Te Kāwanatanga o Aotearoa
New Zealand Government

Provisional Health of Disabled People Strategy

2023

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Minister's foreword

As Minister of Health, I am proud to present this Provisional Health of Disabled People Strategy: the first dedicated, health-system-led strategy for disabled people in Aotearoa New Zealand.

The Provisional Health of Disabled People Strategy (the provisional strategy) sets the direction and long-term priorities to move towards achieving equity in disabled people's health and wellbeing outcomes over the next 10 years. It will contribute to the transformation of the health system by providing a framework that health entities can follow to improve disabled people's health and wellbeing outcomes in Aotearoa New Zealand.

The provisional strategy gives effect to Te Tiriti o Waitangi | the Treaty of Waitangi and is underpinned by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). It also builds upon and draws from other work, such as the New Zealand Disability Strategy 2016–2026, the Disability Action Plan 2019–2023, Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan, the Healthy Ageing Strategy and Enabling Good Lives.

We know disabled people experience poorer health and wellbeing, including both physical and mental health outcomes, compared with non-disabled people. Inequities in health outcomes are acutely felt by specific communities within the broader disabled population, particularly tāngata whaikaha Māori. Despite this, disabled people and their whānau continue to demonstrate their strengths and resiliencies in advocating for and meeting their own health and wellbeing needs, especially where the health system has failed to do so.

This provisional strategy was developed following face-to-face, online and written engagement with disabled people and their whānau. Through such engagement, we heard the importance of providing an equitable, accessible and culturally safe health system for disabled people and their whānau that enables autonomy and agency. We also heard that the health and wellbeing of disabled people and their whānau includes broader factors, such as housing and education. These insights led to the shaping of this strategy's five priority areas. I recognise and sincerely thank everyone who shared their valuable contributions.

The strategy is being published in a provisional form to enable further targeted engagement with the disability community and shaping of priorities as we continue to shift the health system towards achieving pae ora | healthy futures for disabled people and their whānau.

I acknowledge that there is more to do to achieve this vision for disabled people and their whānau. The Provisional Health of Disabled People Strategy offers a strategic pathway to ensure we are moving in the right direction.

Hon Dr Ayesha Verrall
Minister of Health

Acknowledgements

Our gratitude and acknowledgements to the disabled people and their whānau and the disability groups, communities and organisations that have shared or gathered insights about, experiences of and aspirations regarding the health and wellbeing of disabled people with the Crown for many years, including through the engagement on the pae ora strategies.

The contribution from each individual, whānau, group, organisation and community throughout this process has been greatly appreciated.

We acknowledge all who continue to advocate for healthier futures for disabled people and their whānau in Aotearoa New Zealand.

Glossary

Ethnic communities[1]	People who identify their ethnicity as African, Asian, Continental European, Latin American or Middle Eastern. Ethnic communities also include former refugees, asylum seekers, new and temporary migrants, long-term settlers and multi-generational New Zealanders.
Disability	Includes long-term physical, mental, intellectual or sensory impairments that, in interaction with various barriers, may hinder the full and effective participation of disabled people in society on an equal basis with others (UN 2006).
Disability community	Includes disabled people and their whānau, partners, friends, relatives, unpaid carers and others directly involved in informal support for disabled people as determined by disabled people. This includes advocacy/consumer organisations comprising and representing disabled people (Office for Disability Issues 2022).
Tagata sa'ilimalo	A term of identity to replace 'Pacific disabled people, their families, and carers (Tōfā Mamao Collective 2022).
Tāngata whaikaha Māori	An umbrella term to refer to Māori who are disabled and their whānau (including whānau hāpai, or supports for whānau). Whaikaha means to have strength, to have ability and to be enabled.[2]
Whānau hāpai	Supports for whānau of disabled people.

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[1] The Ministry for Ethnic Communities defines "ethnic communities" as people who identify their ethnicity as African, Asian, Continental European, Latin American or Middle Eastern. They also include former refugees, asylum seekers, new and temporary migrants, long-term settlers and multi-generational New Zealanders. This definition is adopted throughout the Provisional Health of Disabled People Strategy when referring to ethnic communities.

[2] In 2016, founding member of the Māori Disability Leadership Group, Maaka Tibble said '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' (Whaikaha 2023b).

Contents

List of Figures

List of Tables

Executive summary

The Provisional Health of Disabled People Strategy (the provisional strategy) is one of six health strategies required under the Pae Ora (Healthy Futures) Act 2022. The other five are: the New Zealand Health Strategy, Pae Tū: Hauora Māori Strategy, Te Mana Ola: The Pacific Health Strategy, Women's Health Strategy and Rural Health Strategy. Together, these strategies provide a framework for achieving pae ora | healthy futures for all New Zealanders.

This provisional strategy sets the direction and long-term priorities for achieving equity in disabled people's health and wellbeing outcomes over the next 10 years. The strategy gives effect to Te Tiriti o Waitangi | the Treaty of Waitangi and is underpinned by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). It also builds on and draws from other work, such as the New Zealand Disability Strategy 2016–2026, the Disability Action Plan 2019–2023 (Office for Disability Issues 2016, 2019), Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan (Ministry of Health 2018), the Healthy Ageing Strategy 2016 (Associate Minister of Health 2016) and Enabling Good Lives (EGL).

We developed the Provisional Health of Disabled People Strategy after engaging with disabled people and their whānau, assessing disabled people's health outcomes and health sector performance and considering population health trends. We are publishing the strategy in a provisional form to allow for further targeted engagement with the disability community and shaping of priorities.

Disabled people make up a significant and diverse part of Aotearoa New Zealand. In the last national Disability Survey, from 2013, a total of 1.1 million people (24% of the population) were identified as disabled (Stats NZ 2014).[3] Disabled people experience poorer health, including both physical and mental health outcomes, compared with non-disabled people. Inequities in health outcomes are acutely felt by specific communities within the broader disabled population, particularly tāngata whaikaha Māori, as well as tagata sa'ilimalo and disabled people from Rainbow communities.

The provisional strategy identifies five key priority areas for the health system to focus on to achieve pae ora | healthy futures for disabled people and their whānau.

- **Priority 1:** Embed self-determination of disabled people and their whānau as the foundation of a person and whānau-centred health system.
- **Priority 2:** Ensure the health system is designed by and accessible for disabled people and their whānau and provides models of care that suit their needs.
- **Priority 3:** Ensure the health system is part of a coherent cross-government system that addresses broader drivers of poor health and wellbeing.
- **Priority 4:** Build health workforce capacity and capability to meet the needs of disabled people and their whānau.

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[3] Stats NZ was developing the 2023 Disability Survey as this provisional strategy was being prepared. We expect to update the strategy with data from the latest survey when it becomes available.

- **Priority 5:** Increase the visibility of disabled people in health data, research and evidence as part of an active learning system.

Implementing and monitoring the provisional strategy will involve setting shorter-term priorities for the Government Policy Statement (GPS) and New Zealand Health Plan (NZHP) which link to strategic objectives, and engaging in more targeted ways with the disability community to develop a final strategy.

Figure 1: Provisional Health of Disabled People Strategy

Purpose
To set the direction and long-term priorities to achive equity in disabled people's health and wellbeing outcomes over the next ten years.

Vision
Pae ora | healthy futures for disabled people and their whānau

Strategic alignment

- Te Tiriti o Waitangi
- Pae Ora Act (Healthy Futures) Act 2022
- UNCRPD
- New Zealand Disability Strategy 2016–26

Current state

- 1.1 million people are identified as disabled (24% of Aotearoa New Zealand's population). 370,000 are aged 65 years or over.
- Māori and Pacific peoples have higher disability rates than non-Māori, non-Pacific peoples.
- Disabled people have higher mortality and lower life expectancy than non-disabled people.
- Disabled people experience higher rates of unmet need for health care due to cost and transport.

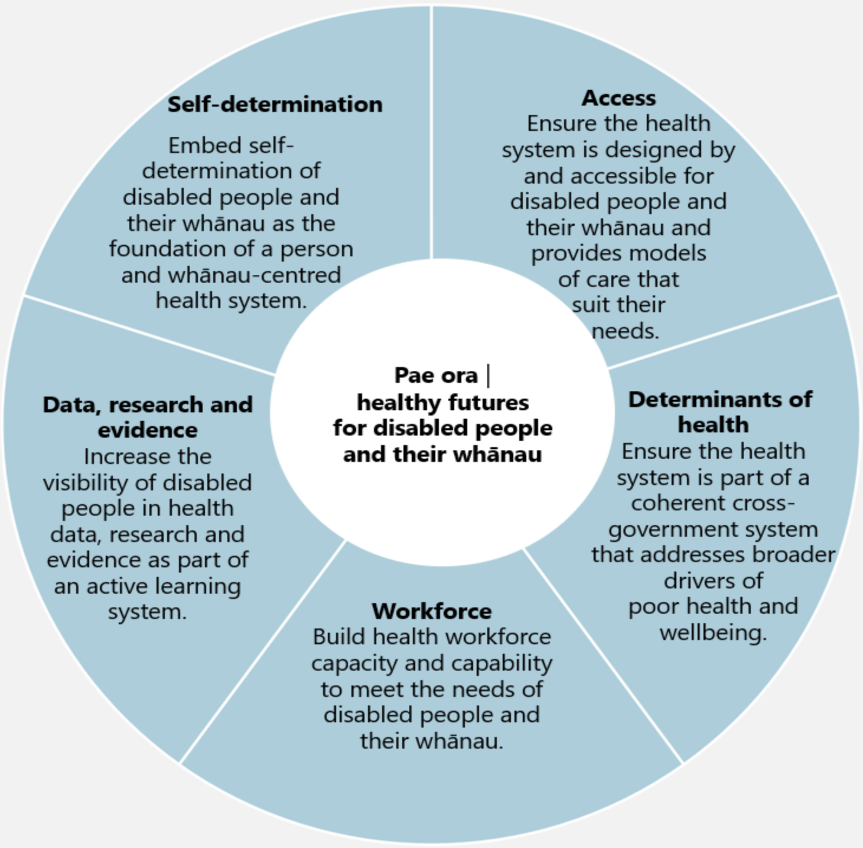
Engagement and development
We developed the priority areas through analysis of:

- approximately 29 meetings and workshops with disabled people and their whānau
- over 50 written submissions
- existing engagements between disabled people and their whānau and the Crown.

