao Mārama supporting the analysis of submissions and survey results.</p> <p>For example, for <i>Where I Live, How I Live: Disability Support Services Community Residential Support Services Strategy 2018–2020</i>, disability support services within the Ministry consulted with Te Ao Mārama and workshops were held, ‘...which included Māori disabled people, family and whānau and providers of residential services’. And for <i>Transforming Respite: Disability Support Services Respite Strategy 2017–2022</i>, survey had over 1200 responses, 14% of which were from people identifying as Māori. Te Ao Mārama discussed the results and Māori providers were consulted.</p> <p>There was no evidence to suggest consultation processes were designed to target Māori with lived experience of disability specifically. There were</p>

⁷⁷⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁷⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁷⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

Principle	Themes
	<p>however examples provided where Māori were not involved in relevant projects.</p> <p>For example, action 9(c) of the Disability Action Plan is to, ‘...increase access to health services and improve health outcomes for disabled people with a specific focus on people with learning/intellectual disabilities’.⁷⁷⁸ The Ministry leads this work and established a Project Reference Group in 2015 with no apparent participation by Māori with lived experience of disability – although the group did have, ‘...the vision...they would ensure Māori disabled people were consulted with.’</p> <p>In one instance the Ministry gives examples of engaging with other government agencies as a proxy for engaging with Māori.</p> <p>For funded family care legislation (in addition to targeted engagement included Māori with lived experience of disability) the Ministry consulted with Te Tumu Whakarae (a network of DHB Māori health managers) and the Ministry of Social Development which has engaged with Māori stakeholders for the carers’ strategy action plan.⁷⁷⁹</p> <p>The Ministry does not set explicit standards for DHBs when it comes to involving Māori with lived experience of disability in decision making.</p> <p>Instead, ‘DHB accountability arrangements reflect expectations that in the service planning process DHBs use framework for the consultation of different groups and communities, such as Māori and people with disability and NGO representing service users and communities’. The Ministry also, ‘...provides DHBs with planning guidance that reinforces that DHB obligations as Treaty partners are specified in legislation, and planning guidance for DHBs includes tools to help with planning equity outcome actions’.⁷⁸⁰</p> <p>There is little information on the involvement of Māori with lived experience of disability in the health and disability workforce.</p> <p>However, the Te Ao Mārama meeting minutes note, ‘...[t]he Ministry consider Māori are well covered apart from leadership roles in governance. (Area for focus is Māori leadership roles)’.⁷⁸¹</p>

⁷⁷⁸ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁷⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1b Ministry of Health.

⁷⁸⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁸¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1ka Ministry of Health.

Principle	Themes
Options	<p>The Ministry does not routinely identify or monitor the number of Māori-owned and -governed disability support service providers and cannot provide information on audits of Māori disability providers.⁷⁸²</p> <p>However, under the Official Information Act the Ministry undertook a manual review of providers contracted to deliver disability support services and those who have received Māori Provider Development Scheme funding. Although there are caveats around the information, it indicates that there are only a small number of Māori disability support service providers (the review identified 33) operating in a large disability support service sector (980 providers).⁷⁸³</p>
Active protection	<p>The Ministry of Health expects that members of its committees, ‘...are aware and responsive to the various cultural considerations required for Māori, as well as other community groups’.⁷⁸⁴</p> <p>The Ministry does indicate that it provides training and induction material for Ministerial Committees and new appointees when appropriate, but does not expand on what that means or whether it includes disability responsiveness training.</p> <p>For its staff, the Ministry provides tools to, ‘...support understanding and decision making when working collaboratively with Māori’, however these were not supplied so it is not possible to tell if they are adequate.</p> <p>The Ministry of Health also has a ‘Te Reo Māori and Tikanga’ framework and offers three training courses to support Māori cultural understanding, te reo Māori competence, including a visit to the National Library of New Zealand as part of staff orientation. Staff are also able to access free online cultural competence training.⁷⁸⁵</p> <p>The Ministry does not collect data on course completion but the Disability Directorate has a focus on cultural competence training and in 2016/17, 90% of staff (of the then disability support services team) completed online cultural competency training.</p> <p>The Ministry has work underway to support its diversity and inclusion strategy, but there is no mention specifically on disability responsiveness training for staff or strategies to recruit Māori with lived experience of disability.</p> <p>The Ministry is more focused on ensuring funding is correctly administered to eligible clients than ensuring spending is targeted toward Māori with lived experience of disability.</p>

⁷⁸² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1b Ministry of Health.

⁷⁸³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1a Ministry of Health.

⁷⁸⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁸⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

Principle	Themes
	<p>The Ministry states it, ‘...is not able to estimate the proportion of Vote Health that is targeted for health services for disabled Māori. Any attempt to produce an estimate would not accurately represent the range of health services that Māori disabled may be receiving’.⁷⁸⁶</p> <p>In contrast, it says on the administration of funding for disability support services, that a,</p> <p>‘...wide range of mechanisms is used to ensure Ministry of Health funding is correctly administered for eligible disabled people, including Māori clients. This includes planning and strategy documents, contracting and legal compliance requirements, business case and funding board mechanisms, and operational policies and specifications for services funded...’.⁷⁸⁷</p> <p><i>Whāia Te Ao Mārama</i> has a small implementation budget, which is not fully spent each year.</p> <p>The <i>Whāia Te Ao Mārama</i> implementation budget is around \$35,000 per year. 2017/18 was the first year in the figures provided (which covered 2013/14 to 2017/18) where more than half of the allocated budget (around \$33,000) was actually spent. Before that only between \$13,000 and \$18,000 was spent each year.</p>
Equity	<p>The Ministry provides little detail on what is done specifically to ensure DHBs meet their obligations to Māori with lived experience of disability.</p> <p>While the Ministry can provide examples of how its monitoring can identify inequities, there is no evidence that the Ministry acts to address the health need of Māori with lived experience of disability. The Ministry states,</p> <p>‘...[f]or example, the Ministry has been monitoring the number of Māori subject to community treatment orders (CTOs) under the Mental Health (Compulsory Assessment and Treatment) Act 1992 (the Mental Health Act). This action recognises that Māori are significantly over-represented in populations treated under the Mental Health Act and there is variation around the country regarding the disparity between Māori and non-Māori subject to CTO’.⁷⁸⁸</p> <p>Annual planning guidance to DHBs reinforces, ‘obligations as Treaty partner’ and equity actions, such as monitoring and reporting by ethnicity where data allows. But there is nothing specific about disability in general guidance.</p> <p>In disability support services planning guidance for 2019/20 DHBs are required to include actions to improve equity for Māori and/or Pacific people.⁷⁸⁹</p>

⁷⁸⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1b Ministry of Health.

⁷⁸⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1b Ministry of Health.

⁷⁸⁸ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁸⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

Principle	Themes
	<p>Quality data for Māori with lived experience of disability is very limited.</p> <p>The Ministry states, ‘...identification of disability is currently not possible in some of the Ministry’s data collection, including the New Zealand Health Survey. This makes it difficult to identify whether some Māori have a disability within the Ministry datasets’.⁷⁹⁰</p> <p>The lack of data also impacts on the ability of the Ministry to monitor its contracted services to ensure they are achieving equity for Māori with lived experience of disability.</p> <p>The Ministry states, ‘...[w]hile the Ministry’s National Screening Unit monitors access to services (and outcomes) by ethnicity its programmes are currently unable to identify participants by their disability status. Screening service providers are, however, expected to consider the needs of participants with disabilities’.⁷⁹¹</p>

District health boards

The following Tables 17–21 present the summary themes from the thematic analysis of information provided by DHBs using a Treaty-principles framework. This includes the following principles: partnership, participation, options, active protection, and equity.

Partnership

Table 17 presents summary themes analysed by the principle of partnership. District health boards make high level statements about the ‘Treaty partnership’, but this does not translate into policies and practices. With regard to partnership in organisational decision making, there is little information to suggest that Māori with lived experience of disability are involved in organisational decision making in a meaningful way. The responsibility for involving Māori with lived experience of disability in decision-making appeared to fall to the Māori relationship boards, rather than the DHB itself.

⁷⁹⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁷⁹¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

When it came to decision making for issues relevant to Māori with lived experience of disability, DHBs largely relied on the Māori representation on their Disability Services Advisory Committee (required by the New Zealand Public Health and Disability Act 2000). However, this rarely included Māori with lived experience of disability. While some DHBs could demonstrate involvement of people with lived experience of disability, there was no suggestion that this included Māori with lived experience of disability. Although some DHBs indicate they consult on their strategies, there is almost no indication that DHBs put effort into consulting specifically with Māori with lived experience of disability.

In terms of identifying priorities for Māori with lived experience of disability, DHBs do not hold the information. Māori with lived experience of disability are either treated by DHBs as part of a generic Māori group, or part of a generic group of people with lived experience of disability. The issues specific to Māori with lived experience of disability are therefore invisible. With regard to insights around population health need, DHBs indicated that they were guided by the views of local primary health organisations and service-providers. There was no indication that this included gaining insights around population health needs of Māori with lived experience of disability.

Table 17: Summary themes from information provided by DHBs, analysed by the principle of partnership

Constituent element	Summary themes
Partnership in organisational decision making	<p>There is little evidence that Māori with lived experience of disability are involved in organisational decision making in a meaningful way.</p> <p>Information does not exist.</p> <p>Three DHBs indicated they didn't collect information on this and so did not give an indication of how Māori with lived experience of disability were involved in organisational decision making.</p> <p>Relationship boards the main mechanism for DHBs.</p> <p>Overall DHBs indicate they consider their formal relationships with Māori in their district to be important.</p> <p>The responsibility for involving Māori with lived experience of disability appears to fall to the Māori Relationship Boards, as one DHB noted, '...Māori disabled are able to discuss and present issues to the Māori Relationship Board through its members. A number of the members have strong relationships with their local disability communities through their roles within communities'.⁷⁹²</p> <p>Māori participation but no lived experience of disability.</p> <p>When it comes to decisions relevant to people with lived experience of disability, DHBs largely rely on Māori representation on their Disability Services Advisory Committee (required by the New Zealand Public Health and Disability Act 2000) – but this rarely includes Māori with lived experience of disability.</p> <p>One DHB indicated that it during 2017/18 and 2018/19, '...examples of significant issues of engagement with Mana whenua included (but are not limited to), addressing the composition of Māori representation on Board sub-committees'.⁷⁹³ But there was no indication that this explicitly included Māori with lived experience of disability, for example, '...[p]olicies are in place to support Māori to give effect to the DHB's obligations, but are not specific to Māori with disabilities'.⁷⁹⁴</p> <p>Lived experience of disability, but not Māori.</p> <p>While some DHBs could show involvement of people with lived experience of disability (eg Southern, Tairāwhiti) there was no suggestion that this included Māori.</p>

⁷⁹² Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 6 Hawke's Bay DHB.

⁷⁹³ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 5 Counties Manukau DHB.

⁷⁹⁴ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 11 Northland DHB.

Constituent element	Summary themes
	<p>Government agency or in-house expertise were used as a proxy for Māori partnership and participation.</p> <p>DHBs referred to their own staff as Māori input into decision making, or staff with disability expertise or in one case a cross-agency forum including, ‘...NGOs, government providers, MSD, Oranga Tamariki and Police’.⁷⁹⁵</p> <p>DHBs make high level statements about the Treaty but this does not translate into policies and practices.</p> <p>Six DHBs indicated they had policies relevant to the Treaty and/or indigenous rights. However, when these policies were given they provided a tenuous link to the principles of the Treaty. For example, one DHB provided its koha policy, which included steps on how to approve payments and the wording to be used when presenting the koha.⁷⁹⁶</p> <p><i>Also refer to responses under the participation principle which include involvement of Māori in more operationally focused advisory or steering groups including consumer advisory groups and the use of co-design.</i></p>
Consultation	<p>While DHBs indicate they consult on strategies (eg MidCentral) there is almost no indication that DHBs seek to consult with Māori with lived experience of disability.</p> <p>One DHB specifically referenced consultation with, ‘whānau with disabilities’, and also indicated that further consultation was scheduled for February and March.⁷⁹⁷</p> <p>A number of DHBs indicated they had plans to consult. Where this happened, limited information was provided about how Māori with lived experience of disability would be included, mirroring the issues above about DHBs able to provide answers for the general Māori population, the general population of people with lived experience of disability but not for Māori with lived experience of disability – for example one DHB stated it is, ‘currently planning its 5 year strategic plan which will require significant input from the disability community’, but made no reference to Māori.</p>
Identifying priorities for Māori with lived experience of disability and their whānau	<p>DHBs do not have the information.</p> <p>Five DHBs declined requests for information on how they identified priorities for Māori with lived experience of disability as on the basis that it was not information they held.</p> <p>There is some suggestion that this is not held because DHBs are not responsible for disability support service funding. However, DHBs are still</p>

⁷⁹⁵ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 17a Wairarapa DHB.

⁷⁹⁶ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 3 Canterbury DHB.

⁷⁹⁷ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 11 Northland DHB.

Constituent element	Summary themes
	<p>responsible for health service delivery, health promotion and public health services.</p> <p>Two DHBs provided partial or incomplete answers to this question.</p> <p>DHBs do not differentiate between Māori with lived experience of disability and Māori without.</p> <p>Although a number of DHBs implied it, one DHB was very clear that this is the case, ‘...[w]e do not determine health priorities for disabled Māori as separate from non-disabled Māori’.⁷⁹⁸</p> <p>DHBs do not differentiate between Māori and non-Māori with lived experience of disability.</p> <p>Although a number of DHBs implied that there was not differentiation between Māori and non-Māori, some DHBs were very clear, ‘Many services being provided to those with disabilities who also have a health condition are provided through services designed to support everyone with the same health condition’.⁷⁹⁹</p> <p>DHBs are guided by the views of providers.</p> <p>DHBs indicated they looked to service providers and PHOs to provide insight into population health need. There was not any indication that this included information about Māori with lived experience of disability.</p>

Participation

Table 18 presents summary themes analysed by the principle of participation. With regard to involvement in governance/formal decision making, there are no Māori board members with lived experience of disability on DHB boards throughout Aotearoa/New Zealand. Three DHBs indicated they have board members with lived experience of disability but in all cases, these board members are non-Māori. There is a notable lack of information on board members, and discrepancies between what the MoH holds, and what DHBs actually released under the Official Information Act on board membership.

⁷⁹⁸ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 20 Whanganui DHB.

⁷⁹⁹ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 14 Tairāwhiti DHB.

When it came to Māori with lived experience of disability participating in governance and decision making, beyond ensuring physical access to meetings and accessible parking, there is little evidence of DHBs ensuring participation needs are met. With regard to involvement in advisory groups and other operational decision making, participation of Māori with lived experience of disability in alliance leadership teams, consumer groups or clinical governance is rare, or non-existent. Where people with lived experience of disability were involved, or recruited, there was no particular attention paid to ensuring those persons included Māori. Where Māori participation was sought or encouraged, little attention was paid to involving people with lived experience of disability. District health boards appear passive (do not take action) with regard to the participation of Māori with lived experience of disability.

With regard to workforce, DHBs do not usually record disability information. District health boards identified definitional issues as a barrier to collecting accurate employment information. Additionally, Māori staff numbers were low and Māori staff with lived experience of disability were almost non-existent. District health boards reported no specific steps to increase the number of Māori with lived experience of disability in their workforce. Similarly, there were no professional development opportunities specifically for Māori with lived experience of disability, with professional development opportunities being described as 'for everybody'.