Themes from engagement

- Disabled people want to be heard in the health system and in control of their own health.
- Tāngata whaikaha Māori and their whānau want the health system to be more responsive to their needs and aspirations.
- Disabled people and their whānau want better access to supportive, community-based primary and preventative health care.
- Disabled people and their whānau want a health system that facilitates access to wider services and supports to address broader drivers of poor health and wellbeing.
- Disabled people want to see themselves represented in a health workforce that is better equipped to meet their health and wellbeing needs.
- Disabled people want to be visible in the health system.

Priority areas for the health system



Pae ora | healthy futures for disabled people and their whānau

Self-determination
Embed self-determination of disabled people and their whānau as the foundation of a person and whānau-centred health system.

Access
Ensure the health system is designed by and accessible for disabled people and their whānau and provides models of care that suit their needs.

Determinants of health
Ensure the health system is part of a coherent cross-government system that addresses broader drivers of poor health and wellbeing.

Workforce
Build health workforce capacity and capability to meet the needs of disabled people and their whānau.

Data, research and evidence
Increase the visibility of disabled people in health data, research and evidence as part of an active learning system.

Introduction

Purpose of the Provisional Health of Disabled People Strategy

> We are children, young people and adults, we are parents and grandparents. We are also friends, family and whānau. What we want is no different to anyone else in New Zealand; we want to belong, contribute to our families and whānau and participate in our communities. We are 1.1 million New Zealanders, and we represent almost a quarter (24 percent) of New Zealand's population. (Office for Disability Issues 2016)

The Provisional Health of Disabled People Strategy (the provisional strategy) is the first dedicated, health-system-led strategy for disabled people in Aotearoa New Zealand. It sets the direction and long-term priorities for achieving equity in disabled people's health and wellbeing outcomes over the next 10 years. The provisional strategy will contribute to the transformation of the health system by providing a framework to guide health entities[4] to improve disabled people's health and wellbeing outcomes in Aotearoa New Zealand.

The provisional strategy is one of six health strategies required under the Pae Ora (Healthy Futures) Act 2022 (the Pae Ora Act). The Pae Ora Act lays the foundation for the transformation of our health system to support all New Zealanders to live longer and have the best possible quality of life by:

- protecting, promoting and improving the health of all New Zealanders
- achieving equity in health outcomes among Aotearoa New Zealand's population groups, including by striving to eliminate health disparities for Māori
- building towards pae ora | healthy futures for all New Zealanders.

The provisional strategy builds on and reflects the higher-level priorities set in Pae Tū: Hauora Māori Strategy and the New Zealand Health Strategy.

The Provisional Health of Disabled People Strategy sets out priorities for improving health and wellbeing, including accessible and community-based primary and preventative health services, addressing the broader determinants of health[5] and health workforce development.

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[4] Section 4 of the Pae Ora (Healthy Futures) Act 2022 defines 'health entities' as Te Whatu Ora | Health New Zealand, Health Quality and Safety Commission, Te Aka Whai Ora | Māori Health Authority, Pharmac and the New Zealand Blood and Organ Service.

[5] The broader determinants of health are a range of social, economic and environmental factors that represent the wider forces in the environments in which people are born, grow up, live, learn, work and age that have a significant influence on health and wellbeing outcomes (Ministry of Health 2023a).

We developed the priorities by engaging with disabled people and their whānau, assessing disabled people's health outcomes and health sector performance and considering population health trends. We received over 50 written submissions and engaged in approximately 29 meetings and workshops with disabled people and their whānau.

This strategy is being published in a provisional form to allow for further targeted engagement with the disability community and further shaping of priorities.

The Provisional Health of Disabled People Strategy recognises the special relationship between New Zealand and countries of the Realm in the Pacific – the territory of Tokelau, and the self-governing states of the Cook Islands and Niue. In recognition of New Zealand's obligations to Realm countries and as citizens of New Zealand, the strategy includes these Pacific peoples when in New Zealand.

The structure of this strategy

- **Part 1** describes a long-term vision for the health of disabled people and identifies the key drivers underpinning that vision.
- **Part 2** provides an assessment of the current state of the health of disabled people and the health system itself, drawing on engagement carried out to develop this strategy.
- **Part 3** identifies the five priority areas where changes are needed to achieve our vision and indicates the types of change required over the next 10 years.
- **Part 4** describes the next steps for how these changes can be delivered, including how the strategic direction will be translated into actions for entities.

A definition of 'pae ora for Māori' is included in the **appendix**.

Part 1: Our vision of pae ora | healthy futures for disabled people and their whānau

Our vision

Our vision is to achieve pae ora | healthy futures for all disabled people and their whānau in Aotearoa New Zealand. These are futures in which all disabled people and their whānau live long, fulfilling and more independent lives in good health.

Pae ora is a holistic concept of health and wellbeing. This means it considers all the broad factors and contexts that influence people's health and wellbeing throughout their lives.

Achieving pae ora | healthy futures means disabled people and their whānau are part of healthy and inclusive communities, live in environments that enhance their quality of life and are supported to maintain their health and wellbeing. This support will be provided by an equitable and fully accessible health system that considers all factors influencing the health and wellbeing of disabled people and their whānau.

To achieve this vision, we must work collaboratively with disabled people and their whānau, with iwi, hapū and Māori communities, Pacific communities, other communities our health system serves, and the wider organisations and agencies that contribute to the health and wellbeing of disabled people and their whānau.

Who this strategy is for

This strategy is for all who identify as, or provide support to, disabled people[6] in Aotearoa New Zealand. It is also for those who may not identify as disabled but can see their lived experiences reflected in the strategy.[7]

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[6] While we acknowledge some people prefer to use other terms, including 'people with disability', we use the term 'disabled people' in this strategy to align with the New Zealand Disability Strategy 2016–2026 (Office for Disability Issues 2016).

[7] For example, we acknowledge that many Deaf people identify as being part of the Deaf community and do not always identify as being disabled. Likewise, people with disabling mental health conditions may identify with the mental health community and not the disability community (Office for Disability Issues 2016).

The strategy acknowledges that for both tāngata whenua and non-Māori New Zealanders, the health system approach to disability is something experienced both by the individual and the wider whānau and support networks.

Whānau and wider support networks play a vital role in supporting and making real a disabled person's independence and aspirations. Thus we have used the term 'disabled people and their whānau' throughout the provisional strategy to encapsulate this collective approach to disabled people's health. The strategy also recognises the overlap between disability and ageing for both individuals and their whānau.

This strategy uses the term 'tāngata whaikaha Māori' as an umbrella term to refer to Māori who are disabled and their whānau (including whānau hāpai).[8] Whaikaha means to have strength, to have ability and to be enabled.[9] We acknowledge that other terms are used by tāngata whaikaha Māori and their whānau, including 'whānau hauā'. This provisional strategy includes terminologies defined by Māori that reflect, strengthen and validate Māori cultural identity, language, values, principles, practices, lineages and links to the land.

Our commitment to Te Tiriti o Waitangi

The health sector is committed to fulfilling the special relationship between Māori and the Crown under Te Tiriti o Waitangi | the Treaty of Waitangi (Te Tiriti). From the text of Te Tiriti and declarations made during its signing, it is clear that the Crown, as kaitiaki and steward of the health system (under article 1 of Te Tiriti), has a duty to enable Māori to exercise authority over their health and wellbeing (under article 2) and achieve equitable health outcomes (under article 3) in ways that enable them to live, thrive and flourish as Māori (Ritenga Māori declaration) (see Ministry of Health 2020b).

The Crown's approach to meeting its obligations under Te Tiriti is outlined in section 6 of the Pae Ora Act. The legislation contains specific provisions intended to give effect to the Crown's obligations. In particular, the health sector principles in section 7 of the Pae Ora Act guide the Minister of Health, Manatū Hauora | the Ministry of Health (Manatū Hauora) and all health entities in how to carry out their functions. The health sector principles incorporate key outcomes and behaviours derived from the principles of Te Tiriti, as articulated by the courts and the Waitangi Tribunal, including:

- **tino rangatiratanga**: providing for Māori self-determination and mana motuhake in the design, delivery and monitoring of health services
- **equity**: being committed to achieving equitable health outcomes for Māori

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[8] The term tāngata whaikaha is used in *Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan* (Ministry of Health 2018) and is included as part of *Te Reo Hāpai – The Language of Enrichment*, a Māori language glossary for use in the mental health, addiction and disability sectors~~,~~ (Te Pou o Te Whakaaro Nui 2020).

[9] In 2016, founding member of the Māori Disability Leadership Group, Maaka Tibble said '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' (Whaikaha 2023b).

- **active protection**: acting to the fullest extent practicable to achieve equitable health outcomes for Māori (This includes ensuring the Crown, its agents and its Te Tiriti partner are well informed on the extent, and nature, of both Māori health outcomes and efforts to achieve Māori health equity.)
- **options**: providing for and properly resourcing kaupapa Māori health services (Furthermore, the Crown is obliged to ensure all health services are provided in a culturally appropriate way that recognises and supports the expression of hauora Māori models of care.)
- **partnership**: working in partnership with Māori in the governance, design, delivery and monitoring of health services – Māori must be co-designers, with the Crown, of the primary health system for Māori.

These principles[10] are central to achieving our vision of pae ora | healthy futures for Māori. Pae ora has a special meaning for Māori, and includes the following three inter-connected elements (A more detailed definition of the term is provided in the **appendix**).

- **Mauri ora (healthy individuals)** seeks to shift the mauri (or life force) of a person from one that is languishing to one that is flourishing.
- **Whānau ora (healthy families)** is a fundamental philosophy for creating strong, healthy and empowered whānau. A strong, healthy and empowered whānau can make the most significant difference to Māori health and wellbeing.
- **Wai ora (healthy environments)** acknowledges the importance of Māori connections to whenua as part of the environments in which we live and belong – and the significant impact this has on the health and wellbeing of individuals, whānau, hapū, iwi and Māori communities.

Our commitment to Te Tiriti o Waitangi and priorities for hauora Māori are described in greater detail in Pae Tū: Hauora Māori Strategy published in tandem with this document.

Wider strategic and international context underpinning the vision

This strategy is underpinned by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which Aotearoa New Zealand ratified in 2008. The strategy uses a social model approach to disability. It also builds on and draws from other work, such as the New Zealand Disability Strategy 2016–2026 and Disability Action Plan 2019–2023 (Office for Disability Issues 2016, 2019), Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan (Ministry of Health 2018), the Healthy Ageing Strategy (Associate Minister of Health 2016) and Enabling Good Lives (EGL).

The UNCRPD describes disability as including 'long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder [the] full

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[10] The principles were recommended in the Waitangi Tribunal's *Hauora* report (Waitangi Tribunal 2019).

and effective participation [of disabled people] in society on an equal basis with others' (UN 2006, Article 1: Purpose, page 3).

This social model approach to disability maintains that it is environments and attitudes that disable people with impairments, not the impairment itself. By adopting a social model approach to disability in this provisional strategy, we are seeking to move towards a health system that supports a rights-based approach to health service delivery and considers all factors that influence people's health and wellbeing. We also recognise that the health system itself can be disabling for disabled people and seek to move towards a system that is enabling.

The EGL principles underpin this strategy, focusing on the principles of self-determination, early intervention (focusing on preventative health care in the community for individuals and whānau) and developing a health system that supports an aspirational approach for adults and children. This approach aligns with that of Whāia Te Ao Mārama (Ministry of Health 2018).

What meeting this vision looks like for disabled people and their whānau

Achieving the vision of pae ora | healthy futures for disabled people and their whānau means that disabled people and their whānau have voice, choice and independence in their health care. Specifically:

- the experiences and voice of disabled people and their whānau are heard, respected and validated by health professionals and decision makers
- people have autonomy and agency over their health, wellbeing and care
- the health system is easy to navigate and access, with support for disabled people and whānau to access services where needed (including health services specific to disability as well as all other health services)
- the health system is part of a broader cross-government system that provides support that is centred around the disabled person and their whānau to address all elements of disabled people's health and wellbeing needs throughout their lives
- there is a representative and culturally and disability competent workforce that is continually supported to provide rights-based care for disabled people and is a safe, inclusive and flexible employer of disabled people
- disabled people see themselves represented in health system data, research and evaluation.

Part 2: Where we are now

Health and wellbeing for disabled people and their whānau

Disabled people make up a significant and diverse part of Aotearoa New Zealand

Twenty-four percent of the Aotearoa New Zealand population (1.1 million people) were identified as disabled in 2013 (Stats NZ 2014).[11] Of this group:

- people aged 65 years or older were much more likely to be disabled (370,000 people, representing 35% of our country’s disabled population)
- Māori and Pacific peoples had higher disability rates than non-Māori, non-Pacific peoples
- for adults, physical limitations were the most common type of impairment
- for children, a learning difficulty was the most common type of impairment
- just over half of all disabled people had more than one type of impairment
- an estimated 242,000 people (5% of New Zealanders) are living with a disability caused by psychological and/or psychiatric conditions.

Subsequent data gathered from the Household Economic Survey for the year ended June 2021 suggests that Rainbow communities have a higher proportion of disabled people than the non-Rainbow population (Stats NZ 2022b).

Disabled people experience poorer health and wellbeing outcomes

Disabled people consider themselves overall to be in poorer health compared with non-disabled people. Evidence shows that:

- disabled people experience poorer health outcomes and have higher rates of mortality and lower life expectancy compared with non-disabled people (Ministry of Health 2011, 2021)

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[11] The Disability Survey 2013 (Stats NZ 2014) identified disability through a series of questions that asked whether a person had difficulty doing certain activities and if the difficulty was long term (lasting six months or more). This included asking if a person had difficulty hearing, seeing or walking and to what degree. We note these questions are about functional impairment rather than self-identified disability, which does not align with the social model of disability.

- disabled people have reported very poor mental health, including high or very high levels of psychological distress, and have unmet mental health needs (Government Inquiry into Mental Health and Addiction 2018; Ministry of Health 2022a)
- adults with physical impairments experience a higher prevalence of chronic diseases[12] (Health and Disability System Review 2020; Te Pou o Te Whakaaro Nui 2013)
- people with long-term mental health conditions report poorer health-related quality of life (Wheeler et al 2015)
- disabled people's use of health services is generally at least double that of the non-disabled population, regardless of age or impairment (Health and Disability System Review 2020).

Inequities in health outcomes are acutely felt by specific communities within the broader disabled population. For example:

- tāngata whaikaha Māori and tagata sa'ilimalo report higher levels of unmet health need (Russell et al 2022)
- disabled young people report experiencing higher rates of mental distress, poorer self-ratings of health and higher rates of inability to access health care than non-disabled young people (Department of the Prime Minister and Cabinet 2019)
- older people have much higher rates of long-term chronic health conditions and other impairments that require support on a daily or regular basis (Associate Minister of Health 2016)
- disabled Rainbow young people reported poorer health and wellbeing, particularly mental health, than other population groups (Roy et al 2021)
- children and young people with impairments known to Oranga Tamariki | Ministry for Children (Oranga Tamariki) have more frequent health service interactions, potentially avoidable hospitalisations, emergency department contact and mental health service contact or treatment (Oranga Tamariki 2020)
- people with intellectual disability experience lower life expectancy, higher rates of specific health conditions (including coronary heart disease, diabetes and chronic respiratory disease) and higher use of health services (apart from preventative screening services) than people without intellectual disability (Ministry of Health 2011; Health and Disability System Review 2020).

Poor health and wellbeing outcomes for disabled people and their whānau are driven by broader determinants of health

The experiences of discrimination and other broader determinants of health, including housing conditions, employment and education, impact heavily on the health and wellbeing of disabled people. Some of these broader determinants are listed in the table below.

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[12] Including arthritis, asthma, cardiovascular disease, diabetes, high blood pressure, high cholesterol and stroke.

Table 1: Determinants of health

Socioeconomic deprivation[13]	• Disabled people are more likely to experience socioeconomic deprivation than non-disabled people (Brennan 2016; Convention Coalition Monitoring Group 2015). Poverty can prevent access to health services and information, as well as to food and housing, and can negatively impact physical, mental and emotional health and wellbeing. • Growing up in poverty has long-term detrimental impacts on children. Disabled children are more likely to be living in poverty and experience material hardship than non-disabled children (Stats NZ 2021, 2023). • Children living in a household where someone (child or adult) has a disability are more likely to be living in poverty than children living in a household where no one has a disability (Stats NZ 2023). • Disabled people are less likely than non-disabled people to eat the recommended number of vegetables and fruit per day and are less likely to be physically active (Ministry of Health 2022a).
Ableism[14] and stigma	• This is experienced by disabled people across all facets of life, which affects their physical and mental health and overall wellbeing (World Health Organization 2023). • The health system has historically been designed by non-disabled people for non-disabled people. The attitudes of health sector workers towards disability can result in disabled people receiving poorer quality care in the health system and experiencing poor health and wellbeing outcomes.
Intersecting discrimination, including racism and sexism	• This drives ongoing disadvantage and poor health outcomes, particularly for tāngata whaikaha Māori. • Disabled women can face intersecting forms of discrimination relating to gender and disability, as well as other intersecting factors such as age, language, ethnicity and religion (YWCA 2019). • Disabled people from Rainbow communities can face specific forms of discrimination, such as transphobia and homophobia, alongside ableism, racism and other forms of discrimination.
Social exclusion	• Disabled people experience greater social exclusion and have lower levels of community participation than their non-disabled peers. This can be due to barriers such as inaccessible community facilities and transport systems. • Social exclusion can result in lower rates of participation in sports, exercise and wider community activities (Cockburn and Atkinson 2018; Mirfin-Veitch et al 2012).
Family violence and sexual violence	• Rates of violence towards disabled people are much higher than those towards non-disabled people and impact on disabled people's health and wellbeing (Fanslow et al 2021; Ministry of Justice 2021; Te Puna Aonui 2022).

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[13] Socioeconomic deprivation is defined as falling below the adequate standard of living according to the majority of society (Robinson et al 2017). DEP-17 is a well-established deprivation index developed for Aotearoa New Zealand by the Ministry of Social Development.