When it came to service delivery, no DHB held information on how much it spent on services provided by Māori with lived experience of disability, and there was no requirement for contracted providers to support workforce development of Māori with lived experience of disability. While a number of DHBs indicated planned or operational 'co-design' projects the DHB responses were not explicit as to what was involved, and there was a lack of consistency as to how the term 'co-design' was defined by DHBs (or most often, no definition of 'co-design' was provided).

Table 18: Summary themes from information provided by DHBs analysed by the principle of participation

Constituent element	Themes
<p>Involvement in governance/formal decision making</p> <p><i>Refer also to Table 27: DHB membership broken down by ethnicity and disability.</i></p>	<p>There are no Māori board members with lived experience of disability on DHB boards throughout Aotearoa/New Zealand.</p> <p>Three DHBs indicated they have board members with lived experience of disability but in all cases, these board members are non-Māori.</p> <p>Most DHBs have the minimum number of Māori board members.</p> <p>All but two DHBs have at least two Māori board members. The exceptions were Hutt Valley DHB (one Māori board member) and Southern DHB (which is governed by a commissioner and two deputy commissioners appointed by the Minister of Health, all non-Māori).</p> <p>Not all DHBs hold information on the ethnicity of board members.</p> <p>Two DHBs declined to provide information on the ethnicity of board members. Another DHB indicated it knew the ethnicity of one Māori board member but did not collect ethnicity for other board members.⁸⁰⁰</p> <p>There are discrepancies between the information the Ministry of Health holds and what DHBs hold on the number of Māori board members.</p> <p>Four DHBs provided different numbers of Māori board members than what the Ministry of Health provided. In all cases the DHB had identified a high number of Māori board members.</p> <p>Just over half of all DHBs hold information on whether board members have lived experience of disability.</p> <p>While nine DHBs were not able to say whether they had board members with disabilities, 11 DHBs gave some answer to this question – usually that there are no known disabilities amongst their board members.</p> <p>Where support is provided by DHBs for Māori with lived experience of disability to participate in governance and decision making, it relates narrowly to increasing physical accessibility of meetings.</p> <p>Five DHBs highlighted wheelchair accessibility for meetings, others indicated the availability of accessible parking for board (and advisory group) members. Most DHBs, however, either indicated arrangements could be made if required⁸⁰¹ or outlined the State Services Commission</p>

⁸⁰⁰ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 7 Hutt Valley DHB.

⁸⁰¹ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 19 West Coast DHB.

Constituent element	Themes
	<p>and/or Cabinet guidance on board fees and travel reimbursement but no particular support for Māori with lived experience of disability.</p> <p>DHBs do not have policies to support Māori with lived experience of disability to participate in formal decision making (eg board or statutory committees).</p> <p>Although DHBs were rarely explicit on this, one DHB stated, ‘...DHB statutory committees do not have any formal protocols in place to ensure participation by disabled Māori’.⁸⁰²</p>
<p>Involvement in advisory groups and other operational decision making</p>	<p>Participation of Māori with lived experience of disability in alliance leadership teams, consumer groups or clinical governance is rare or non-existent.</p> <p>While not all DHBs responded to questions on the advisory and operationally focused DHB groups, those that did showed no evidence that Māori with lived experience of disability participated.</p> <p>Clinical governance/leadership groups, in particular, lacked Māori participation.</p> <p>Often no people with lived experience of disability were involved in key advisory or operational groups.</p> <p>Five DHBs indicated no direct involvement by Māori or non-Māori with lived experience of disability in their alliance leadership teams.⁸⁰³</p> <p>Where people with lived experience of disability were involved, or recruited, there was no particular attention paid to Māori within that group.</p> <p>For example, one DHB stated, ‘...we have sought to include people based on type of disability rather than by ethnicity’.⁸⁰⁴</p> <p>Where Māori participation was sought or encouraged, little attention was paid to involving people with lived experience of disability.</p> <p>One DHB indicated it had a disability advisory group that made provision for Māori membership. ‘While the Māori representatives do not always live with a disability they represent a broad cross section of Māori from a variety of Iwi and diverse backgrounds’.⁸⁰⁵</p>

⁸⁰² Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 3 Canterbury DHB.

⁸⁰³ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 17 Wairarapa DHB.

⁸⁰⁴ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 8 Lakes DHB.

⁸⁰⁵ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 3 Canterbury DHB.

Constituent element	Themes
	<p>DHBs are passive (do not take action) regarding involving Māori with lived experience of disability.</p> <p>A number of DHBs indicated that anyone can apply to be part of their advisory and other groups – or register their interest.⁸⁰⁶ One DHB⁸⁰⁷ provided a link to an online application form for consumer participation that provided no particular information for Māori with lived experience of disability and did not ask for ethnicity or disability information on the online form, stating,</p> <p>‘...[w]e do not advertise specifically for consumers with a disability but happily recruit any applicant if they successfully meet all other criteria’.⁸⁰⁸</p>
Workforce	<p>DHBs do not usually record disability information for their staff.</p> <p>One DHB declined to provide information on ethnicity and disability status of staff on the basis they did not hold that information. A further 12 DHBs provided a partial response, usually only providing staff information broken down by ethnicity.</p> <p>Disability definition issues are perceived by DHBs to be the barrier to holding accurate disability employment information.</p> <p>As one DHB stated, ‘...the number of staff identified as Māori, non-Māori, Disabled Māori and Disabled non-Māori relies on self-identification and is not mandatory, therefore the figures able to be provided are not accurate’.⁸⁰⁹</p> <p>Māori staff numbers overall are low.</p> <p>No DHB provided information to suggest its Māori workforce was equivalent to or reflecting its local resident population, particularly in medicine.</p> <p>Numbers of Māori staff with lived experience of disability are almost non-existent.</p> <p>While fewer than half of the DHBs provided information on numbers of staff with lived experience of disability, where this was provided the</p>

⁸⁰⁶ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 13 Southern DHB.

⁸⁰⁷ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 11 Northland DHB.

⁸⁰⁸ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 14 Tairāwhiti DHB.

⁸⁰⁹ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 3 Canterbury DHB.

Constituent element	Themes
	<p>numbers were very low. For example, one DHB⁸¹⁰ identified one Māori staff member with lived experience of disability. This is in the context of a workforce of over 1000 people.</p> <p>No specific steps are being taken to increase the number or skills of Māori with lived experience of disability in the DHB workforce.</p> <p>DHBs do have projects or work-streams in place to build the Māori workforce but these do not have a disability focus. For example, one DHB indicated its department of surgery has a Māori specific SHO/registrar position for research but stated, ‘...this does not have a particular focus in relation to Māori with disabilities’.⁸¹¹</p> <p>Learning and development and employment opportunities are ‘for everybody’.</p> <p>DHBs make statements such as, ‘...all learning and development programmes offered by [the DHB] provide for any Māori staff, able bodied or disabled, to access and build capability and capacity’.⁸¹² However, there was little evidence provided by DHBs to show whether this was a successful approach (for example, numbers involved in training, career progression).</p>
Service delivery (eg contracted service provision)	<p>No DHB held information on how much it spent on services, including consultancy, provided by disabled Māori.</p> <p>DHBs do not have requirements for contracted providers to support workforce development of Māori with lived experience of disability.</p>
System and service design	<p>A number of DHBs have indicated they are undertaking (or planning to undertake) co-design processes in their districts – but there was no indication of what this meant substantively.</p> <p>Five DHBs indicated they were using ‘co-design’ in their processes but it was not clear what this meant.</p> <p>The co-design sometimes appeared to relate sometimes to designing how meetings were run and service narratives created⁸¹³ and at other times to the creation of strategies and action plans.</p>

⁸¹⁰ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 20 Whanganui DHB.

⁸¹¹ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 11 Northland DHB.

⁸¹² Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 11 Northland DHB.

⁸¹³ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 11 Northland DHB.

Constituent element	Themes
	<p>In some cases co-design appeared to involve Māori with lived experience of disability – for example, one DHB stated it, ‘...has developed whānau engagement and consumer co-design processes to support effective representation of disabled Māori across numerous policy and strategy development processes, and service design’.⁸¹⁴ But this was not always explicit in DHB responses.</p>

Options

Table 19 presents the summary themes from information provided by DHBs analysed by the principle of options. District health boards recognised the role of Māori providers in high level strategy documents but tended to have a stronger focus on ‘mainstream effectiveness’ rather than on the role of Māori providers. District health boards were not able to show how much funding was spent on services by Māori-governed or owned health and/or disability support providers, for Māori with lived experience of disability. Māori health providers were only contracted for a subset of health and disability services and as a result, Māori with lived experience are only able to access Māori providers for a subset of their health and/or disability needs. In addition, DHBs did not provide any detail regarding how they provide support to Māori providers. Where funding details were provided by DHBs, it demonstrated that funding for Māori health providers was very low relative to total DHB funding.

⁸¹⁴ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 6 Hawke’s Bay DHB.

Table 19: Summary themes from information provided by DHBs analysed by the principle of options

Constituent Element	Themes
<p>Recognition of the role of Māori-run and Māori-centred health and/or disability support services</p>	<p>DHBs recognise the role of Māori providers in high level strategy documents.</p> <p>DHBs were asked about how they gave effect to their obligations under legislation and a range of strategies, which all include reference to the role of Māori providers in service delivery. No DHB provided information directly relevant to providers (focusing instead on equity or participation considerations). However, where DHBs provided their Māori health strategies (for example, MidCentral DHB provided a link to <i>Ka Ao Ka Awatea</i>, its Māori health strategic framework) or draft strategy (for example Hutt Valley DHB), they reference the importance of Māori health providers and the contribution they make to the local population.</p> <p>DHBs tended to have a stronger focus on ‘mainstream effectiveness’ rather than the role of Māori health providers.</p> <p>DHBs largely expected all services to be accessible for Māori with lived experience of disability, and did not discuss the value in Māori being able to choose to access services run by Māori and centred on a Māori world view. For example, one DHB stated,</p> <p>‘...[g]enerally the [DHB] expects the health and disability services we contract for or hold contracts with as a provider, to be equitable and accessible for all whānau’.⁸¹⁵</p> <p>DHBs also assert that they make services more accessible for people with lived experience of disability (within their hospital or provider arm, for example ensuring whānau rooms in hospitals are accessible).⁸¹⁶ There was little evidence of this happening across the health and disability system in each district nor how this supported Māori to have the option of accessing Māori-run services.</p>

⁸¹⁵ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 3 Canterbury DHB.

⁸¹⁶ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 13 Southern DHB.

Constituent Element	Themes
<p>Support for Māori-run and Māori-centred health and/ or disability support services.</p>	<p>DHBs are not able to show how much funding they spent on services delivered by Māori-run health and/or disability support providers for Māori with lived experience of disability.</p> <p>Some DHBs said this was because the Ministry of Health funds disability support services directly, although this an insufficient answer as the DHB retains responsibility for funding health services and disability supports for people aged over 65.</p> <p>By and large, DHBs provided high level funding figures or referred to annual reporting figures. This did not include funding information for services provided to Māori with lived experience of disability. A common sentiment was that funding was, ‘...[n]ot known because we don’t differentiate’.⁸¹⁷</p> <p>Māori with lived experience of disability are able to access Māori providers for some, but not all of their health and/or disability needs, as DHBs only contract Māori health providers for a subset of health services.</p> <p>For example, Nelson Marlborough DHB indicated it funds its one Māori health provider to deliver: Te Puna Hauora/whānau ora services, mental health and addictions services, WCTO, outreach immunisation, stop smoking, health of older persons, Kaikoura earthquake response and lactation consultancy.⁸¹⁸</p> <p>Where DHBs provided their total Māori health provider funding, it was very small compared to total DHB funding.</p> <p>One DHB indicated it spent about 1% of its total revenue through Māori NGOs⁸¹⁹ and another indicated it spent around 2%.⁸²⁰ There was no sense of what would be right or appropriate.</p> <p>The information on percentage of funding to Māori providers released by DHB is consistent with Ministry of Health data from 2015/16 which shows that funding to Māori health providers received about 1.5% of total DHB funding.⁸²¹ A number of DHBs referred to this work by the Ministry of Health, which also illustrates that increases in funding to Māori providers have not kept pace with increases to DHB funding overall.⁸²²</p> <p>DHBs do not provide any detail about how they will provide support to Māori providers in their district (for example no specific targets on numbers, skills/capability or funding).</p> <p>DHB strategies do have some high level commitments and actions, such as better understanding Māori health provider needs,⁸²³ but it is not clear why this has not been done earlier by DHBs, given there is an annual funding round of the Māori Provider Development Scheme run by the Ministry of Health and involving DHBs.</p>

⁸¹⁷ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 8 Lakes DHB.

⁸¹⁸ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 10 Nelson Marlborough DHB.

ACTIVE PROTECTION

Table 20 presents the summary themes from information provided by DHBs analysed by the principle of active protection. District health boards do not have accountability mechanisms to ensure services are responsive and effective for Māori with lived experience with disability. Whilst they do have standard Māori health clauses in contracts, there is an assumption that such clauses are sufficient to ensure services will meet the needs of Māori with lived experience of disability. While not all DHBs referred to local Māori providers when questioned about accountability mechanisms, where they did, it was indicated that the Māori providers took responsibility for improving access to all services for Māori with lived disability, and not the DHBs.

Most DHBs did not, or were unable to, provide information about complaints made by Māori with lived experience of disability. District health board health promotion programmes did not usually have a focus on Māori with lived experience of disability.

With regard to spending on services for Māori with lived experience of disability, DHBs do not interrogate their funding to analyse whether or not Māori with lived experience of disability receive appropriate health and disability care funding. Where funding was disaggregated by ethnicity and disability over time, Māori with lived experience of disability were shown to be least likely to receive funding increases. For example, one DHB provided

⁸¹⁹ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 11 Northland DHB.

⁸²⁰ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 20 Whanganui DHB.

⁸²¹ Ministry of Health, *Funding to Māori Health Providers by the Ministry of Health and District Health Boards*.

⁸²² Ministry of Health, *Funding to Māori Health Providers by the Ministry of Health and District Health Boards*.

⁸²³ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 9 MidCentral DHB.

funding figures showing a decrease in funding for Māori with lived experience of disability, while at the same time there was an increase in funding to non-Māori.

Most DHBs reported providing some form of Māori responsiveness training and many provided disability responsiveness training. However, DHBs did not offer training that covered both aspects of responsiveness. One DHB did indicate disability considerations were covered within an element of Māori health training. District health boards do not generally hold information on spending on disability responsiveness training or Māori health training, and not all DHBs tracked the numbers of staff completing training. Where tracked, it was the medical staff who were least likely to have completed Māori health and disability responsiveness training (figures sometimes as low as one per cent).

Table 20: Summary themes from information provided by DHBs analysed by the principle of active protection

Constituent element	Themes
Responsive services	<p>DHBs do not have accountability mechanisms that are specific to ensuring services are responsive and effective for Māori with lived experience of disability.</p> <p>As one DHB put it they had, ‘...no specific accountable measures for disabled Māori but would expect disabled Māori would benefit from the approaches the DHB takes’.⁸²⁴</p> <p>DHB contracted providers might be expected to comply with the Health and Disability Commissioner’s code of consumer rights or health and safety requirements, but there were no specifics given by DHB on how this works to safeguard against unresponsive services for Māori with lived experience of disability.</p> <p>DHBs do have standard clauses in contracts about Māori health and there seems to be an assumption that these are sufficient to cover the needs of Māori with lived experience of disability.</p> <p>Twelve DHBs said they used standard contractual requirements or auditing processes that included reference to Māori health and/or equity.</p> <p>While one DHB stated, ‘...[i]t is expected that compliance with these clauses for Māori will be inclusive of disabled Māori’⁸²⁵, there was no information provided on the grounds it had for this expectation</p> <p>Although not all DHBs made reference to local Māori health providers when we asked about accountability mechanisms, those that did indicated the Māori providers took on responsibility for improving access to services for Māori with lived experience of disability.</p> <p>Most DHBs did not, or were not able to, provide us with information about complaints made by Māori with lived experience of disability.</p> <p>Thirteen DHB said they did not have this information, and three indicated they had information for Māori but not for people with lived experience of disability.</p> <p>One DHB that provided complaint information, noted 14 complaints had been made by Māori who also had ‘disability alerts’ on their records. Ten of these complaints were about the standard of clinical care.⁸²⁶ One other</p>

⁸²⁴ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 8 Lakes DHB.