[14] Ableism is discrimination against disabled people based on disability. It ranges in scale from small microaggressions and offensive stereotypes through to systemic ableism. Many ableist stereotypes and beliefs are deeply ingrained in society and are subconsciously internalised (Office for Disability Issues 2022).

	• Family violence and sexual violence can also result in impairments, including traumatic brain injury, mental health conditions and physical impairments (New Zealand Family Violence Clearinghouse 2019).
Housing	• Disabled people are more likely to live in poor housing conditions and consequently have higher rates of potentially avoidable housing-related hospitalisations (Howden-Chapman et al 2021). • One in six people with a physical impairment has an unmet need for some kind of modification to their home (Stats NZ 2014). • Disabled people have felt they have limited choice when trying to access adequate housing, including limited choice over where and who they live with. This negatively impacts their wellbeing and quality of life (Donald Beasley Institute 2020). • The rising costs of rental accommodation leave limited funds to meet basic needs, including health care.
Digital inclusion	• Widespread digital inclusion of disabled people online likely leads to improved independence, engagement with the workplace and connection with people online, all of which can benefit wellbeing (Department of Internal Affairs 2020). • Disabled people are more likely than non-disabled people to have low access to the internet. This has been associated with lower subjective wellbeing (Grimes and White 2019).
Income and employment	• Disabled people are far less likely to be employed than non-disabled people and, when employed, their weekly incomes are lower than those of other groups (Stats NZ 2019, 2022a). This impacts their financial wellbeing, and they may become solely reliant on superannuation[15] as their source of income when older. It also impacts their overall health and wellbeing due to financial stress. • Disabled children are more likely to be in households that have low incomes and that report having just enough or not enough money (CCS Disability Action 2019; Stats NZ 2021). • For whānau and carers, the additional care required for a disabled member of the household can take away from the ability of whānau and other carers to work or limits their earnings. • Limited income and transport impacts on attending primary health care and specialist appointments due to cost (Ministry of Health 2022a).

The health system can learn from disabled people's experiences during COVID-19

The COVID-19 pandemic has revealed the inequities experienced by disabled people in having their health and wellbeing needs met by our current health system (Independent Monitoring Mechanism 2021). People receiving disability support

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[15] If they meet the eligibility criteria for New Zealand Superannuation, see the New Zealand Superannuation (NZ Super) webpage on the Work and Income website at URL: **www.workandincome.govt.nz/eligibility/seniors/superannuation/index.html**

services (DSS)[16] were at greater risk of COVID-19 attributed hospitalisation and mortality than the rest of the population throughout 2022 (Ministry of Health 2022b; Whaikaha 2023a). Tāngata whaikaha Māori and disabled non-Māori New Zealanders reported not being listened to or understood by the health sector in terms of both their general health care needs and their COVID-19 circumstances, including long-COVID symptoms (Baker and King 2022; Russell et al 2022). The prevalence of anxiety and/or depression were significantly higher among disabled people than non-disabled people, and disabled people experienced disproportionate physical and social isolation (Donald Beasley Institute 2022; Paipa et al 2022). Public health information was not always delivered in accessible formats, and disabled people reported experiencing more difficulties in accessing health and disability services when they needed them (Donald Beasley Institute 2022).

Across all modes of health care, disabled people were also more likely than non-disabled people to report at least one barrier to seeing a general practitioner (GP) and barriers to getting a COVID-19 test and to report that COVID-19-related lockdowns affected their access to health care services (HQSC 2021; Russell et al 2022). This included being more likely to experience cancelled hospital appointments, being unable to access their GP as usual, avoiding emergency departments when they usually would have attended and experiencing difficulties in obtaining medicine from pharmacies. These insights demonstrate the failures of the health system in meeting the health and wellbeing needs of disabled people and their whānau and a lack of partnership between the health system and the disability community.

During COVID-19, disabled people were more likely than non-disabled people to use telehealth options (HQSC 2021). Some disabled people noted that the provision of telehealth services improved their access to health care by removing the need for them to travel, reducing their travel times and reducing the amount of unnecessary contact they had with other people who might have been unwell. However, other disabled people felt that telehealth led to increased difficulties in communicating with their GP. Such different experiences highlight the fact that needs, including accessibility needs, differ across the diverse disabled population, and health care services need to be tailored accordingly.

COVID-19 has also highlighted the strengths of disabled people and their whānau and disability communities and organisations in advocating for and meeting their own health and wellbeing needs, especially when the health system failed to do so (Russell et al 2022).

[16] Whaikaha | Ministry of Disabled People (Whaikaha) funded DSS are available to people who have a physical, intellectual or sensory disability (or a combination of these) that is likely to continue for at least six months and who need some level of ongoing support to live independently. The services are mainly for people under the age of 65 years. Whaikaha will also fund DSS for people with some neurological conditions that result in permanent disabilities, some developmental disabilities in children and young people, such as autism, and physical, intellectual or sensory disability that co-exists with a health condition and/or injury (Whaikaha 2023c).

Disabled people and the current health system

We acknowledge the strength of disabled people and their whānau in navigating a health system that has not always enabled or supported them in the ways they have needed. It is with this acknowledgement that we approached disabled people and their whānau to better understand their perspective of the current state of the health system. Clear themes emerged from this engagement as discussed below.

Disabled people want to be heard in the health system and in control of their own health

During the engagement disabled people were clear that they want the health system to support them in taking an active and independent role in meeting their health and wellbeing needs. They felt that the current health system does not respect disabled people or acknowledge their mana and does not put the rights and wellbeing of disabled people at the heart of health service provision. This is particularly the case for tāngata whaikaha Māori, tagata sa'ilimalo, people with learning disabilities, people with intellectual disabilities, neurodivergent people, disabled people from Rainbow communities, disabled women and disabled children.

Some people felt that the intersection of ableism with other forms of discrimination, including sexism, racism and transphobia, in the health system prevented them from exercising self-determination over their own health care. People who felt this included tāngata whaikaha Māori, tagata sa'ilimalo, disabled women, disabled people from ethnic communities[17] and disabled people from Rainbow communities.

For tāngata whaikaha Māori, tagata sa'ilimalo and disabled people from ethnic communities in particular being seen collectively within the context of their whānau is essential to both individual and overall whānau wellbeing. This means that whānau, including carers and supporters, must also be included in and listened to by the heath system. However, this is currently not the experience of many whānau, carers and supporters of disabled people.

Tāngata whaikaha Māori and their whānau want the health system to be more responsive to their needs and aspirations

Through the engagement process, we heard that tāngata whaikaha Māori do not feel Te Tiriti principles are being upheld across all aspects of the health system, and this is

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[17] The Ministry for Ethnic Communities defines "ethnic communities" as people who identify their ethnicity as African, Asian, Continental European, Latin American or Middle Eastern. They also include former refugees, asylum seekers, new and temporary migrants, long-term settlers and multi-generational New Zealanders. This definition is adopted throughout the Provisional Health of Disabled People Strategy when referring to ethnic communities.

directly impacting their health and wellbeing. A health system that upholds Te Tiriti principles would improve health outcomes not only for tāngata whaikaha Māori but all disabled people. Engagement with the community reflected many of the experiences being shared by tāngata whaikaha Māori in the Waitangi Tribunal's Health Services and Outcomes Inquiry (Waitangi Tribunal 2019).

Tāngata whaikaha Māori reported feeling uninvolved in the decision-making surrounding their own health care (Russell et al 2022). Tāngata whaikaha Māori felt they are not being empowered to lead their own health care as the current health system does not recognise their self-determination and they are not supported by models of care that consider all their health and wellbeing needs.

Tāngata whaikaha Māori reported that Te Tiriti principle of active protection is not apparent in preventative care as it is not accessible or culturally safe. The current system lacks support for, or acknowledgement of, the wider whānau, including whānau hāpai, as active, and crucial, factors in disabled people's health care.

Disabled people and their whānau want better access to supportive, community-based primary and preventative health care

Having accessible, local and high-quality primary and preventative health care services was a clear priority for many disabled people and their whānau, with clear frustration evident about the current inaccessibility of primary health care services. Such lack of access contributes to poor health outcomes and can lead to a power imbalance between practitioners and disabled patients.

Key barriers to accessing primary and preventative health care services included:

- the short 15-minute slots for GP appointments not giving disabled people enough time to communicate their health needs in their preferred communication style, with longer appointment slots costing more
- the limited opening hours and rigid appointment times of primary health care services, which can lead to delaying or neglecting care
- physically inaccessible preventative health care services (for example, physically inaccessible breast cancer screening and bowel cancer screening programmes)
- challenges in finding a GP and other primary health care providers and the high turnover of health care staff in rural areas, which can impede relationship building
- inaccessible physical spaces of health services
- limited provision of health information in accessible formats, including labels on medicines, and information on the availability and importance of publicly funded screening services, which impacts on privacy and undermines informed consent
- the high cost of oral health services and allied health services
- inconsistent access to preventative health care and disability supports during key life-stage transitions, such as from childhood to adulthood and adulthood to older age.

Disabled people and their whānau want a health system that facilitates access to wider services and supports to address broader drivers of poor health and wellbeing

Disabled people were consistent in their messaging that the health system was a key gateway to accessing other government supports. Disabled people and their whānau explained that accessing timely and affordable diagnoses would help improve their broader wellbeing.

There were repeated calls for clearer pathways to accessing specialist diagnoses, including for rare conditions and for adults accessing diagnoses for conditions normally diagnosed during childhood. Waiting for a diagnosis can delay access to other support services, which is detrimental to overall health and wellbeing. This is particularly the case when a health care diagnosis can strengthen an application for funding for support in a non-health related area.

Those whose impairments are not always recognised as disabilities in criteria for support services, such as those with global learning delay, fetal alcohol spectrum disorder (FASD) and myalgic encephalomyelitis (ME) (also known as chronic fatigue syndrome, CFS) felt that service access was too focused on diagnostic criteria rather than need.

Along with the different diagnostic criteria, people have struggled with constant reassessments for services in a health system (and wider social support system) that is exceedingly difficult to navigate. People felt they constantly had to prove their disability and repeat information and frequently felt disbelieved, which negatively impacted their physical and mental wellbeing.

Disabled people want to see themselves represented in a health workforce that is better equipped to meet their health and wellbeing needs

The disabled people we engaged with highlighted the importance of having a health workforce with sufficient skills and capacity to meet the needs of disabled people and their whānau. A strong theme was the lack of recognition and support from the health system for the skills and roles of the carer and support workforce in meeting the needs of disabled people. Carers and support workers must be valued, supported, resourced and trained to assist disabled people and their whānau to safely move through the health system.

Disabled people and their whānau also felt the health workforce has limited understanding of and reflective practice around ableism, racism and other forms of discrimination. This echoes the findings from the Health Quality and Safety Commission (2021), which showed disabled people are less likely to report that doctors, nurses and other health care professionals treated them with kindness, understanding or respect and are less likely to trust their doctors, nurses and other health care professionals. This is in part due to a lack of disabled representation in the workforce and a lack of training programmes within health qualification tertiary providers based around Te Tiriti and disability rights. This limits the cultural safety of health services for disabled people and their whānau.

Disabled people want to be visible in the health system

Disabled people and their whānau reported that the lack of data on the disabled population in Aotearoa New Zealand limits their visibility in the health system. They stated that robust data would enable the health system to tailor supports to meet their specific needs. This lack of data has particularly negative effects for tāngata whaikaha Māori: in its December 2021 report *Haumaru*, the Waitangi Tribunal found the Crown was in active breach of the equity and active protection principles of Te Tiriti for not holding sufficient data on tāngata whaikaha Māori (Waitangi Tribunal 2021).

Disability organisations noted there is no system-wide framework to identify disabled people by the National Health Index (NHI) or any other digital identifier to provide a more accurate assessment of the prevalence of disability in the population. They also noted there is a lack of disaggregated data by ethnicity, geographic location and nature of impairment, which limits the health system's understanding of the compounding effects of disability with other identity markers.

Medium- and long-term trends

Aotearoa New Zealand has an ageing population. As ageing is associated with higher rates of disability, we can expect the disabled population to grow (Ministry of Health 2021). This will disproportionately affect Māori and Pacific populations, who have the greatest growing proportion of older people (see Pae Tū: Hauora Māori Strategy and Te Mana Ola: The Pacific Health Strategy for more details) (Ministry of Health 2020a; Stats NZ 2018, 2020). Our current disabled population is likely to live longer than previous generations, and existing impairments and conditions are often exacerbated with age. This will result in increased demand for specialised support as disabled people age.

The changing nature of our population profile is likely to create pressures across the health system, including through increased prevalence of some types of impairments that become more common with age (Health and Disability System Review 2020). Meeting the needs of the growing disabled population in Aotearoa New Zealand will likely increase the demand for a culturally competent health workforce that has capacity and capability to provide culturally safe health services. This workforce will need to understand the needs of disabled people, including impairment-specific and culturally specific needs.

In addition to the direct effects on individuals with impairments, the ageing nature of our population is likely to put more pressure on whānau, particularly intergenerational whānau with multiple members with impairments. Age will also lead to more people living alone, with associated impacts on health outcomes from loneliness and income disparity.

The disabling impacts of long-COVID are also projected to grow. There is evidence that long-COVID can take the form of physical and/or cognitive impairments (Morrow et al 2021; Maddux et al 2022; Ministry of Health 2022d; Stephenson et al 2022; U.S. Department of Health and Human Services 2021), and an increasing number of people are identifying as disabled due to their disabling experience of long-COVID (Russell et al 2022; Tak 2023). Long-COVID is seen in all age groups, but the risk of it being identified increases for those who are older and have multiple underlying chronic medical conditions (Ministry of Health 2021). While data is still emerging, it is likely that Māori will be disproportionately affected by long-COVID (Russell et al 2022). Māori continue to experience inequities in vaccination rates and incidence of severe illness requiring hospitalisation (Ministry of Health 2022c), both of which are associated with a higher likelihood of leading to long-COVID.

Emerging research shows there is a rising number of people who need high levels of support because of degenerative cognitive impairments, such as dementia. There is also increasing awareness of the prevalence of neurodevelopmental conditions, such as attention deficit hyperactive disorder (ADHD), autism spectrum disorder (ASD), traumatic brain injury and FASD, especially in children (Saraf and Marks 2019; Cure Kids 2023). This includes increased recognition of different presentations of neurodiversity, including ADHD and ASD, in women (Mental Health Foundation 2022a, 2022b). Increased prevalence and awareness of these conditions will likely result in increasing demand for health services.

The current state of health and wellbeing for disabled people shows the health system must do more

The research cited in this provisional strategy and our engagement with the disability community show there are gaps in the health system's ability to meet the health and wellbeing needs of disabled people in Aotearoa New Zealand.

To address these gaps:

- the self-determination of disabled people and their whānau must be at the centre of the health system
- the health system must be accessible for disabled people and their whānau, and disabled people must be involved in system and service design
- the health workforce must be inclusive of disabled people and must be culturally safe and responsive to the rights and needs of disabled people
- the health system must be a stronger enabler for disabled people and their whānau to access supports from other agencies to address their broader health and wellbeing needs

- there must be a robust health system data and evidence base that identifies the diverse disabled population and their health and wellbeing needs, including rare and complex needs, and tailors support accordingly.

The role of this provisional strategy is to guide health entities to work to improve the health and wellbeing of disabled people by filling these gaps. The next section outlines five priority areas for health entities to focus on to achieve pae ora | healthy futures for disabled people and their whānau, including what needs to change in the current health system.

Part 3: Priority areas for action

We have identified five priority areas for the next 10 years from our analysis of research and engagement with disabled people. These priority areas will drive improvements in health and wellbeing outcomes for disabled people and their whānau:

- **Priority 1:** Embed self-determination of disabled people and their whānau as the foundation of a person and whānau-centred health system.
- **Priority 2:** Ensure the health system is designed by and accessible for disabled people and their whānau and provides models of care that suit their needs.
- **Priority 3:** Ensure the health system is part of a coherent cross-government system that addresses broader drivers of poor health and wellbeing.
- **Priority 4:** Build health workforce capacity and capability to meet the needs of disabled people and their whānau.
- **Priority 5:** Increase the visibility of disabled people in health data, research and evidence as part of an active learning system.

In this section, we describe the key priority areas where we need to see change. The priority areas are interdependent and outline where action is most needed to continue shifting the health system towards achieving pae ora | healthy futures for disabled people and their whānau.

Figure 2: Provisional Health of Disabled People Strategy – Priority areas

Priority 1: Embed self-determination of disabled people and their whānau as the foundation of a person and whānau-centred health system.	**Priority 2**: Ensure the health system is designed by and accessible for disabled people and their whānau and provides models of care that suit their needs.	**Priority 3:** Ensure the health system is part of a coherent cross-government system that addresses broader drivers of poor health and wellbeing.	**Priority 4:** Build health workforce capacity and capability to meet the needs of disabled people and their whānau.	**Priority 5:** Increase the visibility of disabled people in health data, research and evidence as part of an active learning system.
• The health system will enable disabled people to exercise self-determination over their health and wellbeing. • Disabled people, including disabled children, and their whānau will be confident that their agency, autonomy, rights, will and preferences will be respected when engaging with the health system. • The health system will enable disabled people and chosen whānau, carers and supporters to exercise supported decision-making where appropriate. • Accessible health information will be provided and communicated clearly and appropriately throughout the entire health system. • The health system will prioritise prevention approaches, public health promotion and good health and wellbeing throughout disabled people's lives.	• Health entities will meaningfully partner with disabled people and their whānau to design fully accessible and community-based primary and preventative health care services. • Health services for both disability needs and other health needs will be of high quality, responsive and flexible in meeting the specific access needs of disabled people and their whānau. • Health entities will embrace the opportunities offered by technology to improve access to health information, health services and improved health outcomes for disabled people and their whānau. • Care pathways will be clear and streamlined to ensure continued care for disabled people across the lifespan and during key transition periods.	• The health system will meet the needs of disabled people and their whānau by considering all of the factors that influence their health and wellbeing collectively. • The health system will support disabled people and their whānau to access the right support at the right time, to meet broader and intersecting health and wellbeing needs. • The health system will work closely with other agencies to ensure it is part of a coherent cross-government system that facilitates easy, timely and seamless access to information and services that address the broader health and wellbeing needs of disabled people and their whānau.	• The health system will build health workforce capacity through recognising, valuing and enabling the development of diverse sets of required skills and capabilities. • There will be increased representation of the disability community, in its diverse breadth and including tāngata whaikaha Māori, at every level of the health system, including in senior leadership positions. • The health workforce will be a culturally safe environment for all disabled people, particularly tāngata whaikaha Māori. • The workforce will have improved understandings and application of Te Tiriti and Enabling Good Lives principles as they apply to the health of disabled people. • The wellbeing of the health workforce will be supported by the health system.	• Disabled people and their whānau will have authority over how their data is used within the health system and how services are designed. • There will be a specific focus on improved data collection for those who experience the greatest inequities within the disabled population, including tāngata whaikaha Māori, as well as tagata sa'ilimalo, disabled ethnic communities and disabled Rainbow communities. • Disabled people and their whānau will play a leading role in planning, designing, implementing, monitoring and evaluating health services to best meet their own health needs. • Health entities will report back to disabled people and their whānau regularly on how their insights are being leveraged to effect meaningful change.