⁸²⁵ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 19 West Coast DHB.

⁸²⁶ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 4 Capital and Coast DHB. Note the DHB includes caveats around these figures For example, the disability data comes from CCDHB’s patient administration system and therefore it may be that the person sustained a permanent disability after the complaint but there is no clear way of identifying this.

Constituent element	Themes
	<p>DHB could provide information on a disability-related complaint (about lack of accessible parking) but did not have ethnicity data for this complaint.</p> <p>DHB health promotion programmes do not usually have a strong focus on Māori with lived experience of disability.</p> <p>Although some public health activity has a focus on disability issues, for example advocating to council, ‘...have the potential to improve access for all people who have limited mobility, including kāpō Māori’.⁸²⁷</p>
<p>Spending on services for Māori with lived experience of disability</p>	<p>DHBs don’t interrogate their funding to analyse whether or not Māori with lived experience of disability receive appropriate health care funding.</p> <p>Half of the DHBs did not provide funding information. Those that did provide information broke it down in vastly different ways.</p> <p>Where we know about funding broken down by ethnicity and disability over time, Māori with lived experience of disability are least likely to receive equitable funding increases.</p> <p>One DHB provided figures that showed funding to people with lived experience of disability is increasing, but the proportion of funding to Māori with disability is increasing at a slower rate than funding to non-Māori with lived experience of disability.⁸²⁸</p> <p>Another DHB provided funding figures showing a decrease in funding for Māori with lived experience of disability, while funding to non-Māori generally increased.⁸²⁹</p>
<p>Responsive workforce</p>	<p>Most DHBs provide Māori responsiveness training of some sort, and many provide disability responsiveness training.</p> <p>Thirteen DHBs indicated they offered disability responsiveness training. One DHB indicated they did not have disability targeted training for staff, but they use Health and Disability Commission training materials.⁸³⁰</p> <p>One DHB provided information about Pacific health courses even though it was not requested.⁸³¹</p>

⁸²⁷ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 13 Southern DHB.

⁸²⁸ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 11 Northland DHB.

⁸²⁹ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 9 MidCentral DHB.

⁸³⁰ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 8 Lakes DHB.

⁸³¹ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 10 Nelson Marlborough DHB.

Constituent element	Themes
	<p>DHBs did not offer courses that covered both aspects of responsiveness.</p> <p>Although one DHB did indicate disability considerations were covered within an element of Māori health training.</p> <p>DHBs do not generally hold information on spending on disability responsiveness or Māori health training.</p> <p>Where funding was specified, funding to on Māori focused courses (eg Treaty of Waitangi) had decreased. For example, for one DHB it had nearly halved (from around \$41,000 to round \$24,000) over five years to 2017/18, the total training budget has increased from around \$574,000 to around \$782,000.⁸³²</p> <p>Not all DHBs tracked numbers of staff completing training.</p> <p>Only eight DHBs provided complete information on the proportion of staff having undergone relevant training. The following answer notes that while the information does not currently exist DHBs are now thinking about how to track this information,</p> <p>‘...[u]nfortunately we do not have the ability to report on total proportion of staff or by profession at this point in time – over the next 12 months we have upgrades planned for our payroll system to enable us to do reporting which should include the above’.⁸³³</p> <p>Medical staff were least likely to have completed Māori health and disability responsiveness training.</p> <p>While not all DHBs provided figures, where they were provided medical staff were less likely to have completed training (sometimes as low as 1% of medical staff) while allied and nursing workforces were more likely to have completed both. Data provided by DHBs varied greatly in what the covered so cannot be compared.</p>

⁸³² Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 2 Bay of Plenty.

⁸³³ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 19 Wairarapa DHB.

Equity

Table 21 presents the summary themes from information provided by DHBs analysed by the principle of equity. District health boards had high level equity statements repeated throughout their key strategy documents. The quality and impact of these statements however, was variable. District health boards do have specific Māori health strategies or frameworks, however, these do not refer to Māori with lived experience of disability, nor do they make provision for action to address their needs. Half of the DHBs reported having disability action plans or policies in existence, others talked about strategies plans or policies under development. On review, these did not have a strong focus on Māori.

Almost all DHBs indicated having processes in place to use the MoH's *Ethnicity Data Protocols*⁸³⁴ and many indicated they are audited or monitored against these standards. However, no DHB was able to give accurate and comprehensive disability information in response to information requests. District health boards do not have accurate disability data that can be used in service monitoring, planning and development. They also do not track spending in a way that shows how much is spent by ethnicity and disability across their population. As DHBs do not collect information on Māori with lived experience of disability, there was no information on the performance monitoring of services for Māori with lived experience of disability, that could be provided by the DHBs.

Standard DHB contracts include equity and Māori health clauses and some include Treaty clauses. However, these do not have specific reference to Māori with lived experience of disability. Most DHBs referenced the use of existing equity tools and some have developed their own. These tools do not explicitly discuss Māori and disability issues together.

⁸³⁴ Ministry of Health. HISO 10001:2017 Ethnicity Data Protocols. Ministry of Health (Wellington: 2017). <https://www.health.govt.nz/publication/hiso-100012017-ethnicity-data-protocols>.

Table 21: Summary themes from information provided by DHBs analysed by the principle of equity

Constituent element	Themes
Equity goals embedded in organisation	<p>DHBs have high level equity statements, which are repeated in key strategy documents. The quality and impact of these statements vary.</p> <p>DHB said that equity requirements are considered fundamental principles.⁸³⁵ DHBs said they included equity statements in a number of places including strategy documents that give guidance to DHBs in decision making and delivery.</p> <p>Statements, like this from the Northland DHB annual report (2018) are fairly common throughout DHB responses:</p> <p>‘Eliminating health inequities for Māori and their whānau is fundamental to building a healthier Northland’.⁸³⁶</p> <p>One DHB said in its answer that its people strategy had a clear expectation of addressing inequity and delivering services that work for Māori.⁸³⁷ However, the people strategy itself showed that there were minimal references to Māori – most focused on the explanation of the whakatauki at the start of the document. The only substantive reference to Māori was a statement about diversity of the workforce, where one DHB stated,</p> <p>‘...[w]e value and acknowledge the ethnic diversity of our community and our workforce. We aim to ensure our staff and organisation reflect the community which we serve, in particular the growing Māori and Pacific populations’.⁸³⁸</p> <p>There were no references in that document to addressing inequity.</p> <p>DHBs often have specific Māori health strategies or frameworks, but these do not refer to Māori with lived experience of disability nor make provision for action to address their needs.</p> <p>A number of DHBs responded with statements such as, ‘...[t]here is reference to Māori within all these documents, however we have not specifically identified Māori with Disability’.⁸³⁹ DHBs tended to take the</p>

⁸³⁵ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 8 Lakes DHB.

⁸³⁶ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 11 Northland DHB.

⁸³⁷ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 6 Hawke’s Bay DHB.

⁸³⁸ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 6c Hawke’s Bay DHB.

⁸³⁹ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 14 Tairāwhiti DHB

Constituent element	Themes
	<p>view that a reference to Māori encompassed Māori with lived experience of disability.⁸⁴⁰</p> <p>Half of all DHBs talked about disability action plans or policies in existence and others talked about disability strategies, plans or policies under development. These do not have a strong focus on Māori.</p> <p>Māori were referenced in some of these plans, however the pursuit of equity is not always clear. For example, in one Disability Strategy (shared by three DHBs) the references to equity are strong but it is not clear how equity is understood in this context. It appears to be equity between people with lived experience of disability and those without (ie no ethnicity dimension). One DHB stating,</p> <p>‘...[h]ealth disparities will be reduced and equity will be promoted, in order to improve and promote the health of disabled people’.⁸⁴¹</p> <p>Other DHBs clearly stated that although they had developed disability policy statements, ‘...there are no specific strategies or policies that have a focus on Disabled Māori’.⁸⁴²</p>
Quality data	<p>Almost all DHBs indicated they had processes in place to use the Ministry of Health’s ethnicity data protocols and many indicated they are audited or monitored against these standards.</p> <p>Although the Ministry of Health declined an information request on how it monitors DHB ethnicity data, one DHB stated,</p> <p>‘...[t]he provider arm services are monitored by the Ministry on accuracy of data each quarter, and we have received an outstanding for accurate ethnicity data recording’.⁸⁴³</p> <p>DHBs do not have accurate disability data that can be used in service monitoring, planning and development.</p> <p>No DHB was able to give accurate and comprehensive disability information in response to information requests. Versions of the below statement were common,</p>

⁸⁴⁰ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 20 Whanganui DHB.

⁸⁴¹ “Wairarapa, Hutt Valley and Capital and Coast District Health Boards – Sub-regional Disability Strategy 2017–2022. Enabling Partnerships: Collaboration for effective access to health services.” <https://www.ccdhb.org.nz/news-publications/publications-and-consultation-documents/sub-regional-disability-strategy-2017-2022.pdf>, Accessed 1 April 2019.

⁸⁴² Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 2 Bay of Plenty DHB.

⁸⁴³ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 8 Lakes DHB.

Constituent element	Themes
	<p>‘...[the] DHB does not collect patient data/information specific to a person’s disability or impairment. There is therefore no basis for understanding how well we respond to those with impairment or disability’.⁸⁴⁴</p>
Use of equity tools	<p>Each DHB is required to demonstrate the use of equity tools in all service planning. In their responses, most make some reference to the existing equity tools, some have developed their own. Most do not explicitly discuss disability issues and Māori together.</p> <p>One DHB indicated it had developed an equity think piece to support its work. This think piece had a disability focused case study in it, but did not discuss disability, either generally or issues for Māori with lived experience of disability.</p> <p>Another DHB indicated it had developed a guidance document for its clinical network. It articulates the rationale for focusing on equity and Māori health without reference to the Treaty of Waitangi and its principles, and instead focuses on its view that, ‘Māori are one of the most disadvantaged ethnicities in the New Zealand health system, with real disparities between Māori and non-Māori in relation to health outcomes and life expectancy’.⁸⁴⁵</p>
Spending	<p>DHBs do not track spending in a way that shows how much it spends across populations broken down by ethnicity and disability.</p> <p>Responses varied as to what information DHBs could provide. Some DHBs were able to provide an answer that broke down some element of their spending by ethnicity and disability but this was not consistent and did not apply to all of the DHB spend.</p>
Performance monitoring	<p>As DHBs were not able to collect information on Māori with lived experience of disability, there was no performance monitoring information provided by DHBs.</p> <p>One DHB stated that it,</p> <p>‘...regularly monitors health outcomes for Māori compared to non-Māori (or the total population, depending on the data source). The DHB does not have sufficient data on disability affecting Māori or others, for example because it does not have a suitable marker to systematically identify those who have a disability. This prevents monitoring of health equity with respect to disability for Māori.’⁸⁴⁶</p>

⁸⁴⁴ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 11c Northland DHB.

⁸⁴⁵ Canterbury Clinical Network, *He Kete Hauora Waitaha*, (Canterbury District Health Board, 2014). <http://ccn.health.nz/Portals/18/Documents/He%20Kete%20Hauora%20Waitaha%20-%20Compressed.pdf>.

⁸⁴⁶ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 19 West Coast DHB.

Constituent element	Themes
	<p>Standard DHB contracts include equity and Māori health clauses, and some include Treaty of Waitangi clauses. These do not have specific reference to disability.</p> <p>At least one DHB is looking into this, as part of the disability transformation work, and may include specific clauses in contracts, stating,</p> <p>‘...focusing on equity is a key strategic objective and could be included in contracts alongside the learnings from the Enabling Good Lives Initiative’.⁸⁴⁷</p>

Crown health agencies

The following Tables 22–26 present the summary themes from the thematic analysis of information provided by Crown health agencies and using a Treaty principles framework. These include the following principles: partnership, participation, active protection, and equity.

Partnership

Table 22 presents summary themes analysed by the principle of partnership. With regard to organisational decision making, there were no formal policies for involving Māori with lived experience of disability. Some, but not all, agencies have Māori board members. The use of Māori advisory groups is common, but these groups do not necessarily include Māori with lived experience of disability. Additionally, not all agencies had formally established a Māori advisory group.

⁸⁴⁷ Index of supplementary information provided to the researcher under the OIA – Responses from DHBs: 9 MidCentral DHB.

Table 22: Summary themes from information provided by Crown health agencies⁸⁴⁸ analysed by the principle of partnership

Constituent element	Themes
Organisational decision making	<p>Across the agencies there were no formal policies for involving Māori with lived experience of disability in organisational decision making.</p> <p>One agency stated that, ‘...[w]e do not have specific mechanisms pertaining to disabled Māori’.⁸⁴⁹</p> <p>Some agencies have Māori board members, but this is not universal.</p> <p>Agencies like the New Zealand Artificial Limb Service, the Health Promotion Agency (HPA) and the Health Quality and Safety Commission (HQSC) have Māori board members, but others such as ACC,⁸⁵⁰ and the Health and Disability Commissioner,⁸⁵¹ do not. For example,</p> <p>‘...[n]one of the members of ACC’s Board, and its sub-committees (including independent advisors), identify as being Māori or as disabled. This includes the seven Board Members, its two independent Investment committee members, its one independent Risk Assurance and Audit Committee member, and the five members of Shamrock Superannuation Ltd (a wholly owned ACC company)’.⁸⁵²</p> <p>The use of Māori advisory groups is common. But these groups do not necessarily include Māori with lived experience of disability, and not all organisations have formally established such an advisory group.</p> <p>The HQSC has a number of Māori advisory groups. For example, its Te Rōpū Māori advisory group provides advice and expertise to every Board meeting.⁸⁵³ However, the HQSC also states, ‘...[m]embership of our</p>

⁸⁴⁸ Agencies covered in this table are: PHARMAC, Health Promotion Agency (HPA), New Zealand Blood Service (NZBS), Health Quality and Safety Commission (HQSC), Health Research Council (HRC), Health and Disability Commissioner (HDC), and New Zealand Artificial Limb Service (NZALS).

⁸⁴⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 8 New Zealand Blood Service.

⁸⁵⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 10 ACC.

⁸⁵¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁸⁵² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 10 ACC.

⁸⁵³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 5 Health Quality and Safety. Commission

Constituent element	Themes
	<p>advisory bodies is not determined by the disability status of applicants. We do not collect data specifically related to Māori disability'.⁸⁵⁴</p> <p>Despite advisory groups being common across government, some health agencies are only now establishing such groups. For example, although it was established in 2012, the HPA indicated in February 2019 it is, 'setting up a Māori Advisory Group'.⁸⁵⁵ While the agency states it has no advisory committees to the Board, it does have a Pacific Advisory Group that provides advice on the HPA's Pacific work programme.⁸⁵⁶</p> <p>In one case the advisory group appears to be made up of internal staff members, rather than Māori whānau, Hapū, Iwi or other community representatives.⁸⁵⁷</p>
Determining priorities	<p>Although agencies were not directly asked for information on how they determined priorities, one agency provided detail on how they accounted for Māori with lived experience of disability.</p> <p>ACC indicated it used its research base in developing <i>Whāia Te Tika</i> including two 2015 research reports looking at Māori services under-utilisation and Māori barriers to utilisation. ACC states,</p> <p>'...[w]e are refreshing our Research Ethics Committee and implementing an Ethics Panel – not just for research, but also for projects where customers' information is used for analytical purposes. A core ethical consideration with these projects is how the needs of Māori and people with disabilities are taken into account'.⁸⁵⁸</p>

⁸⁵⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 5 Health Quality and Safety. Commission

⁸⁵⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 3a Health Promotion Agency.

⁸⁵⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 3a Health Promotion Agency.

⁸⁵⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 8 New Zealand Blood Service.

⁸⁵⁸ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 10 ACC.

Participation

Table 23 presents summary themes analysed by the principle of participation. It is rare for Māori with lived experience of disability to be included in Māori advisory and other groups. Outside of these advisory groups there was limited information provided on how Māori with lived experience of disability were consulted on regarding the work of organisations.

There was some indication that consultation with Māori was undertaken as 'part of core business' and some agencies gave examples of consulting with, or involving people with lived experience of disability. These examples did not include Māori with lived experience of disability, or Māori providers. When it came to involvement in strategy and design work, both ACC and PHARMAC have strategies that were developed with involvement of Māori, but not necessarily involvement of Māori with lived experience of disability.

Table 23: Summary themes from information provided by Crown health agencies⁸⁵⁹ analysed by the principle of participation

Constituent element	Themes
<p>Involvement in advisory groups and other operational decision making</p>	<p>It is rare for Māori with lived experience of disability to be included in advisory and other groups.</p> <p>For example, ACC has three consumer advisory panels. All three include Māori and one – the serious injury panel – includes a Māori member with lived experience of disability.</p> <p>ACC is also establishing a Māori Customer Advisory Panel and states it will include, ‘...two seats for individual Māori clients, two for Māori providers and two for Māori business’.</p> <p>Although there is no mechanism to ensure participation by Māori with lived experience of disability, ACC states:</p> <p>‘...[t]he four seats held by Māori providers and Māori business will be organisations which represent broad Māori population groups under their particular auspices. We expect these organisations will therefore represent disabled Māori members’.⁸⁶⁰</p>
<p>Consultation</p>	<p>Outside of advisory groups, limited information was provided on how Māori with lived experience of disability were consulted on the work of the organisations.</p> <p>However, one agency – the New Zealand Artificial Limb Service (NZALS) – did outline its processes to involve Māori living with limb loss in design and delivery of services.⁸⁶¹</p> <p>There was some indication that consultation with Māori was undertaken as part of core business.</p> <p>For example, the HDC includes the mental health commissioner, and in their work they have feedback sessions eg with mental health and addiction services consumers, deliberately held in communities with a higher proportion of Māori.⁸⁶²</p> <p>Some agencies gave examples of consulting/involving people with lived experience of disability. But these examples did not include Māori with lived experience of disability or Māori organisations.</p>

⁸⁵⁹ Agencies covered in this table are: PHARMAC, Health Promotion Agency (HPA), New Zealand Blood Service (NZBS), Health Quality and Safety Commission (HQSC), Health Research Council (HRC), Health and Disability Commissioner (HDC), and New Zealand Artificial Limb Service (NZALS).

⁸⁶⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 10 ACC.

⁸⁶¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 7 NZ Artificial Limb Service.

⁸⁶² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 2 Health and Disability Commissioner.

Constituent element	Themes
	<p>For example, PHARMAC provides an example of, ‘...working with the Blind Foundation to get advice on blood glucose meters for visually impaired’.⁸⁶³</p>
<p>Involvement in strategy and design work</p>	<p>Both ACC and PHARMAC have Māori focused strategies. And Māori were involved in development but not necessarily Māori with lived experience of disability.</p> <p>ACC states that, ‘...[w]hen the Māori Strategy Whāia te Tika was drafted, it was able to draw on the ACC ‘Diversity and Inclusion Strategy’ to provide for a diverse and inclusive approach to participation’.</p> <p>ACC did not include the diversity and inclusion strategy, but its other material indicates the strategy has two areas of focus. These are stated to be,</p> <p>‘...Māori to uphold our commitment to the Treaty of Waitangi and people with disabilities to be role models for our clients, customers and the community.’</p> <p>There are no explicit statements about the need to include Māori with lived experience of disability.</p> <p>PHARMAC did not specifically ensure participation of Māori with lived experience of disability in its strategy. As it stated in its response,</p> <p>‘...[w]e worked with a range of government and non-government organisations, regional and local Māori health providers, and relevant Māori organisations, and with PHARMAC staff, to develop Te Whaioranga (2013–2023). This involved reviewing the previous version and developing a new action plan. We undertook a variety of activities to consult widely and gain participation from a broad range of stakeholders, however we did not specifically ensure participation of disabled Maori’.⁸⁶⁴</p>

⁸⁶³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 9 PHARMAC.

⁸⁶⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 9 PHARMAC.

Active protection

Table 24 presents summary themes analysed by the principle of active protection. Due to the variety of functions carried out by the group of agencies, only two agencies were questioned about responsive services. There was no information provided on whether services were responsive to the needs of Māori with lived experience of disability. On workforce responsiveness, most agencies offer some kind of Māori responsiveness or cultural competency or safety training to staff, and two agencies offered Māori responsiveness, cultural competence or cultural safety training to board and advisory group members – two did not. Agencies do not however, usually offer disability responsiveness training.

Table 24: Summary themes from information provided by Crown health agencies⁸⁶⁵ analysed by the principle of active protection

Constituent element	Themes
Responsive services	<p>Because of the variety of functions carried out by this group of health agencies, requests were only made of two agencies related to responsive services.</p> <p>There was no information provided on whether services were responsive to the needs of Māori with lived experience of disability.</p> <p>The Health and Disability Commissioner’s Director of Advocacy contracts with the National Advocacy Trust to provide advocacy services. As part of that contract the National Advocacy Trust its outputs must, ‘...reflect our diverse stakeholder group’. For example, the National Advocacy Trust is required to ensure education sessions, ‘...include a proportion with Māori, disabled, and Pacific peoples, and with refugee, migrant and Deaf communities’. And every Advocate hired by the Trust receives Māori cultural training as part of their induction.</p> <p>The Health and Disability Commissioner only began routinely recording ethnicity data as part of complaints in 2018, but stated that in 2017/18, 23% of all complaints to the advocacy service were from Māori health consumers, and that 10.2% of complaints made by Māori were about disability services, (compared to 10.1% of complaints by non-Māori).⁸⁶⁶</p> <p>The Health Promotion Agency (HPA) runs a range of health promotion activity and,</p> <p>‘...almost all (with the exception of skin cancer prevention) of HPA’s core health topics ie, alcohol, tobacco control, minimising gambling harm, immunisation, nutrition and physical activity and mental health have Māori as a target (priority) audience. Initiatives, including campaigns, are developed to either target Māori specifically or to ensure they resonate with Māori’.⁸⁶⁷</p> <p>The specific example provided by HPA is its oral health campaign aimed at parents and caregivers of children under five years with Māori and Pacific as a priority. Audience testing showed messages resonated strongly with the Māori target audience (87%) and Pacific (88%) compared with other ethnicities (71%). However, no information is provided on Māori with lived experience of disability, and whether services are delivered and designed to be responsive to their needs.</p> <p><i>Also refer to Table 25: Health agencies (excluding Ministry of Health) themed responses to equity themed questions.</i></p>

⁸⁶⁵ Agencies covered in this table are: PHARMAC, Health Promotion Agency (HPA), New Zealand Blood Service (NZBS), Health Quality and Safety Commission (HQSC), Health Research Council (HRC), Health and Disability Commissioner (HDC), and New Zealand Artificial Limb Service (NZALS).

⁸⁶⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 2 Health and Disability Commissioner.

⁸⁶⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 3a Health Promotion Agency.

Constituent element	Themes
Workforce responsiveness	<p>Most agencies offer some kind of Māori responsiveness or cultural competence or cultural safety training to staff.</p> <p>For example, PHARMAC offers cultural competence training to all new staff. It also offers Te Tiriti o Waitangi training (which has been completed by 75% of current staff).⁸⁶⁸</p> <p>Other types of training offered included te reo Māori and Te Rito/ everyday tikanga training.</p> <p>It is noted that one agency (HPA) had offered training in bicultural competencies (Te Rito), Māori models of health, te reo Māori and tikanga had been offered in the past. But training in 2018 offered to all staff was limited to two Ministry of Health presentations on its equity framework. In addition, the leadership team were invited to unconscious bias training.</p> <p>Two agencies offered Māori responsiveness, cultural competence or cultural safety training to board and advisory group members, but two did not.</p> <p>Neither the HPA, nor PHARMAC offered cultural competence training to their board members.</p> <p>It was common for agencies to use waiata practices or marae visits as evidence of cultural responsiveness training or staff development.</p> <p>Agencies use internal staff to upskill others in the use of tikanga, te reo Māori and cultural competence.</p> <p>For example the Health Quality and Safety Commission (HQSC) runs staff-led presentations on tikanga Māori at meetings,⁸⁶⁹ and the HPA indicated that specialist Māori advisors support staff on a day to day basis to build cultural competence and give tikanga advice.⁸⁷⁰</p> <p>Agencies do not usually offer disability responsiveness training.</p> <p>An exception is ACC, which states:</p> <p>‘...[w]e are members of the Accessibility Tick programme. As part of this programme, we are providing accessibility training to our employees who develop content for our customers and employees, and we are (sic) working with our property team to ensure that access needs are considered for new sites and site renovations’.⁸⁷¹</p> <p>Agencies do not usually collect information on course completion.</p>

⁸⁶⁸ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 9 PHARMAC.

⁸⁶⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 5d Health Quality and Safety Commission.

⁸⁷⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 3a Health Promotion Agency.

⁸⁷¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 10 ACC.

Constituent element	Themes
	Other than Te Tiriti o Waitangi training offered by PHARMAC (discussed above), only ACC's Te Rito training included staff completion rates (5% of staff completed the training). ⁸⁷²

Equity

Table 25 presents summary themes analysed by the principle of equity. Regarding equity goals and expectations, most agencies do have high level equity statements or objectives for Māori. However, these statements do not make reference to disability issues or Māori with lived experience of disability, with the exception of ACC which focuses on health equity for Māori as well as injury prevention. Regarding equity tools, agencies appear to reference MoH tools in their work.

Agencies were unable to provide a breakdown of their spending based on population by ethnicity and/or disability in addition, agencies do not include disability issues in their health quality data. The Health Quality & Safety Commission (HQSC) is responsible for an Atlas of Healthcare Variation tool, and all domains are intended to, ‘...highlight variation and inequity in disease prevalence, and in access to, experience of and outcomes of care for Māori’. However, the HQSC also states, ‘...we advise no Atlases cover disability therefore none have commented on inequities for disabled Māori’.

It is also noted the HQSC states that although they report on health inequities, they are unable to lead system change to support equity, having, ‘...no powers to compel system change, and providing data highlighting inequity does not in itself “address inequity”, but it

⁸⁷² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 10 ACC.

can be used as a basis for addressing inequities’. Thus, the impacts of lack of data and analysis are compounded by the Crown not acting on the information that it does have.

Table 25: Summary themes from information provided by Crown health agencies⁸⁷³ analysed by the principle of equity

Constituent element	Themes
Equity goals/expectations	<p>Most agencies have high level equity statements or objectives for Māori.</p> <p>The Health Research Council, for example, has a formal commitment to investing in research that targets health inequities for Māori (including in the New Zealand Health Research Strategy).⁸⁷⁴</p> <p>There is a suggestion that the focus on addressing inequity has been strengthened more recently. For example, the Health Quality and Safety Committee (HQSC) states,</p> <p>‘...[i]n recent years the Commission has prioritised greater responsiveness to inequity within its planning and prioritisation, with the introduction of initiatives such as Te Whai Oranga, our Māori Advancement Framework, and the inclusion of reducing inequity as a strategic priority in our 2017–21 Statement of Intent’.⁸⁷⁵</p> <p>High level equity statements do not usually make reference to disability issues or Māori with lived experience of disability.</p> <p>The exception is ACC which focuses on health equity for Māori as well as injury prevention. ACC states,</p> <p>‘...Whāia Te Tika, ‘to pursue what is right’, is our strategy to achieve equitable outcomes for Māori. By pursuing what is right, ACC will be delivering services that are appropriate, in a manner which best meets the needs of Māori. We take a system-wide approach to addressing known disparities and inequities, represented by four dimensions: preventing injuries, improving access to services, improving rehabilitation outcomes and building increased levels of trust and satisfaction. This is underpinned by improving the cultural diversity and capability of our workforce’.⁸⁷⁶</p>

⁸⁷³ Agencies covered in this table are: PHARMAC, Health Promotion Agency (HPA), New Zealand Blood Service (NZBS), Health Quality and Safety Commission (HQSC), Health Research Council (HRC), Health and Disability Commissioner (HDC), and New Zealand Artificial Limb Service (NZALS).

⁸⁷⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 6 Health Research Council.

⁸⁷⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 5 Health Quality and Safety Commission.

⁸⁷⁶ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 10n ACC.

Constituent element	Themes
Equity tools	<p>Agencies appear to reference Ministry of Health equity tools in their work.</p> <p>For example, the HPA and HQSC indicated their staff received training or presentation in tools (the Ministry of Health’s <i>Equity of Health Care for Māori</i> framework and the <i>Health Equity Assessment Tool</i> respectively).</p>
Quality data and monitoring	<p>Health quality data does not include disability issues.</p> <p>The Health and Disability Commissioner indicated it only recently started collecting and recording ethnicity data routinely for its services. It does not collect disability data.⁸⁷⁷</p> <p>The HQSC is responsible for an Atlas of Healthcare Variation tool, and all domains, ‘...highlight variation and inequity in disease prevalence, and in access to, experience of and outcomes of care for Māori’.⁸⁷⁸</p> <p>However, the HQSC also states, ‘...[w]e advise no Atlases cover disability therefore none have commented on inequities for disabled Māori’.⁸⁷⁹</p> <p>It is also noted that HQSC is not able to lead system change to support equity, stating that,</p> <p>‘...[t]he Commission has no powers to compel system change, and providing data highlighting inequity does not in itself “address inequity”, but it can be used as a basis for addressing inequities’.⁸⁸⁰</p>
Spending	<p>Agencies were not able to provide a break down in spending based on population when asked.</p> <p>For example, the HQSC states,</p> <p>‘...[t]he Commission does not allocate its spending on the basis of ethnicity. It has not to date allocated funds focused on disability’.⁸⁸¹</p>

⁸⁷⁷ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 2 Health and Disability Commissioner.

⁸⁷⁸ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 5 Health Quality and Safety Commission.

⁸⁷⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 5z Health Quality and Safety Commission.

⁸⁸⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 5 Health Quality and Safety Commission.

⁸⁸¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 5 Health Quality and Safety Commission.

Office for Disability Issues

Table 26 presents the summary themes from the thematic analysis of information provided by Office for Disability Issues (ODI) using a Treaty principles framework. These include the following principles: partnership; options; active protection; and equity.

The ODI does not address partnership directly but does indicate it uses the ‘three P’s’ (which include partnership) outlined in the *New Zealand Disability Strategy*. Regarding participation, ODI works with the Disabled People’s Organisations (DPO) in developing strategy and policy work. The DPO are also relied upon with regard to raising issues as priorities for the Chief Executive’s group on disability issues. Outside of the DPO (which includes Kāpō Māori Aotearoa), there is little evidence provided of ODI engaging with, and involving Māori with lived experience of disability, other than through occasional consultation. *The New Zealand Disability Strategy* development included two Māori specific hui, though information was not provided on the number of hui overall.