Priority 1: Embed self-determination of disabled people and their whānau as the foundation of a person and whānau-centred health system

What we heard from disabled people and their whānau

Tāngata whaikaha Māori want ‘a system that listens to our insights and [is] shaped by us’ – Ngā Wānanga Pae Ora 2023 participant

‘Don't question my authority to make the best decisions for me’ – Ngā Wānanga Pae Ora 2023 participant

Tāngata whaikaha Māori need ‘Mana motuhake: more voices in positions of leadership / boards that are tāngata whaikaha’ – Ngā Wānanga Pae Ora 2023 participant

‘[Tāngata] Whaikaha need the support of the people they choose’ – Ngā Wānanga Pae Ora 2023 participant

Pae ora | healthy futures looks like ‘Having medical professionals understand and listen to people with invisible disabilities’ – Health of Disabled People Strategy engagement participant

Having needs met at a health care appointment would involve ‘Having [health care] professionals listen to me and not my support person … Having all the [health care] professionals take the time to listen to me properly to understand what my needs are’ – Health of Disabled People Strategy engagement participant

‘The new system must require all NZ health providers, hospitals, doctors, pharma[cists], vaccine centres, therapists, psychiatrists, etc, etc, etc to provide all health-related information that is available to any other person in the requested accessible format, including but not limited to: Braille (contracted, [non-contracted] and digital file), Large print, digital text (screen-reader accessible), audio, easy read and NZSL. They must also accept information from the patient in all these formats’ – Tātou user

Why this is a priority

A person’s decision-making and agency over their health needs is critical to their health and wellbeing and necessary for achieving their rights.

We heard from disabled people that they do not feel listened to within the health system and are sometimes not given the opportunity to express their health needs. This was particularly noted by people with communication impairments, people who use interpreters, disabled young people and people with intellectual and learning disabilities, who reported that practitioners often interacted with their supporters rather than directly with them. We also know government does not often hear disabled children and young people, especially those in state care.

The health system must recognise that disabled people and their whānau are experts in their own lives and enable those people to exercise self-determination and authority over their health and wellbeing. This includes enabling disabled people to choose their support network and still be heard alongside their supporters when exercising supported decision-making[18] over their health and wellbeing needs.

Whānau and carers told us they often feel ignored and dismissed by health practitioners when advocating for their disabled whānau member’s needs. The health system must listen to and enable the expertise of whānau, carers and supporters to help disabled people exercise their self-determination, including through supported decision-making and safeguarding[19] responses where appropriate.

The concept of ‘disability’ has no equivalent within te ao Māori, and most Māori with disability identify as Māori first. The Crown must meet its Te Tiriti obligations and partner with tāngata whaikaha Māori to enable them to fully exercise self-determination over their health and wellbeing, ensuring they have options for and choice over how to best meet their own health needs.

Enabling self-determination in the health system for disabled people and their whānau in their personal care also requires knowledge and leadership of disabled people and their whānau at all levels of the health system. The voices of disabled people and their whānau must drive health service design, delivery, monitoring and improvement.

What it will look like in the future

Disabled people and their whānau will be recognised as experts in their own lives, and the health system will enable them to exercise self-determination over their health and wellbeing. Disabled people and their whānau will be confident that their agency,

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[18] Supported decision-making is a way for people to make their own decisions based on their will and preferences, so they have control of their life. It ensures the person who needs support is at the centre of all decisions that concern them. The person who needs to make a decision works with appropriate support, which can be one or more supporters. The supporters make sure the person gets the right information, at the right time, in the right way, with the time they need to consider their decision (Ministry of Social Development 2023).

[19] Safeguarding is a range of activities and responses that promote and protect human rights, health, wellbeing and culture, and prevent or reduce harm, abuse and neglect (Personal Advocacy and Safeguarding Adults Trust 2023).

autonomy, rights, will and preferences will be respected when engaging with the health system. Disabled children and young people will have their voices heard and their rights respected, including tamariki and rangatahi Māori, Pacific youth, Rainbow youth, and children and young people in state care. Health entities will recognise the maturity of young disabled people.

The health system will enable disabled people, whānau, carers and supporters to exercise supported decision-making where appropriate, and disabled people will feel confident that advanced care planning and advanced directives will be followed by health care practitioners.

Accessible health information will be provided and communicated clearly and appropriately throughout the entire health system. For example, labels on medication and accompanying information will be in Braille for patients who choose Braille as their preferred communication method to enable disabled people to exercise their self-determination.

Health entities and services will regularly and meaningfully engage with disabled people and their whānau across the country, including in rural areas, to ensure disabled people and their whānau can influence health system decision-making. The health system will listen to the lived experience of disabled people and their whānau and partner with them to respond to their particular needs and aspirations.

The health system will be guided by the voice of tāngata whaikaha Māori to ensure systems, processes and services reaffirm self-determination for tāngata whaikaha Māori.

The health system will prioritise prevention approaches, public health promotion and good health and wellbeing throughout disabled people's lives. This includes early diagnosis and intervention to ensure disabled people and their whānau have the appropriate information and supports available to them from an early age to enable them to exercise bodily autonomy and self-determination over their health and wellbeing.

It also includes prioritising initiatives that promote healthy ageing. These initiatives aim to maintain quality of life for disabled older people to help them do things that are important to them, enhance their participation and social connection, provide appropriate care and assure their dignity in their later years.

What needs to change

Health entities need to:

- ensure the health system is re-oriented to be culturally safe for disabled people and their whānau to voice their health and wellbeing needs (This includes for tāngata whaikaha Māori, as well as tagata sa'ilimalo, disabled people from ethnic communities, Rainbow communities and the Deaf community to ensure they can fully exercise self-determination over their health and wellbeing throughout their life.)

- ensure health entities enable, incentivise and value regular, meaningful engagement and ongoing, reciprocal relationships with disabled people and their whānau, particularly tāngata whaikaha Māori, including in rural areas
- ensure disabled people and their whānau are empowered and supported to participate equitably in decision-making through systemic provision of accessible communication methods and information in all health services and decision-making bodies
- ensure disabled people have choice over the people who provide them with decision-making support, whether that be whānau, carers or other supporters
- ensure whānau, carers and supporters who disabled people choose as their support network are equipped to provide decision-making support
- improve access to interpreters for disabled people and their whānau, including New Zealand Sign Language interpreters, in all health care settings
- ensure the Safeguarding Framework and Safeguarding Adults from Abuse (SAFA) response is embedded across all health settings
- support disabled people to exercise decision-making over their own health and wellbeing (This includes through tailored support for tāngata whaikaha Māori, as well as tagata sa’ilimalo, disabled people from Rainbow communities, disabled people from ethnic communities, young disabled people and disabled older people to exercise decision-making over their own health and wellbeing).

Links to other pae ora strategies

The themes in this priority area link to the following sections in the other pae ora strategies.

- **New Zealand Health Strategy:** Priority 1 – Voice at the heart of the system
- **Pae Tū: Hauora Māori Strategy:** Priority 1 – Enabling whānau, hapū, iwi and Māori community leadership, decision-making and governance at all levels
- **Te Mana Ola: The Pacific Health Strategy:**
    - Priority 2 – Te pāruru`anga, te apii`anga, e te akateretere`anga no te ora’anga meitaki (Disease prevention, health promotion and management for good health)
    - Priority 3 – Soalaupule (Autonomy and determination)
- **Women’s Health Strategy:** Priority 1 – A health system that works for women
- **Rural Health Strategy:** Priority 1 – Considering rural communities as a priority group

Priority 2: Ensure the health system is designed by and accessible for disabled people and their whānau and provides models of care that suit their needs

What we heard from disabled people and their whānau

'[Tāngata whaikaha Māori need] access to kaupapa Māori services underpinned by Māori worldviews/principles' – Ngā Wānanga Pae Ora 2023 participant

'A lot of the poor outcomes experienced by disabled people are through lack of access … to treatment, … to information …' – Health of Disabled People Strategy engagement participant

'I would … like to see one directory where people with disabilities can look up the type of service they need and find a provider or process easily – for example, where do I go if my equipment needs to be upgraded or repaired? What follow-up/treatment needs to be initiated by my GP, and where can I self-refer?" – Tātou user

'Once our children become young adults, services seem to be non-exist[ent]' – Health of Disabled People Strategy engagement participant

Why this is a priority

Disabled people and their whānau are finding the health system inaccessible, contributing to poor health and wellbeing outcomes. Here, the health system can be disabling itself for disabled people and their whānau and can create barriers to their achieving pae ora | healthy futures. For example, a lack of access to appropriate equipment in health services can prevent disabled people from having their health needs addressed in a timely and effective way.

Disabled people and their whānau have told us that they want more accessible, flexible, integrated, community-based and culturally safe health care, focused on preventative health care. This includes models of care that consider disabled people's physical, mental and emotional health in the context of their broader whānau, community and environment.