The ODI indicates that it engages with other Crown agencies on Māori health and disability outcomes more readily than engaging with Māori with lived experience of disability directly. They also reported that if specialist Māori advice was required, then the ODI would seek advice from, or refer the agency to, Kāpō Māori Aotearoa specifically. The ODI does not offer training to individuals on Māori responsiveness – although some staff have had Treaty training and been on marae visits, and all staff are expected to be conscious of cultural safety in their work.

Table 26: Summary themes from information provided by the Office for Disability Issues (ODI) analysed by Treaty principles⁸⁸²

Principle	Themes
Partnership	<p>ODI does not address partnership directly but does indicate it uses the ‘three Ps’ (which include partnership) as outlined in the NZ Disability Strategy.</p>
Participation	<p>ODI works with Disabled People’s Organisations (DPO) in developing strategy and policy work (eg the Disability Action Plan 2019–2022, which is under development).</p> <p>For example, ODI states, ‘...[a]s part of this, ODI and the DPO Coalition have held or will hold targeted consultation workshops with Māori to ensure that a Māori perspective on disability issues is a dedicated area of focus in the NZDS’.</p> <p>DPO are also relied on to raise issues as priorities for the Chief Executive’s group on disability issues. The Chief Executive group meets 2–3 times a year, for one hour.</p> <p>Outside of the DPO (including Kāpō Māori Aotearoa) there is little evidence provided of ODI engaging with, and involving, Māori with lived experience of disability, other than through occasional consultation.</p> <p>Consultation is an ‘imperative’ in policy design according to ODI.</p> <p>The NZ Disability Strategy development included two Māori specific hui. No information is provided that offers a comparison, for example the total number of hui overall. ODI also indicate that it engages with other Crown agencies on Māori health and disability outcomes more readily than with Māori directly (eg on the ODI Outcomes Framework).</p>
Options	<p>Perhaps because of its relationships with DPO, ODI acknowledges that if specialist Māori advice was required, ‘...ODI would seek advice from or recommend that the agency makes direct contact with Kāpō Māori Aotearoa’.</p>
Active protection	<p>ODI does not offer training to individuals on Māori responsiveness – although some staff have had Treaty training and been on marae visits and all staff are expected to be conscious of cultural safety in their work.</p> <p>Staff also receive training in NZ Sign Language.</p>

⁸⁸² Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 15 & 15a Office for Disability Issues.

Representation of Māori with lived experience of disability on health and disability sector boards and committees

Table 27 presents membership of ministerial committees of Māori and non-Māori, however information on whether members on ministerial committees have lived experience of disability is unknown by the MoH. Table 28 shows board membership of the district health boards by ethnicity and disability. There are no Māori board members with lived experience of disability on DHB boards throughout Aotearoa/New Zealand. Three DHBs indicated they have board members with lived experience of disability but in all cases, these board members are non-Māori. Not all DHBs hold information on the ethnicity of board members. Just over half of all DHBs hold information on whether board members have lived experience of disability. While nine DHBs were not able to say whether they had board members with disabilities, 11 DHBs stated there are no known disabilities amongst their board members.

Table 27: Breakdown of Māori and non-Māori members on ministerial committees

Crown entity/ board/ committee	Māori members	non-Māori members	Total members	Responsible legislation
Advisory Committee on Assisted Reproductive Technology	2	7	9	Section 32, Human Assisted Reproductive Technology Act
Ethics Committee on Assisted Reproductive Technology *	0	7	7	Section 27, Human Assisted Reproductive Technology Act
Expert Advisory Committee on Drugs **	0	9	9	Section 5AA Misuse of Drugs Act
Central Health and Disability Ethics Committee	1	5	6	Section 11, New Zealand Public Health and Disability Act
Chiropractic Board	1	6	7	Section 120, Health Practitioners Competence Assurance Act
National Cervical Screening Programme Review Committee	1	2	3	Section 1120, Health Act 1956
Dental Council of New Zealand	2	10	12	Section 120, Health Practitioners Competence Assurance Act
Dieticians Board of New Zealand ***	1	8	9	Section 120, Health Practitioners Competence Assurance Act
Health and Disability Commissioner	0	4	4	Health and Disability Commissioner Act, Crown Entities Act

Crown entity/ board/ committee	Māori members	non-Māori members	Total members	Responsible legislation
Health and Disability System Review Panel ****	0	7	7	Section 11, New Zealand Public Health and Disability Act
Health Promotion Agency	2	5	7	New Zealand Public Health and Disability Act, Crown Entities Act
Health Practitioners Disciplinary Tribunal ****	13	162	175	Section 87, Health Practitioners Competence Assurance Act
Health Quality and Safety Commission	2	6	8	New Zealand Public Health and Disability Act, Crown Entities Act
Health Research Council of New Zealand	1	9	10	Health Research Council Act, Crown Entities Act
Hospital Rebuild Partnership Group	0	4	4	Cabinet directive – CAB Min (12) 30/3A
Medical Council of New Zealand	2	9	11	Section 120, Health Practitioners Competence Assurance Act
Mental Health Review Tribunal ****	3	16	19	Section 101, Mental Health (Compulsory Assessment and Treatment) Act 1992
Midwifery Council of New Zealand	1	7	8	Section 120, Health Practitioners Competence Assurance Act

Crown entity/ board/ committee	Māori members	non-Māori members	Total members	Responsible legislation
Medical Radiation Technologists Board	0	8	8	Section 120, Health Practitioners Competence Assurance Act
Medical Science Council of New Zealand ****	0	8	8	Section 120, Health Practitioners Competence Assurance Act
National Kaitiaki Group	4	1	5	Health (Cervical Screening (Kaitiaki)) Regulations
National Ethics Advisory Committee	3	6	9	Section 16, New Zealand Public Health and Disability Act
Northern A Health and Disability Ethics Committee	1	5	6	Section 11, New Zealand Public Health and Disability Act
Northern B Health and Disability Ethics Committee	1	7	8	Section 11, New Zealand Public Health and Disability Act
Nursing Council of New Zealand ****	2	7	9	Section 120, Health Practitioners Competence Assurance Act
New Zealand Blood Service	1	6	7	New Zealand Public Health and Disability Act, Crown Entities Act
Occupational Therapy Board of New Zealand	1	6	7	Section 120, Health Practitioners Competence Assurance Act

Crown entity/ board/ committee	Māori members	non-Māori members	Total members	Responsible legislation
Optometrists and Dispensing Opticians Board of New Zealand	0	8	8	Section 120, Health Practitioners Competence Assurance Act
Osteopathic Council of New Zealand	1	8	9	Section 120, Health Practitioners Competence Assurance Act
PHARMAC	1	4	5	New Zealand Public Health and Disability Act, Crown Entities Act
Pharmacy Council of New Zealand	1	6	7	Section 120, Health Practitioners Competence Assurance Act
Physiotherapist Board of New Zealand	1	7	8	Section 120, Health Practitioners Competence Assurance Act
Podiatrists Board of New Zealand	2	5	7	Section 120, Health Practitioners Competence Assurance Act
Psychoactive Substances Expert Advisory Committee	0	6	6	Section 44, Psychoactive Substances Act
Psychologist Board of New Zealand	2	6	8	Section 120, Health Practitioners Competence Assurance Act
Psychotherapists Board of New Zealand	0	6	6	Section 120, Health Practitioners Competence Assurance Act

Crown entity/ board/ committee	Māori members	non-Māori members	Total members	Responsible legislation
Southern Health and Disability Ethics Committee	1	5	6	Section 11, New Zealand Public Health and Disability Act
Southern Partnership Group	0	5	5	Cabinet approval
West Coast Partnership Group ****	0	5	5	Cabinet approval
Medicines Adverse Reactions Committee ****	1	12	13	Section 8, Medicines Act
Medicines Assessment Advisory Committee ****	0	12	12	Section 8, Medicines Act
Medicines Classification Committee ****	0	6	6	Section 9, Medicines Act
Total	55	438	493	

Source: Ministry of Health⁸⁸³

* Committee must have a minimum of two Māori members. These are currently under consideration by the Minister of Health.

** Ethnicity data is not collected for this Committee.

*** Total membership includes a member with undisclosed ethnicity.

**** Total membership includes members with undisclosed ethnicity.

⁸⁸³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

Table 28: Board membership of district health boards broken down by ethnicity and disability

DHB ⁸⁸⁴	Māori	non-Māori	Māori / disability ⁸⁸⁵	non-Māori /disability	Total Members
Auckland	2	9	-	-	11
Bay of Plenty	2	9	-	-	11
Canterbury	2	9	0	0	11
Capital and Coast ⁸⁸⁶	2	8	0	0	10
Counties Manukau	2	9	0	3	11
Hawke's Bay ⁸⁸⁷	4	7	0	0	11
Hutt Valley	1	9	-	-	10
Lakes	3	8	0	0	11
MidCentral	2	9	0	0	11
Nelson Marlborough	2	9	-	-	11
Northland	2	9	0	0	11
South Canterbury	2	9	No response	No response	11

⁸⁸⁴ Information on Māori and non-Māori board members is sourced from the Ministry of Health's first OIA response. Information on disability status comes from DHB OIA responses.

⁸⁸⁵ Where a DHB said it did not collect disability information on the Board a '-' is used. Where the DHB made statements like 'no known disability' a '0' is used.

⁸⁸⁶ Capital and Coast DHB response differs from information provided by the Ministry of Health. In its response, Capital and Coast said, 'There are currently 10 Board members, 3 identified as Māori, and 4 are non-Māori, no Board member has confirmed or identified as a disabled Māori or disabled non-Māori'.

⁸⁸⁷ Hawke's Bay DHB response differs from information provided by the Ministry of Health. In its response it stated 45% of the Board were Māori. This would mean 5 Board members were Māori, not 4 as indicated by the Ministry of Health.

DHB ⁸⁸⁴	Māori	non-Māori	Māori / disability ⁸⁸⁵	non-Māori /disability	Total Members
Southern	0	3	-	-	3
Tairāwhiti ⁸⁸⁸	4	7	0	0	11
Taranaki ⁸⁸⁹	3	8	0	1	11
Waikato ⁸⁹⁰	2	9	-	-	11
Wairarapa	2	9	0	1	11
Waitemata	2	9	-	-	11
West Coast	2	9	0	0	11
Whanganui	2	9	-	-	11

Source: Ministry of Health and district health boards ⁸⁹¹

Table 29 shows membership of DHB Disability Support Advisory Committees by ethnicity and disability. When it comes to decisions relevant to Māori with lived experience of disability, DHBs largely rely on the Māori representation on their Disability Services Advisory Committee (required by the New Zealand Public Health and Disability Act 2000). However, this does not appear to include Māori with lived experience of disability.

⁸⁸⁸ Tairāwhiti DHB response differs from information provided by the Ministry of Health. In its response it states there are five Māori Board members and six non-Māori Board members.

⁸⁸⁹ Taranaki DHB response differs from information provided by the Ministry of Health. In its response it states, 'Māori – 4 out of 12 members; Non-Māori – 8 out of 12 members'.

⁸⁹⁰ On 7 May 2019, the Minister of Health fired the Waikato board members, replacing them with a commissioner.

⁸⁹¹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

Table 29: Membership of DHB Disability Support Advisory Committee broken down by ethnicity and disability⁸⁹²

District Health Board ⁸⁹³	Māori	non-Māori	Māori/ disability ⁸⁹⁴	non-Māori/ disability
Auckland ⁸⁹⁵	1	5	-	-
Bay of Plenty ⁸⁹⁶	3	9	-	-
Canterbury ⁸⁹⁷	1	13	0	1
Capital and Coast ⁸⁹⁸	-	-	-	-
Counties Manukau ⁸⁹⁹	1	5		3
Hawke's Bay ⁹⁰⁰	5	6	0	0
Hutt Valley ⁹⁰¹	-	-	-	-

⁸⁹² Index of supplementary information provided to the researcher under the OIA – Responses from DHBs

⁸⁹³ Information on Māori and non-Māori Board members is sourced from the Ministry of Health's first OIA response. Information on disability status compiled from DHB OIA responses.

⁸⁹⁴ Where a DHB said it did not collect disability information on the Board a '-' is used. Where the DHB made statements like 'no known disability' a '0' is used.

⁸⁹⁵ A joint committee with Waitemata DHB.

⁸⁹⁶ The DHB has a single committee combining the two statutory committees (DSAC and the Community and Public Health Advisory Committee).

⁸⁹⁷ The DHB has a single committee combining the two statutory committees (DSAC and the Community and Public Health Advisory Committee).

⁸⁹⁸ Shared DSAC with Wairarapa and Hutt Valley DHBs. No specific membership numbers are given but the DHB notes that there is an individual on the group who identifies as Māori and also identifies as having a disability.

⁸⁹⁹ Counties Manukau DHB provided a table of membership that differs from these numbers as the non-Māori members only included those without a disability.

⁹⁰⁰ Based on Hawke's Bay DHB's response that 45 per cent of the Board is Māori. The DSAC is made up of the full DHB Board.

⁹⁰¹ Shared DSAC with Wairarapa and Capital and Coast DHBs. DHB provides a webpage url link to a membership list of the DSAC but no ethnicity or disability information is provided.

District Health Board ⁸⁹³	Māori	non-Māori	Māori/ disability ⁸⁹⁴	non-Māori/ disability
Lakes ⁹⁰²	3	9	0	0
MidCentral ⁹⁰³	3	10		1
Nelson Marlborough	-	-	-	-
Northland	1	8		1
South Canterbury	No response	No response	No response	No response
Southern	3	3	-	-
Tairāwhiti ⁹⁰⁴	7	5	0	0
Taranaki ⁹⁰⁵	4	8	0	1
Waikato	-	-	-	-
Wairarapa	-	-	-	-
Waitemata ⁹⁰⁶	1	5	-	-
West Coast ⁹⁰⁷	3	14	-	-
Whanganui ⁹⁰⁸	5	11	-	-

⁹⁰² The DHB has a single committee combining the two statutory committees (DSAC and the Community and Public Health Advisory Committee).

⁹⁰³ The DHB doesn't specify which Statutory Committees this response relates to but gives it as the answer for all statutory committees.

⁹⁰⁴ The DHB doesn't specify which Statutory Committees this response relates to but gives it as the answer for all statutory committees.

⁹⁰⁵ The DHB doesn't specify which Statutory Committees this response relates to but gives it as the answer for all statutory committees.

⁹⁰⁶ A joint committee with Auckland DHB.

⁹⁰⁷ The DHB doesn't specify which Statutory Committees this response relates to but gives it as the answer for all statutory committees.

⁹⁰⁸ The DHB doesn't specify which Statutory Committees this response relates to but gives it as the answer for all statutory committees.

Table 30 shows the numbers of Māori and non-Māori members of the Health Quality & Safety Commission (HQSC) board, Expert Advisory Groups (EAGs), Mental Health & Addictions Advisory Group, Consumer Advisory Group, Consumer Network and National Mortality Review Committees (MRCs). The HQSC has a number of Māori advisory groups. For example, its Te Rōpū Māori advisory group provides advice and expertise to every Board meeting. However, the HQSC also states, ‘membership of our advisory bodies is not determined by the disability status of applicants. We do not collect data specifically related to Māori disability’.⁹⁰⁹

Table 30: Numbers of Māori and non-Māori members of Health Quality & Safety Commission (HQSC) board and committees

Body	Māori	non-Māori
HQSC Board	2	6
Primary Care EAG	2	12
Mental Health and Addictions (MHA) Māori Advisory Group	11	0
MHA Consumer Advisory Group	1	5
Medication Safety Expert Advisory Group (EAG)	0	10
Adverse Events EAG	1	8
Infection Prevention & Control EAG	1	12
Patient Deterioration EAG	1	9
Safe Surgery NZ EAG	1	10
Antibiotic Dispensing Atlas EAG	3	5
Variations EAG	2	9
Te Rōpū Māori	7	0
Child and Youth Mortality Review Committee (MRC)	2	6
Family Violence Death Review Committee	4	5
Perinatal & Maternal MRC	3	6

⁹⁰⁹ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 5 Health Quality and Safety Commission.