For tāngata whaikaha Māori, an understanding of health and pae ora includes mauri ora, whānau ora and wai ora. Tagata sa'ilimalo and ethnic communities have similarly voiced the need for the health system to acknowledge Pacific and ethnic community-specific collectivist approaches to understanding health and wellbeing.

Health services and systems need to be integrated so disabled people and their whānau have seamless access to, and choice of, timely, affordable, high-quality, high-performing and culturally safe services that meet their needs throughout their lives. This includes during key transition periods, for example, when disabled people are leaving prison and reintegrating into the community, to ensure these people do not fall through the gaps.

What it will look like in the future

Disabled people and their whānau will play an active and leading role in the design and delivery of health services across the whole health system. Health entities will meaningfully partner with disabled people and their whānau to plan, design, commission, deliver, monitor, evaluate and deliver fully accessible and community-based health services, particularly in primary and preventative health care, according to disabled people's needs.

Health services for both disability and other health needs will be of high quality, responsive and flexible in meeting the specific access needs of disabled people and their whānau. Services that are designed and delivered by disabled people and their whānau will make the health system an attractive place for disabled people to work and will support the broader health workforce to deliver high-quality and responsive care tailored to meet disabled people's needs.

Health entities will support disabled people and their whānau, including disability organisations, to deliver their own accessible and local services to their communities. The health system will recognise the value of kaupapa Māori services and mātauranga Māori, including rongoā Māori, in meeting the health needs of tāngata whaikaha Māori, as well as ensuring that tāngata whaikaha Māori have adequate and appropriate access to mainstream services.

Health services will be provided in locations and settings that are accessible to disabled people and their whānau, to keep people well in their communities. This will include supports that enable disabled older people to remain in their homes and with their whānau for longer and screening services being provided closer to home for disabled people in rural areas. Each locality will lead the work on identifying and addressing the health needs of its disabled population.

Health entities will ensure that disabled people receive equitable access to high-quality health care, including care unrelated to their impairments. For example, disabled people and their whānau will have equitable access to high-quality sexual and reproductive health care services and to health care that appropriately and safely responds to any experiences of violence and abuse. The same level of preventative health care will be available to disabled people as non-disabled people, particularly cancer screening services.

Health entities will embrace the opportunities offered by technology to improve access to health information, services and outcomes for disabled people and their whānau. This may include leveraging potential opportunities, where appropriate and in partnership with disabled people and their whānau, provided by precision health services, including the use of artificial intelligence and machine learning, to help personalise health care in a targeted way (Ministry of Health 2023b).[20] Health entities will take into consideration the gaps in digital literacy within the disabled population and will ensure any leveraged technological opportunities will not leave behind those with lower levels of digital literacy. Health entities will also work in partnership with disabled people and their whānau to ensure that the purpose and use of precision health meets ethical and moral obligations.

Care pathways will be clear, especially for people with complex and chronic conditions. Referrals and information sharing will be seamless and timely between health services, including through innovative technologies, to ensure continued care for disabled people and their whānau across disabled people’s lifespan and during key transition periods.

Disabled people and their whānau will have increased access to multidisciplinary health care teams to streamline care pathways, reduce unnecessary duplication of health services and ensure all disabled people’s health needs are being met. Where needed, navigators will support disabled people and their whānau to make the right connections across health services.

Physical health service spaces will meet all accessibility needs to enable disabled people and their whānau to enter and move safely through their health service experience in a way that best meets their needs. This includes spaces that are inclusive and culturally safe physical environments for all disabled people and their whānau, including Māori, Pacific peoples, Rainbow communities, ethnic communities and the Deaf community.

What needs to change

Health entities need to:

- ensure everything that affects disabled people and their whānau in the health system is guided by the voice of disabled people and their whānau (The diversity of the disability community must be listened to, including those who have not always been heard. This includes partnering with tāngata whaikaha Māori, whānau, hapū, iwi and Māori communities and providers to ensure the voices of tāngata whaikaha Māori are heard.)
- ensure disabled people and their whānau are enabled to lead the delivery of services in their communities that are responsive to community needs and flexible to be able to adapt as circumstances change
- partner with whānau, hapū, iwi and Māori communities and providers, including tāngata whaikaha Māori, to improve the capability and capacity of kaupapa Māori

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[20] This will require reviewing the legislative and regulatory framework, considering infrastructure and investment implications, and tackling ethical issues to ensure new technologies are delivered safely and equitably. See Precision Health: Exploring opportunities and challenges to predict, prevent, diagnose and treat disease more precisely in Aotearoa New Zealand (Ministry of Health 2022e).

and whānau-centred service providers (This includes making kaupapa Māori services and mātauranga Māori practices more available and accessible and therefore offering more choice of services and health care models for tāngata whaikaha Māori.)

- partner with tagata sa'ilimalo and Pacific providers, Rainbow providers, ethnic communities and the Deaf community to improve the availability and accessibility of culturally safe health services
- invest in identifying unmet need, early diagnosis and intervention, including for rare conditions and disabling mental health and chronic health conditions
- invest in research and initiatives that help all parts of the health system harness innovation and new technologies to improve access to health information, health services and improved health outcomes for disabled people and their whānau (This includes initiatives aimed at improving digital literacy within the disabled population, while recognising that digital means are not accessible to all disabled people.)
- ensure all health care spaces are accessible for disabled people and their whānau, including waiting rooms and hospital emergency departments that are accessible for those with sensory impairments and sensitivities
- systematically address known barriers to care for disabled people and their whānau, including cost of services, opening hours of services and fragmented referrals processes, particularly in rural areas
- invest in health care approaches that address as many aspects of disabled people's health care needs as possible with a focus on the person and their whānau, including multidisciplinary team approaches to health care where applicable
- review the current use of navigators across the health system to identify and strengthen what is working well and fill gaps in places where culturally safe navigators could improve connections for disabled people and their whānau, ensuring consistency across regions.

Links to other pae ora strategies

The themes in this priority area link to the following sections in the other pae ora strategies.

- **New Zealand Health Strategy:** Priority 2 – Flexible, appropriate care
- **Pae Tū: Hauora Māori Strategy:** Priority 4 – Enabling culturally safe, whānau-centred and preventative primary health care
- **Te Mana Ola: The Pacific Health Strategy:** Priority 4 – Haitiaaga moui malolo (Access)
- **Women's Health Strategy:**
  - Priority 2 – Improving health care for issues specific to women
  - Priority 3 – Better outcomes for mothers, whānau and future generations
- **Rural Health Strategy:**
  - Priority 2 – Prevention: Paving the path to a healthier future
  - Priority 3 – Services are available closer to home for rural communities
  - Priority 4 – Rural communities are supported to access services at a distance

Priority 3: Ensure the health system is part of a coherent cross-government system that addresses broader drivers of poor health and wellbeing

What we heard from disabled people and their whānau

'[Being healthy means] living a full life surrounded by whānau doing things that matter' – Ngā Wānanga Pae Ora 2023 participant

'It shouldn't leave people with health issues having to cart around their entire notes and things like that to make sure that they are getting the help that they need' – Health of Disabled People Strategy engagement participant

'I don't even understand the difference between the health system and the education system, and I felt really pinged around for a long time … if we had issues around things like ramps it was very difficult … I just used to feel that health would say that's education, and education would say that's health. I just felt so drowning in the middle' – Health of Disabled People Strategy engagement participant

'Most of my work is juggling the different agencies we have in our community' – Health of Disabled People Strategy engagement participant

Why this is a priority

Health and wellbeing extend beyond the health system and include broader determinants of health, such as housing, education and income. An approach that considers all factors that influence health and wellbeing, such as te ao Māori and Pacific world views, is essential to achieve pae ora | healthy futures for disabled people and their whānau.

Wai ora acknowledges the importance of Māori connections to whenua as part of the environments in which Māori live and belong. It also recognises the significant impact of such connections to the health and wellbeing of individuals, whānau, hapū, iwi and Māori communities. An environment that is compatible with good health reflects the need for Māori, including tāngata whaikaha Māori, to have access to resources (such as quality housing, safe drinking-water, clean air, healthy food) and to live in environments that support and sustain a strong, flourishing mauri and a healthy and empowered whānau.

There is a range of broader determinants that particularly impact the health and wellbeing of disabled people and their whānau (see Part Two: Where we are now). Key determinants include quality, safe and accessible housing, income, suitable employment and supportive and accessible education. The inequitable distribution of these determinants impacts Māori, including tāngata whaikaha Māori (see Pae Tū: Hauora Māori Strategy for more detail). To improve the health and wellbeing of and achieve pae ora | healthy futures for disabled people and their whānau, health entities must work closely with other agencies.

According to the New Zealand Productivity Commission, a barrier to addressing persistent disadvantage is the 'fragmented and siloed nature of government' (New Zealand Productivity Commission 2022, page 1). The health system should be an enabler for disabled people and their whānau to access support from other agencies that will address their broader health and wellbeing needs. We have heard that receiving a health condition or disability diagnosis from the health system can assist disabled people and their whānau to access support from other agencies, as this diagnosis serves as a 'validation' of their need for support. Delays in receiving diagnoses from the health system can therefore result in delays to accessing these other forms of support. For example, we have heard that delays in receiving a health system-based specialist assessment and diagnosis for ASD, ADHD and FASD has led to delays in accessing support in education settings.

What it will look like in the future

The health system will meet the needs of disabled people and their whānau by considering all the factors that influence their health and wellbeing collectively. This means the health system will recognise and consider the intersectional nature of people's identities and lived experiences, and the impact of the different factors on disabled people's overall health and wellbeing. This includes recognising that disabled people have different experiences and health and wellbeing needs based on gender, ethnicity, sexuality, geographic location and other aspects of their identity.