Body	Māori	non-Māori
Perioperative MRC	3	7
Suicide MRC	2	6
Consumer Advisory Group	2	2
Consumer Network	5	8

Source: Health Quality & Safety Commission⁹¹⁰

Representation of Māori with lived experience of disability in the health and disability sector workforce

The number of Māori with lived experience of disability employed by the public service (in one of the 32 public service departments) is unknown. In its report, *Our People: Public Service Workforce Data 2018*,⁹¹¹ the State Services Commission (SSC) notes that its human resource capability survey does not collect data on disability in the public service, instead using 'customised information' from Statistics New Zealand. This customised information based on the *2013 Disability Survey*, estimates that the rate of disability in the public service (at 16 per cent), is slightly less than the rate of disability in the workforce overall (at 19 per cent) – although this difference is not statistically significant.

The report also looks at the ethnic make-up of people employed in the public service. Māori make up 16 per cent of the public service workforce over all, but Māori are underrepresented in the top tiers of the public service (where senior leaders are those in the top three tiers of management, with the chief executive being tier one, their direct reports, tier two, and so on). The report provides no information on Māori with lived experience of disability in the public service workforce.

⁹¹⁰ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 5 Health Quality and Safety Commission.

⁹¹¹ State Services Commission, *Our People: Public Service Workforce Data 2018*. (Wellington: State Services Commission, 2018).
http://www.ssc.govt.nz/sites/all/files/2018%20Public%20Service%20Workforce%20Data_pdf_0.pdf.

Although *Whāia te Ao Marama 2018–2022* includes a commitment from the MoH to involve Māori with lived experience of disability in service design, implementation, and delivery, and suggests other organisations, ‘contract tāngata whaikaha as consultants to co-design organisational policies and procedures’,⁹¹² health sector agencies, including the MoH, were not able to provide information on consultants and contractors broken down either by ethnicity, or by disability status. For example, the MoH states that it ‘...is not able to provide details on the ethnicity as [the MoH’s] systems do not routinely capture this information’.⁹¹³

A number of health sector agencies, for example, the Health Promotion Agency, the Health Quality and Safety Commission, the Health Research Council, and PHARMAC, provide ethnicity, and sometimes disability information, about their employees in their annual reports. Additionally, ACC provided information on its workforce in its OIA response.⁹¹⁴ Overall agencies employ a low percentage of Māori within their organisations. Whilst ACC is the highest at 12 per cent, the rest employ between four per cent and seven per cent of Māori staff, with similar rates of people with lived experience of disability (although this is not further broken down by ethnicity). Table 31 provides a summary of health sector agency staffing by ethnicity and disability status for 2017/18 (where information is available).

⁹¹² Ministry of Health, *Whāia Te Ao Marama 2018 to 2022: The Māori Disability Action Plan*, p.9.

⁹¹³ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 1 Ministry of Health.

⁹¹⁴ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 10 ACC.

Table 31: Proportion of agency staffing by ethnicity and disability status 2017/18

Agency	Māori	non-Māori	Total % lived experience of disability	Full-time equivalent staff numbers
ACC ⁹¹⁵	12%	88%	15%	-
Health Promotion Agency ⁹¹⁶	7%	93%	-	89.6
Health Quality and Safety Commission ⁹¹⁷	6%	94%	7%	63
Health Research Council ⁹¹⁸	5.5%	94.5%	5.5%	30.5
PHARMAC ⁹¹⁹	4%	96%	-	126 ⁹²⁰

⁹¹⁵ Index of supplementary information provided to the researcher under the OIA – Responses from Agencies: 10 ACC.

⁹¹⁶ Health Promotion Agency, *Annual Report for the year ending 30 June 2018*. (Wellington: Health Promotion Agency, 2018). https://www.hpa.org.nz/sites/default/files/6.1%20HPA132%20Annual%20Report%202018_Full.pdf.

⁹¹⁷ Health Quality and Safety Commission, *Annual Report 2017/18*. (Wellington: Health Quality and Safety Commission, 2018). https://www.hqsc.govt.nz/assets/General-PR-files-images/AnnualReport2017-18_WEB.pdf.

⁹¹⁸ Health Research Council of New Zealand, *Annual Report 2018 for the year ended 30 June 2018*. (Wellington: Health Research Council, 2018). <http://www.hrc.govt.nz/sites/default/files/Annual%20Report%202018.pdf>.

⁹¹⁹ PHARMAC, Pharmaceutical Management Agency *Annual Report for the year ended 30 June 2018*. (Wellington: PHARMAC, 2018). <https://www.pharmac.govt.nz/assets/annual-report-2017-2018.pdf>.

⁹²⁰ PHARMAC reported total staff numbers, not full-time equivalent numbers in its 2018 annual report.

Summary

Māori with lived experience of disability are made 'invisible' by Crown organisations. Where Crown organisations do show responsiveness to Māori, generally this does not include Māori with lived experience of disability. Where Crown organisations show responsiveness to people with lived experience of disability, this does not usually include Māori. In turn, this leads to a sense of Crown inaction when it comes to the health and well-being interests of Māori with lived experience of disability.

Crown organisations might articulate high level strategic statements that indicate a commitment to Māori health and equity but these are not clearly mapped to actions that support improved outcomes for Māori. Furthermore, these statements are usually silent on Māori with lived experience of disability. Aspirational statements about Māori participation at all levels of the health and disability system lack follow through generally, and this is amplified when it comes to Māori with lived experience of disability. There are no Māori with lived experience of disability on the boards of any district health board in Aotearoa/New Zealand. Crown organisations do not ensure Māori with lived experience of disability are part of advisory groups, participation in the health and disability workforce by Māori with lived experience of disability is not well documented, and the number of Māori-owned and Māori-governed providers involved in disability support service provision is greatly outweighed by their non-Māori counterparts.

The Crown has very limited data, information or other insights about the population health and disability needs of Māori with lived experience of disability. This impacts on the ability of Crown organisations to effectively plan and fund services to meet the needs of Māori with lived experience of disability, and also prevents accurate performance reporting and monitoring of these Crown organisations. Where there is data providing evidence of health inequities, there is no matching evidence of proportionate action to address said health inequities for Māori, and for Māori with lived experience of disability.

The permissive nature of the health and disability system seems to go hand in hand with Crown organisations merely ‘hoping for the best’ when it comes to Māori with lived experience of disability. There is the assumption that ‘mainstream’ service providers will be responsive to Māori with lived experience of disability, that Māori with lived experience of disability will participate in consultation, apply to be part of consumer groups, and that members of committees and expert advisory will be aware of issues for Māori with lived experience of disability. However, what information there is suggests this ‘strategy of hope’ has not delivered positive health and well-being outcomes for Māori with lived experience of disability.

District health boards, although responsible for the bulk of health service delivery in Aotearoa/New Zealand, are not able to say how they are meeting the actual health needs of Māori with lived experience of disability. This is erroneously reduced to a funding issue – conflating the fact that the Ministry of Health has retained funding responsibility for disability support services for people aged under 65 years, with the core functions of district health boards under the legislation to, ‘...improve, promote and protect the health of people and communities [and] reduce health disparities by improving health outcomes for Māori...’⁹²¹

The consequences of systematic Crown inaction all fall on Māori with lived experience of disability. There are no clear accountability mechanisms, and thus no consequences for Crown organisations that do not perform with regard to equitable outcomes for Māori with lived of experience of disability (even if performance was routinely monitored).

⁹²¹ New Zealand Public Health and Disability Act 2000, section 22(1)(a) and (e).

Conclusion

This section uses the Waitangi Tribunal’s original research commission questions⁹²² to present the findings. This report has demonstrated that significant inequities exist for Māori with lived experience of disability in health outcomes – in terms of exposure to the determinants of health and well-being, access to health and disability services, and the quality of health and disability care received (including health and disability system responsiveness). There is clear evidence of multiple systemic and structural barriers affecting these health outcomes for Māori with lived experience of disability. These systemic barriers have been created, maintained, and reinforced by the strategies of the Crown. The resulting effects include redistributing resources, preventing meaningful involvement, and a failure to monitor outcomes or respond appropriately to inequities that have emerged. In other words, the significant inequities which impact on Māori with lived experience of disability have not occurred through happenstance.

Compared with non-Māori, Māori experience significant inequities across many health and socioeconomic indicators. These pervasive and persistent inequities are situated within the context of the systematic and structural misappropriation of Māori land, power, and resources through colonisation. Inequities are then compounded by the maldistribution of the structural determinants of health and well-being through systems underpinned by, and maintained through, coloniality and racism.⁹²³ Within the Māori population however, the intersection of indigeneity and disability leads to even further significant inequities for Māori with lived experience of disability.

⁹²² Refer to Appendices 1–2.

⁹²³ Refer to Introduction for further discussion of the links between colonisation, coloniality and racism on health outcomes for Māori in Aotearoa/New Zealand.

The following section presents the Tribunal's research questions, and summary responses from the researcher.

What key historical developments have contributed to the current system of government disability services for Māori and to Māori experiences and attitudes to disability services?

The key historical developments and contemporaneous Western models of disability described in this report denote Crown actions and inactions contributing to the poor treatment of Māori with lived experience of disability, and the resultant inequitable health outcomes.⁹²⁴ Evidence from the 1840s demonstrates that the evolution of the Crown's approaches to addressing health and disability issues for Māori have involved purposeful exclusion of Māori from access to services. The services that were available were Pākehā-centric and conflicted with Māori worldviews of health and well-being. Activities undertaken by Māori to advance Māori health, although not specifically directed towards disability, will likely have had positive impacts for Māori with lived experience of disability. However, any of this activity or advancement has been stymied by legislation and policies supporting the Crown's agenda for assimilation.

Between 1840 and the 1990s, Crown approaches have included segregation and removal of Māori with lived experience of disability from their whānau, assimilation of Māori through the suppression of cultural practices, and attempts to systematically eliminate 'undesirables' on the basis of policies underpinned by eugenics ideologies. Resulting Crown policies led to the establishment of a series of large institutions based on paternalistic and culturally unsafe approaches to the health and well-being needs of Māori with lived experience of disability. This has caused immeasurable damage for those who were subsequently lost from their whānau and those who abused whilst in Crown institutions.

Historically, the Crown's approach to disability issues has been reductionist and ableist. It has often employed the same strategies of segregation, suppression and paternalism that

⁹²⁴ Refer to Chapter II.

characterise the Crown's approach and actions toward Māori. However, Māori with lived experience of disability have been impacted even further due to the intersection of Māori experience of disability with colonisation, coloniality and racism.⁹²⁵ These impacts are compounded by culturally unsafe models of health imposed upon Māori, in addition to Māori experiences of institutional racism, and explicit and implicit bias within health and disability services. As a population group, the persistent, significant, and pervasive inequities impacting on Māori with lived experience of disability, demonstrate that they have experienced, and continue to experience, the disproportionate impact of the Crown's actions and inactions.⁹²⁶

The legacy of the Crown's historic approaches to Māori health and well-being since the 1840s includes no acknowledgement of the right of Māori to be self-determining. It has restricted the opportunity for Māori to develop, establish and sustain indigenous approaches to disability. Māori with lived experience of disability have for a long time undertaken activities to advance the health and well-being of their communities. Recent Crown activity suggests that the government now also aims to reflect the Social and Rights-based Models. However, the Crown's current actions offer no counterweight to history – the impact of which is manifest in the increased inequities between Māori and non-Māori with lived experience of disability, and within Māori groups with lived experience of disability (as a result of differential Crown responses to impairment depending on the mechanism of impairment. For example, accidental injury versus non-injury-related impairments).

⁹²⁵ Refer to Introduction and Chapter II.

⁹²⁶ Refer to Introduction, and Chapters II–V.

How does the contemporary health system, including legislation, policies and practices recognise and provide for the needs of Māori with disabilities? To what extent, if any, do implementation and outcomes diverge from policy objectives?

The current health and disability system (and its core institutions) was established in 2000 through the New Zealand Public Health and Disability Act. Flowing from this legislation came the requirement for a high-level disability strategy and the creation of district health boards who were assigned the responsibility for most personal health services. The Ministry of Health retained its role in the provision of disability support services for under 65 years. But in amongst all of this the needs of Māori with lived experience of disability are made invisible, illustrating one aspect of the disconnect between policy and practice that disproportionately impacts on Māori with lived experience of disability.⁹²⁷ Crown organisations for example, often use high level strategic statements to indicate a commitment to Māori health and equity but these statements are usually silent on Māori with lived experience of disability. Furthermore, there is no clear connection between these statements and tangible actions by the Crown organisation, or positive outcomes for Māori. The disconnect between high level statements and on-the-ground action is reinforced by the information provided in this report by Crown organisations. It suggests that statutory accountability mechanisms for legislative requirements around Māori health equity are not exercised. This non-accountability allows for a permissive legislative and structural framework regarding how objectives are carried out by Crown organisations in the health and disability sector.

⁹²⁷ Refer to Chapters III and V.

To what extent have Māori had opportunities to contribute to relevant policy and legislative developments?

Māori with lived experience of disability are not actively prevented from participating in policy and legislative developments, but neither is the opportunity to participate guaranteed, or actively sought by the Crown. Nor is there evidence that reasonable accommodations and supports are put in place by Crown organisations to support participation of Māori with lived experience of disability. This amounts to something close to the exclusion of Māori with lived experience of disability from health and disability sector decision making.

Aspirational statements about Māori participation at all levels of the health and disability system lack follow-through generally, but this is amplified when it comes to Māori with lived experience of disability. There are no Māori with lived experience of disability identified on the boards of any district health board in Aotearoa/New Zealand, or on the board of the Accident Compensation Corporation. Māori membership of boards generally is low. Crown organisations do not ensure Māori with lived experience of disability are part of advisory groups, and participation in the health and disability workforce by Māori with lived experience of disability is not well documented. Additionally, the number of Māori-owned and Māori-governed providers (Māori providers) involved in disability support service provision is greatly outweighed by their non-Māori counterparts. This is not due to a lack of demand, as Māori with lived experience of disability have highlighted that given the option, they would prefer a Māori provider. Despite the requirements of the New Zealand Public Health and Disability Act 2000 being nearly 20 years old, some health and disability sector agencies are only now considering options for Māori advisory groups. Again, these do not explicitly involve Māori with lived experience of disability.

For Ministry of Health-led work focused on disability issues, some form of consultation with Māori is common. However, there are examples provided where Māori with lived experience of disability are not involved in relevant projects. Notable, because of its explicit focus on Māori with lived experience of disability, Te Ao Mārama has been established by

the Ministry of Health. This expert group is external to the Ministry of Health, and includes Māori with lived experience of disability, Māori working in the disability sector, and experts in Māori culture. However, the quality of advice it receives from the Ministry of Health, and its level of support (both in terms of time, and financial support) is a challenge to its influence.⁹²⁸ There is also evidence that the group is not involved in decision making even when it clearly would add considerable value, for example, when it came to restructuring the Ministry of Health and re-establishing both a Māori health unit and a Disability directorate.

To what extent does 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?

Māori with lived experience of disability have few options when it comes to accessing disability support services provided by Māori. There are potentially only 33 providers nationwide, and geographically there are a number of areas where they are not available. Furthermore, when adding in health services more broadly, the total funding Māori providers receive still only makes up around 1.5 per cent of all health funding. Crown organisations do little to compensate when it comes to culturally responsive mainstream services, except offer variable levels of cultural competence training, and only very rarely, disability responsiveness training. It also brings to light that the resourcing provided by the Crown to Māori providers of disability support services is starkly disproportionate to the scale of health inequities for Māori with lived experience of disability.

The Crown has not ensured that culturally safe care reflecting tikanga Māori is provided across all health and disability services.⁹²⁹ Health and disability policies and practices claim to acknowledge the value of culturally responsive health and disability services for Māori overall. But other than actions within *Whāia Te Ao Marama 2018 to 2022*, for example,

⁹²⁸ Refer to Chapter V.

⁹²⁹ Refer to Chapters III and V.

where the Ministry of Health states its commitment to, ‘...grow Māori capacity and capability, including cultural competency, within the Ministry’s Disability Support Services group’,⁹³⁰ there is limited evidence of awareness by Crown organisations of what culturally responsive services for Māori with lived experience of disability would involve.

Crown organisations routinely offer Māori responsiveness training of some sort, for example, cultural competence training. However, it is less common for Crown organisations to offer disability responsiveness training, and very rare for training that covers the intersection of Māori health and disability responsiveness. There is no evidence that the Crown has recognised the need for such training, required its provision or monitored the impact of the training on Māori with lived experience of disability. Organisations do not always track course completion by their staff, but those that do show variation in health and disability sector commitment to Māori with lived experience of disability. For example, on one hand, 90 per cent of Ministry of Health staff working in disability support services completed cultural competence training, whilst on the other, some district health boards indicated less than one per cent of their medical professional staff were likely to have completed both Māori health, and disability responsiveness training.

What barriers, if any, do Māori experience in accessing disability services and what are existing Crown policies and practices for recognising and addressing any such barriers?

Overall there is strong evidence that the health, well-being and disability support needs of Māori with lived experience of disability are not being met equitably by the Crown. However, the Crown does not have adequate data monitoring mechanisms in place to be able to quantify the extent of the multiple barriers to access for Māori with lived experience of disability. What is clear are sector-wide responsiveness issues, characterised by a lack of systems and processes, coupled with a lack of accountability on the part of Crown organisations.

⁹³⁰ Ministry of Health, *Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan*, p.13.

Inequities that remain in health and disability services do so for a range of reasons. These include access to health and disability services and the lack of health system responsiveness underpinned by outdated models of disability. But also, the manifestation of institutional racism, particularly in the form of inaction by the Crown in the face of ongoing and compelling Māori health and disability need.⁹³¹ District health boards, although responsible for the bulk of health service delivery in Aotearoa/New Zealand, are not able to monitor how they are meeting the health needs of Māori with lived experience of disability. The reason given for this is erroneous, and reduced to a funding issue – conflating the fact that the Ministry of Health has retained funding responsibility for disability support services only for people aged under 65 years, with the core functions of district health boards under the legislation to, ‘...improve, promote and protect the health of people and communities [and] reduce health disparities by improving health outcomes for Māori...’.⁹³²

When it comes to contracted services, district health boards do not have the accountability mechanisms in place to ensure that the services they purchase are effective for Māori with lived experience of disability. Nor are district health boards required by the Ministry of Health to have these accountability mechanisms. The district health boards’ contracted providers might be expected to comply with the Health and Disability Commissioner’s Code of Consumer Rights or health and safety requirements. However, there are no specifics given by district health boards on how this works to safeguard against unresponsive services for Māori with lived experience of disability.

To what extent have Crown acts or omissions if any contributed to disparities in disability services and outcomes between Māori and non-Māori and how are these recognised and addressed?

The significant inequities for Māori in the health and disability system are more pronounced for Māori with lived experience of disability. In addition to inequitable

⁹³¹ Refer to Introduction, and Chapters IV and V.

⁹³² New Zealand Public Health and Disability Act 2000, section 22(1)(a) and (e).

outcomes, there are inequities in the quality of care received, and in non-evidenced based practices, for example, the Crown's use of seclusion on Māori with lived experience of disability. Data provided by the Crown shows that the inequities in secluded Māori compared with non-Māori have actually increased over a 10-year period, following the introduction in 2009 of the Crown's seclusion reduction policy. Also, the Crown's (over)use of seclusion on Māori with lived experience of learning/intellectual disability is of considerable concern. According to data provided by the Crown for the year 2017, Māori with lived experience of learning/intellectual disability, on average, are being secluded up to 36 times each. This compares with Ministry of Health figures from 2017 which report that, on average, people in adult inpatient services are secluded twice. This case study is particularly damning against the backdrop of the Crown's 'aspirational goal' of zero seclusion by 2020.

How effective is current monitoring and data collection for identifying and addressing any disparities in disability services and outcomes for Māori?

The Crown does not collect adequate data to monitor its performance for Māori with lived experience of disability. There are large knowledge gaps where the Crown simply does not collect data, or where it does collect data, it does not interrogate the data that it has. The impact of this is that the Crown is not able to fund, plan and design services based on real time data and insights that would address demonstrated Māori health and disability support needs. It also means that much of the Crown's most sensitive work in the health and disability sector is not routinely scrutinised. The fact that it continues to permit these data gaps to exist, developing policy and funding services in spite of this, demonstrates a lack of regard for the health and well-being of Māori with lived experience of disability.

The findings of this report have demonstrated that district health boards are not as responsive to Māori with lived experience of disability as the Crown purports to be in its strategic and legislative frameworks. As district health boards simply do not have any systems in place to routinely collect and monitor the health needs of Māori with lived experience of disability in their catchment areas, they are unable to demonstrate

performance against high level obligations and strategic directions. The semi-devolved structure of the health and disability system means that Māori with lived experience of disability are reliant on district health boards for high quality health and disability services. Yet the mechanisms in place for the Crown to ensure that these services are responsive to their health aspirations and needs are weak.

There is also very limited data, information or other insights about health aspirations and needs of Māori with lived experience of disability in other parts of the health and disability sector. This impacts on the ability of Crown organisations to effectively plan and fund services to meet the needs of Māori with lived experience of disability. It also prevents accurate performance reporting and monitoring of Crown organisations.

Where there is data that provides evidence of health inequities, there is no corresponding evidence of proportionate action to address health inequities for Māori, and for Māori with lived experience of disability. As an indicative example of this widespread phenomenon, under the Official Information Act 1982, the Ministry of Health provided examples of how monitoring has identified inequities for Māori subjected to community treatment orders under the Mental Health (Compulsory Assessment & Treatment) Act. However, it doesn't identify any actions to respond to, and address the inequities that are being monitored.

There are also examples of the Crown 'signalling' that it is doing something about equity more generally, whilst failing to examine inequities impacting Māori with lived experience of disability. The Health Quality & Safety Commission (HQSC) is responsible for an Atlas of Healthcare Variation tool, and all domains, '...highlight variation and inequity in disease prevalence, and in access to, experience of and outcomes of care for Māori'. However, the HQSC also states, '...we advise no Atlases cover disability therefore none have commented on inequities for disabled Māori'. The HQSC example also calls into question the value of identifying inequity if there is no commitment to act on this knowledge. For example, the HQSC states it is unable to lead system change to support equity, as it, '...has no powers to compel system change, and providing data highlighting inequity does not in itself "address inequity", but it can be used as a basis for addressing inequities'. Thus, the impact of a lack

of information and analysis is compounded by the Crown not acting on the information it does have. This same issue occurs for the Crown's use of seclusion on Māori.⁹³³

Additionally, there are significant gaps in data collection for young Māori with lived experience of disability. This is particularly concerning, considering the youthful demographic of the Māori population.⁹³⁴ This report has demonstrated critical gaps in identifying and addressing inequities in health and disability services and outcomes for both Māori children and young people, and Māori children and young people with lived experience of disability in the Ministry for Children's care and protection and youth justice residences. Nor is there any monitoring of the Crown's own practices of 'secure care' on Māori children and young people, and Māori children and young people with lived experience of disability within the Ministry for Children's residences.

There are also significant gaps in the data collection for identifying and addressing inequities in health and disability services and outcomes for both Māori and Māori with lived experience of disability who are imprisoned by the Crown. There is also an absence of the monitoring of the Crown's use of directed segregation on Māori with lived experience of disability, use of mechanical restraints on Māori, and Māori with lived experience of disability within prisons, or on Māori with lived experience of disability who are detained in regional forensic mental health services or care facilities, during their transportation to and from court appointments or medical appointments. The lack of any systems in place to monitor health and disability services and outcomes, or the described practices of Crown organisations within institutions where Māori children, young people, and adults make up the greatest proportion of the population, is of considerable concern.

⁹³³ Also refer to Waitangi Tribunal Research Question (8.c)/Wai 2575, #2.3.3 – 'To what extent have Crown acts or omissions if any contributed to disparities in disability services and outcomes between Māori and non-Māori and how are these recognised and addressed?'.

⁹³⁴ Bridget Robson and Ricci Harris, eds. *Hauora: Māori Standards of Health IV. A Study of the Years 2000-2005*, (Wellington: Te Rōpū Rangahau Hauora a Eru Pōmare, University of Otago, 2007).

With regard to the advancement of high quality research for Māori with lived experience of disability, the Health Research Council does not ring-fence funding for Māori health research on disability. This places Māori with lived experience of disability in the position of applying for contested funding, along with all other applicants (Māori and non-Māori), in an area where high quality research for Māori with lived experience of disability is greatly required.

The Crown has also previously identified the need for data quality improvement for disability issues. However, Action 9E of the *Disability Action Plan 2014–18*, which was intended to address this, was never completed and has instead been refocused. Additionally, poor data quality for Māori with lived experience of disability will be compounded by the disproportionate impacts that the Crown's poorly executed 2018 Census will have on Māori. This is because Census data are used for distribution of resources (for example, district health board funding), monitoring of the Crown's actions, and in the case of Iwi and Hapū affiliation in particular, used by Māori to support their own aspirations.

Overall, the findings of this report demonstrate that the disconnect between the Crown's contemporary ambitions,⁹³⁵ versus its actions and inactions, has had unjust and inequitable impacts on Māori with lived experience of disability. This continues the repeating patterns across the history of the colonisation of Aotearoa/New Zealand, which have devalued and diminished Māori with lived experience of disability in favour of Western models of disability, health and well-being, whilst constraining Māori self-determination.

⁹³⁵ The evidence of this disconnect historically is less clear as the Crown considered Māori with lived experience of disability (and other population groups) to be 'undesirables' at one stage, in which case Crown actions may have accurately reflected ambitions at the time. Refer to Chapter II.

Appendices

Appendix 1:
Memorandum-directions of Judge S R Clark

OFFICIAL

Wai 2575, #2.3.3

IN THE WAITANGI TRIBUNAL

Wai 2575

CONCERNING

the Treaty of Waitangi Act 1975

AND

the Health Services and
Outcomes Kaupapa Inquiry

MEMORANDUM-DIRECTIONS OF JUDGE S R CLARK

27 November 2018

Direction Commissioning Research

1. On 28 June 2018, I confirmed that the Tribunal would commission three separate research reports for stage two of the inquiry, including one on Māori with disabilities.¹
2. I have now been informed by Waitangi Tribunal Unit staff that in order to maximise efficiency and meet the June 2019 deadline for stage two research, it will be most useful to commission the report on Māori with disabilities in two parts. Both parts together will fulfil the scope of the report as originally planned. However, parts one and two will be commissioned and completed by separate authors.
3. Part one of the report will address the commission questions below. Part two will also have regard to these questions, but will draw primarily on oral interviews with claimants to fill the existing gap in primary source material relating to Whānau Hauā experiences. Part two will also provide a qualitative analysis and synthesis of key issues identified in claimant interviews.
4. This memorandum-directions commissions part one. A direction commissioning part two will be issued shortly.
5. Therefore, pursuant to clause 5A of the second schedule of the Treaty of Waitangi Act 1975, the Tribunal commissions Dr Paula King to prepare part one of a report on Māori with disabilities, for the Health Services and Outcomes Kaupapa Inquiry.
6. The researcher should focus on providing an outline of contemporary disability services relevant to Māori, how these are implemented, the impacts and outcomes for Māori, and Māori responses. Māori participation in legislation, governance and policy developments in respect to disability services should also be examined.
7. The researcher will provide a brief outline of significant historical developments relevant to the development of the current health system including Māori historical experiences of government disability services and how these may have contributed to any current barriers to service.
8. Utilising the four key topics identified in the pre-casebook discussion paper of disparities in outcomes for Māori with disabilities; accessibility of disability services for Māori; responsiveness of disability services to Māori; and effectiveness of disability services for Māori, where possible the overview will address:
 - (a) How does the contemporary health system, including legislation, policies and practices recognise and provide for the needs of Māori with disabilities? To what extent, if any, do implementation and outcomes diverge from policy objectives?
 - (b) To what extent does 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?
 - (c) To what extent have Crown acts or omissions if any contributed to disparities in disability services and outcomes between Māori and non-Māori and how are these recognised and addressed?
 - (d) What barriers, if any, do Māori experience in accessing disability services and what

¹ Wai 2575, #2.5.29 at [14].

are existing Crown policies and practices for recognising and addressing any such barriers?

- (e) How effective is current monitoring and data collection for identifying and addressing any disparities in disability services and outcomes for Māori?
 - (f) To what extent have Māori had opportunities to contribute to relevant policy and legislative developments?
 - (g) What key historical developments have contributed to the current system of government disability services for Māori and to Māori experiences and attitudes to disability services?
9. The completed report draft will be made available to parties for feedback by 30 April 2019 to be followed by quality assurance and final revision with the final report filed by 28 June 2019. An electronic copy of the report and supporting documentation should be submitted to the Registrar in Word or PDF file format.

The Registrar is to send this direction to all those on the notification list for Wai 2575, the Health Services and Outcomes Kaupapa Inquiry.

DATED at Hamilton this 27th day of November 2018



Judge S R Clark
Presiding Officer

WAITANGI TRIBUNAL

Appendix 2: Supplementary table (a): Mapping Waitangi Tribunal research questions to research objectives

Waitangi Tribunal research question ⁹³⁶	Research objectives ⁹³⁷
<p>Directive 6</p> <p>The researcher should focus on providing an outline of contemporary disability services relevant to Māori, how these are implemented, the impacts and outcomes for Māori, and Māori responses. Māori participation in legislation in relation to disability services should also be examined.</p>	<p>Objective 2</p> <p>To provide an outline of contemporary health and disability services relevant to Māori with lived experience of disability, including how these are implemented, impacts and outcomes for Māori and Māori responses, examining how legislation, policies and practices, recognise and provide for the needs of Māori with lived experience of disability, and the extent to which, if any, implementation and outcomes diverge from policy objectives.</p> <p>Objective 3</p> <p>To identify the extent to which Māori with lived experience of disability have had opportunities to participate in relevant policy and legislative developments, and health and disability governance.</p>
<p>Directive 7</p> <p>The researcher will provide a brief outline of significant historical developments relevant to the development of the current health system including Māori historical experiences of government disability services and how these may have contributed to any current barriers to service.</p>	<p>Objective 1</p> <p>To describe the key historical developments that have contributed to the development of the current system of government health and disability services for Māori with lived experience of disability, and to Māori historical and contemporary experiences of, and views toward health and disability services, examining how these may have contributed to barriers to service.</p>
<p>Research Question 8(a)</p> <p>How does the contemporary health system, including legislation, policies and practices recognise and provide for the needs of Māori with disabilities? To what extent, if any, do implementation and outcomes diverge from policy objectives?</p>	<p>Objective 2</p> <p>To provide an outline of contemporary health and disability services relevant to Māori with lived experience of disability, including how these are implemented, impacts and outcomes for Māori, and Māori responses, examining how legislation, policies and practices, recognise and provide for the needs of Māori with lived experience of disability, and the extent to which, if any,</p>

⁹³⁶ Outlined in Appendix 1.

⁹³⁷ Outlined in Chapter 1.

Waitangi Tribunal research question ⁹³⁶	Research objectives ⁹³⁷
	implementation and outcomes diverge from policy objectives.
<p>Research Question 8(b)</p> <p>To what extent does 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?</p>	<p>Objective 4</p> <p>To examine the extent to which health and disability policies and practices provide culturally appropriate health and disability services for Māori with lived experience of disability, or provide for Māori led and developed systems and methods of health and disability care.</p>
<p>Research Question 8(c)</p> <p>To what extent have Crown acts or omissions if any contributed to disparities in disability services and outcomes between Māori and non-Māori and how are these recognised and addressed?</p>	<p>Objective 5</p> <p>To identify the extent to which, if any, Crown action, inaction or omissions have contributed to inequities in services and outcomes for Māori with lived experience of disability compared with non-Māori, and how these have been recognised and addressed.</p>
<p>Research Question 8(d)</p> <p>What barriers, if any, do Māori experience in accessing disability services and what are existing Crown policies and practices for recognising and addressing any such barriers?</p>	<p>Objective 6</p> <p>To identify any barriers to the accessibility of, responsiveness to, and effectiveness of, services for Māori with lived experience of disability, and existing Crown policies and practices for recognising and addressing any such barriers.</p>
<p>Research Question 8(e)</p> <p>How effective is current monitoring and data collection for identifying and addressing any disparities in disability services and outcomes for Māori?</p>	<p>Objective 7</p> <p>To examine how effective, the current monitoring and data collection is, for identifying, and addressing, inequities in services and outcomes for Māori with lived experience of disability.</p>
<p>Research Question 8(f)</p> <p>To what extent have Māori had opportunities to contribute to relevant policy and legislative developments?</p>	<p>Objective 3</p> <p>To identify the extent to which Māori with lived experience of disability have had opportunities to participate in relevant policy and legislative developments, and health and disability governance.</p>

Research Question 8(g)

What key historical developments have contributed to the current system of government disability services for Māori and to Māori experiences and attitudes to disability services?

Objective 1

To describe the key historical developments that have contributed to the development of the current system of government health and disability services for Māori with lived experience of disability, and to Māori historical and contemporary experiences of, and views toward health and disability services, examining how these may have contributed to barriers to service.

Appendix 3: PsychInfo and Medline search strategy⁹³⁸

1. birth*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonym]

2. gestation*.mp.

3. health*.mp.

4. well-being.mp.

5. wellbeing.mp.

6. impair*.mp.

7. disab*.mp.

8. identi*.mp.

9. chronic.mp.

10. disease*.mp.

11. illness*.mp.

12. sensory.mp.

13. physical*.mp.

⁹³⁸ The search strategy was amended as required for the other databases searched.

14. intellect*.mp
15. cognit*.mp.
16. develop*.mp.
17. learn*.mp.
18. comm*.mp.
19. neurodis*.mp.
20. neuro-dis*.mp.
21. "neuro dis".mp.
22. neuro*.mp.
23. vis*.mp.
24. blind*.mp.
25. asper*.mp.
26. "fetal alcohol".mp.
27. FASD.mp.
28. autis*.mp.
29. ASD.mp.
30. arthri*.mp.

31. rheum*.mp.
32. congen*.mp.
33. cerebr*
34. stroke*
35. injur*.mp.
36. rehab*.mp.
37. deaf*.mp.
38. hear*.mp.
39. distress.mp.
40. stress.mp.
41. depressi*.mp.
42. anxi*.mp.
43. ((social* or behav* or emotio* or develop* or psych*) and (difficul* or problem* or delay* or adjust*)).mp.
44. self-esteem.mp.
45. "self esteem".mp.
46. "life satisfaction".mp.

47. "quality of life".mp.
48. resilien*.mp.
49. alcohol.mp.
50. tobacco.mp.
51. smok*.mp.
52. "substance use".mp.
53. drug*.mp.
54. medic*.mp.
55. elder*.mp.
56. older*.mp.
57. child*.mp.
58. (youth or "young people" or "young person").mp.
59. carer*.mp
60. famil*.mp
61. (whanau or whānau).mp
62. institution*.mp.
63. hous*.mp.

64. edu*.mp.
65. employ*.mp.
66. income.mp.
67. (health and (care or service* or clinic* or support)).mp.
68. (disabl* and (care or service* or clinic* or support)).mp.
69. (discrim* or bias or prejud* or hostil* or harass* or bully* or “unfair treat*” or oppress*).mp. or exp Prejudice/ or exp RACISM/
70. (rac* or ethnic* or cultur* or religio* or migra* or immigra* or refugee*).mp. or exp Ethnic Groups/ or exp Minority Groups/
71. (longit* or cohort* or trial* or “follow up” or prospective or retrospective or “cross section*” or cross-section* or intervention* or quantitative or survey* or “case-control” or “case control” or “randomised control* trial*” or “randomized control* trial*” or “before and after” or “interrupted time series” or questionnaire* or registr* or evaluat* or audit*).mp.
72. exp Longitudinal Studies/
73. exp Epidemiologic Research Design/
74. exp Randomized Controlled Trials as Topic/
75. exp EPIDEMIOLOGIC STUDIES/
76. exp REGISTRIES/
77. exp QUALITATIVE RESEARCH/

78. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77

79. (indigen* or aborigin* or "first nation" or native or maori or māori).mp.

80. 79 and 80

Appendix 4: Template email for Crown organisation Official Information Act requests

To: OIA contact on website

CC: Agency contacts provided by Crown Law where relevant

Kia ora,

I am working with Dr Paula King who has been commissioned by the Waitangi Tribunal to complete a research report on disabled Māori. This report will contribute to stage two of the Tribunal's kaupapa inquiry into health services and outcomes (Wai 2575).

You can access the commissioning directions for this research from the Tribunal online [here](#).

The following information request is designed to support us to answer the research questions, which cover policy and services for disabled Māori, how they've been implemented and impacts and outcomes for Māori. Māori participation in legislation, governance and policy developments in respect to disability services will also be examined.

Information requested under the Official Information Act

[questions for each Crown organisation inserted here]

Nāku noa, nā

Gabrielle Baker

Appendix 5: Analysis of DHB responses to OIA requests by question (as at 31 March 2019)

Appendix 6: Index of supplementary information provided to the researcher under the OIA – Responses from Agencies⁹³⁹

Index number	Agency, type of response
1	Ministry of Health, response one
1a	Ministry of Health, response two – cover letter
1b	Ministry of Health, response two – main response
1f	Ministry of Health, response three – cover letter
1g	Ministry of Health, response three – main response
1h	Ministry of Health, response 3 – appendix, Te Ao Mārama minutes April 2017
1ij	Ministry of Health, response 3 – appendix, Te Ao Mārama minutes July 2017
1j	Ministry of Health, response 3 – appendix, Te Ao Mārama minutes March 2018
1k	Ministry of Health, response 3 – appendix, Te Ao Mārama minutes June 2018
1ka	Ministry of Health, response 3 – appendix, Te Ao Mārama minutes October 2018
1l	Ministry of Health, response 3 – appendix, DHB correspondence IDDCR (5)
1m	Ministry of Health response 3 – appendix DHB correspondence IDDCR (4)
1n	Ministry of Health response 3 – appendix DHB correspondence IDDCR (3)
1o	Ministry of Health response 3 – appendix DHB correspondence IDDCR (2)
1p	Ministry of Health response 3 – appendix DHB correspondence IDDCR (1)
1z	Ministry of Health response – mental health seclusion report

⁹³⁹ Excluding district health boards, for their responses refer to Appendix 7.

Index number	Agency, type of response
1za	Ministry of Health – further response and clarification
1zb	Ministry of Health – further clarification NKG membership
1zc	Ministry of Health – clarification on restraint reporting to PRIMHD
2	Health and Disability Commissioner, main response
3	Health Promotion Agency, cover letter
3a	Health Promotion Agency, main response
4	Te Puni Kōkiri, main response
5	Health Quality and Safety Commission, response one
5a	Health Quality and Safety Commission, response one – attachment Marae agenda May 2016
5b	Health Quality and Safety Commission, response one – attachment Marae agenda June 2017
5c	Health Quality and Safety Commission, response one – attachment Marae agenda August 2018
5d	Health Quality and Safety Commission, response one – attachment tikanga August 2018
5e	Health Quality and Safety Commission, response one – attachment PMMRC agenda 29.10.18
5f	Health Quality and Safety Commission, response one – attachment MRC Māori caucus terms of reference
5g	Health Quality and Safety Commission, response one – attachment Te Whai Oranga
5h	Health Quality and Safety Commission, response one – attachment Treaty of Waitangi in Health (February 2017)
5i	Health Quality and Safety Commission, response one – attachment Treaty in Health evaluation
5j	Health Quality and Safety Commission, response one – attachment MRC Māori rubric workshop agenda
5k	Health Quality and Safety Commission, response one – attachment beginners Te Reo handbook

Index number	Agency, type of response
5l	Health Quality and Safety Commission, response one – attachment Hotaka Kura Reo
5m	Health Quality and Safety Commission, response one – attachment anti racism praxis
5n	Health Quality and Safety Commission, response one – attachment HEAT workshop
5x	Health Quality and Safety Commission, response two
5z	Health Quality and Safety Commission, response three
6	Health Research Council, main response
7	NZ Artificial Limb Service, main response
7a	NZ Artificial Limb Service – attachment, clinical governance policy
7b	NZ Artificial Limb Service – attachment, medical device prescription policy final draft
7c	NZ Artificial Limb Service – attachment, rehabilitation policy
7d	NZ Artificial Limb Service – attachment, future design ethos
8	NZ Blood Service, main response
9	PHARMAC, main response
9a	PHARMAC – attachment, Te Whaioranga Strategy
9b	PHARMAC – attachment, Te Ara Poutama Reference Book
9c	PHARMAC – attachment, Lifeline – Te Whaioranga
10	ACC, main response
10a	ACC – appendix, Statement of Intent
10b	ACC – appendix, Māori services underutilisation

Index number	Agency, type of response
10c	ACC – appendix, Māori barriers to utilisation
10d	ACC – appendix, Whaia Te Tika
10e	ACC – appendix, Whaia Te Tika stocktake
10f	ACC – appendix, privacy and ethics threshold analysis
10g	ACC – appendix, diversity and inclusion strategy
10h	ACC – appendix, diversity and inclusion information
10j	ACC – appendix, Board training material
10k	ACC – appendix, WAI research rehab evaluation
10m	ACC – appendix, kaumatuatanga
10n	ACC – appendix, use of technology by disabled people
10o	ACC – appendix, Māori utilisation of ACC
15	Office for Disability Issues, response one
15a	Office for Disability Issues, response two
16	Department of Corrections, main response
16a	Department of Correction, appendices
16b	Department of Correction, response
17	Oranga Tamariki–Ministry for Children, main response

Appendix 7: Index of supplementary information provided to the researcher under the OIA – Responses from district health boards (DHB)

Index number	DHB, type of response
1	Auckland and Waitemata DHBs, main response
1x	Auckland and Waitemata DHBs, response two
2	Bay of Plenty DHB, main response
2a	Bay of Plenty DHB, attachment – terms of reference
2b	Bay of Plenty DHB, attachment – CPHAC-DSAC terms of reference
2c	Bay of Plenty DHB, attachment – BOPHAC terms of reference
2e	Bay of Plenty DHB, attachment – BOPALT terms of reference
2f	Bay of Plenty DHB, attachment – HSC terms of reference
2g	Bay of Plenty DHB, attachment Q8
2x	Bay of Plenty DHB, response two
3	Canterbury DHB, main response
4	Capital and Coast DHB, main response
5	Counties Manukau DHB, main response
5x	Counties Manukau DHB, response two
5y	Counties Manukau DHB, attachment HIT Equity Identifier
6	Hawke's Bay DHB, main response

Index number	DHB, type of response
6a	Hawke's Bay DHB, attachment - 2018 Annual Report
6b	Hawke's Bay DHB, attachment – 2018 Health Inequities
6c	Hawke's Bay DHB, attachment – People Plan
6d	Hawke's Bay DHB, attachment – privacy policy
6e	Hawke's Bay DHB, attachment – consumer participation policy
6f	Hawke's Bay DHB, attachment – Transform and Sustain
6g	Hawke's Bay DHB – clarification
6k	Hawke's Bay DHB – further clarification
6l	Hawke's Bay DHB – third clarification
7	Hutt Valley DHB, main response
7a	Hutt Valley DHB, attachment – Draft Māori Health Strategy
7b	Hutt Valley DHB, attachment – Framework for involving whānau-families
7c	Hutt Valley DHB, attachment – Guidelines for the care of Māori patients
7d	Hutt Valley DHB, attachment – Māori health unit presentation
7e	Hutt Valley DHB, attachment – Recognising community participation policy
7f	Hutt Valley DHB, attachment – Whānau Family participation policy
8	Lakes DHB main response
8a	Lakes DHB, attachment – Kairangi (current)
8b	Lakes DHB, attachment – HDC DVD text

Index number	DHB, type of response
8c	Lakes DHB, attachment – Te Tiriti o Waitangi Policy
8d	Lakes DHB, attachment – Fees and expenses policy
8x	Lakes DHB, response two
9	MidCentral DHB, main response
9a	MidCentral DHB, attachment – training attendance
9b	MidCentral DHB, attachment – Tikanga guidelines (draft)
9c	MidCentral DHB, attachment – Consumer council appoints five new members
9x	MidCentral DHB, response two
10	Nelson Marlborough DHB, main response
10x	Nelson Marlborough DHB, response two
11	Northland DHB, main response
11a	Northland DHB, attachment – service specifications
11b	Northland DHB, attachment – Cabinet paper on fees
11c	Northland DHB, attachment – Disability support options analysis
11d	Northland DHB, attachment – Consumer Council TOR
11e	Northland DHB, attachment – Consumer Council Resource Kit
11f	Northland DHB, attachment – NDHB Disability Support Options Paper
11g	Northland DHB, attachment – Māori Health Plan
11h	Northland DHB, attachment – MoH Service specification

Index number	DHB, type of response
11i	Northland DHB, attachment – service specification
11j	Northland DHB, attachment – homebased support
11k	Northland DHB, attachment – info on consultant
11l	Northland DHB, attachment – Te Reo o te Iwi report
11m	Northland DHB, attachment – Annual Report
11w	Northland DHB, response two
11x	Northland DHB, attachment – PHU annual plan 2018
12	South Canterbury DHB, part one response
13	Southern DHB, main response
13x	Southern DHB, response two
14	Tairāwhiti DHB, main response
14x	Tairāwhiti DHB, response two
15	Taranaki DHB, main response
15x	Taranaki DHB, response two
16	Waikato DHB, main response
16a	Waikato DHB, follow up email
16b	Waikato DHB, additional response
17	Wairarapa DHB, initial response
17a	Wairarapa DHB, main response

Index number	DHB, type of response
19	West Coast DHB, main response
20	Whanganui DHB, main response
20a	Whanganui DHB, attachment
20b	Whanganui DHB, attachment, Long term contract
20c	Whanganui DHB, attachment, Board training programme
20x	Whanganui DHB, response two

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