The health system will support disabled people and their whānau to access the right supports at the right time to meet their broader and intersecting health and wellbeing needs. This means the health system will work closely with other agencies to ensure it is part of a coherent cross-government system that facilitates easy, timely and seamless access to information and services that address broader health and wellbeing needs. Health services will be better connected to social services, including housing and education services, to prevent disabled people and their whānau from having to unnecessarily repeat their stories and concerns multiple times and to prevent delays in accessing support.

Where health is not the lead sector for some areas of work (for example, housing and income), health entities will take an active role in advocating for, supporting and partnering with other agencies, organisations and communities to deliver information and services that meet the broader health and wellbeing needs of disabled people and their whānau.

This will include working in partnership with agencies from other sectors to improve health and wellbeing outcomes for tāngata whaikaha Māori and to respond to the needs, aspirations and priorities identified by tāngata whaikaha Māori, whānau, Iwi-Māori Partnership Boards and local leaders.

What needs to change

Health entities need to:

- assess current interaction points between health and wider government services and leverage cross-agency partnerships (at both central and local levels) to improve connections between these services, including housing, education, employment, justice and child and youth wellbeing services
- strengthen partnerships with tāngata whaikaha Māori and Māori providers to deliver kaupapa Māori and other mātauranga Māori services that consider all the factors that influence the health and wellbeing of tāngata whaikaha Māori
- strengthen partnerships with non-governmental organisations, communities and disabled people and their whānau to deliver community-based supports and services for disabled people and their whānau that consider all the factors that influence disabled people's health and wellbeing (This includes improved partnerships with:
  - tagata sa'ilimalo and Pacific providers to deliver by-Pacific for-Pacific services
  - other community organisations, such as Rainbow organisations and ethnic community organisations.)
- continue to support the *Social Sector Commissioning Action Plan 2022–2028* (Ministry of Social Development 2022), which explicitly focuses on implementing a relational approach to commissioning across the social sector, to address the broader determinants of health and wellbeing for disabled people and their whānau
- ensure there is effective navigation in the health system to help disabled people and their whānau access the appropriate supports to meet their broader health and wellbeing needs.

Links to other pae ora strategies

The themes in this priority area link to the following sections in the other pae ora strategies.

- **New Zealand Health Strategy:**
  - Priority 5 – A resilient and sustainable system
  - Priority 6 – Partnerships for health and wellbeing
- **Pae Tū: Hauora Māori Strategy:** Priority 2 – Strengthening whole-of-government commitment to Māori health
- **Te Mana Ola: The Pacific Health Strategy:** Priority 1 – Vaqaqacotaka na yavutu ni tiko bulabula (Population health)
- **Women's Health Strategy:** Priority 4 – Living well and ageing well
- **Rural Health Strategy:** Priority 1 – Considering rural communities as a priority group

Priority 4: Build health workforce capacity and capability to meet the needs of disabled people and their whānau

What we heard from disabled people and their whanau

> ‘[Tāngata whaikaha Māori need] cultural safety from all employers. Equal opportunity and progression for tāngata whaikaha in the workforce’ – Ngā Wānanga Pae Ora 2023 participant
>
> ‘It’s a person you’re going to … you don’t know them. You see them probably once, I mean, I see them quite a lot unfortunately, but I don’t have a relationship with them. And you have 15 minutes with them, and less than 15 minutes, to get the things you need.’ – Health of Disabled People Strategy engagement participant
>
> ‘Require all those responsible for providing health services to have a basic knowledge of disabilities, accessibility and disability rights, the Deaf community and d/Deaf rights. And a knowledge of how to interact with and provide care that meets the basic requirements of disabled people and d/Deaf people.’ – Tātou user

Why this is a priority

The health workforce needs to be better equipped to understand and act on the needs of the diverse disability community. This includes improving its understanding of disability rights, disability- and impairment-specific needs, including communication needs, and culturally specific needs. The health system must address the intersection of ableism, racism, transphobia, sexism and other forms of discrimination that can lead to disabled people feeling ignored when advocating for their health needs, not receiving the same quality of care as non-disabled people and ultimately experiencing poorer health and wellbeing outcomes. This has particularly been voiced by tāngata whaikaha Māori, as well as tagata sa’ilimalo, disabled older people, disabled women, disabled people from Rainbow communities and disabled people from ethnic communities.

The health system must acknowledge the skills and capabilities required to support the needs of disabled people and their whānau, including tāngata whaikaha Māori, as well as tagata sa’ilimalo, and people with disabling complex and chronic conditions, such as FASD, ME or CFS, long-COVID and disabling mental health conditions.

Disabled people should be represented in all parts of the health workforce throughout the health system, particularly in senior leadership and decision-making positions. There should be opportunities for the health workforce to grow capability to better reflect and service the needs of the disability community. This includes for tāngata whaikaha Māori, as well as tagata sa'ilimalo and people with intellectual and learning disabilities.

The disabled and non-disabled health workforce needs better support, including wellbeing support. We have heard that the workforce is experiencing burnout, including unpaid and informal carers and supporters, who have limited access to respite to allow them to rest and prioritise their own wellbeing. This particularly affects the wellbeing of women, who disproportionately make up the paid and unpaid carer workforce (Carers New Zealand 2023)[21], and carers who are reaching older age[22] and/or develop physical and mental impairments themselves. It also affects the health, including mental health, and wellbeing of young people who are ongoing carers of disabled whānau members (Hanna and Chisnell 2019).[23]

What it will look like in the future

The New Zealand Health Strategy states that to protect, promote and improve the health of New Zealanders, achieve equity in health outcomes and build towards pae ora | healthy futures, we need:

- a workforce that is available to meet service and population needs
- a workforce that is equitably accessible to provide choice and timely care
- a responsive workforce that is culturally safe, representative of and flexible to population health needs
- a productive workforce that is motivated and empowered
- a quality workforce that delivers safe, effective and efficient care and partners with Māori.

We describe what this looks like for the disabled health workforce and disabled people receiving care below.

The health system will build its workforce capacity by recognising, valuing and enabling the development of the diverse sets of skills and capabilities required to deliver equitable health outcomes for disabled people and their whānau. This includes valuing and enabling the skill development of unpaid carers, supporters, advocates and navigators who hold critical skills and capabilities to meet the health and wellbeing needs of disabled people. The disabled health workforce will also be enabled to develop the skills they want and need to work in ways that effectively meet community needs.

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[21] 63% of Aotearoa New Zealand's whānau carers are female. Unpaid carers are twice as likely to be female.

[22] In 2019, approximately 16% of carers were aged 65 years or older (Office for Seniors 2019).

[23] Approximately 5% of young people aged 12 to 18 years provide regular care to someone seriously affected by a disability or long-term illness (Malatest International et al 2022).

The health workforce will be well connected to disabled people and their whānau. This means that disabled people and their whānau will be able to access a diverse, multidisciplinary workforce with appropriately qualified health professionals in accessible locations. This will offer disabled people and their whānau choice when accessing the health workforce.

The health system will become a leading employer of disabled people in Aotearoa New Zealand. There will be increased representation of the disabled population, in its diverse breadth, at every level of the health system, including in senior leadership positions. This will include increased representation of tāngata whaikaha Māori, as well as tagata sa'ilimalo, disabled women, disabled people from Rainbow communities and disabled people from ethnic communities. Health entities will recognise and address ableism in employment practices and adapt these practices to meet the needs of disabled employees. Increased disability representation will ensure that health services are funded, designed and delivered by disabled people, who will have the skills and disability-specific and culturally specific understandings required to deliver accessible, community-based and better-quality care.

The health workforce will be a culturally safe environment for all disabled kaimahi and patients, particularly tāngata whaikaha Māori, as well as tagata sa'ilimalo, disabled women, the Deaf community, disabled people from ethnic communities and disabled people from Rainbow communities.

The health workforce, including mental health professionals, will have improved understandings and application of Te Tiriti and EGL principles as they apply to the health of disabled people, as well as improved understandings of disability rights and disability- and impairment-specific needs. This will include improved understandings of the needs of disabled older people, and of the sexual and reproductive health needs of disabled people, particularly disabled women and disabled people from Rainbow communities, including gender affirming health care. The health workforce will be supported to understand the rights and needs of disabled people and their whānau through appropriate funding, training and other supports, including wellbeing support.

The wellbeing of the workforce will be supported by the health system to enable the workforce to improve health and wellbeing outcomes for disabled people and their whānau. Working in the health system will be more rewarding and empowering, with greater opportunities to move between careers. Employers, regulators, educators and service designers will collaborate to enable the workforce to work flexibly, empowering them to deliver care where and how disabled people and their whānau need. This means a stronger inter-professional culture and leadership, fairer working conditions and embedding the norms of flexible working.

The Māori health workforce, including tāngata whaikaha Māori, will be representative of the Māori population and will have increased capacity and capability in both mainstream and kaupapa Māori health services.

What needs to change

Health entities need to:

- ensure the health system values the breadth of skills and capabilities required to support the health and wellbeing needs of disabled people and their whānau
- partner with disabled people and their whānau, iwi and Māori, Pacific, Rainbow and ethnic communities’ disability organisations to understand the skills and capabilities required to meet the health and wellbeing needs of disabled people and their whānau and design health services accordingly (This will provide opportunities for the workforce to utilise their skills and deliver models of care that meet the health and wellbeing needs of disabled people and their whānau.)
- support the health workforce to build the skills, capabilities and competencies needed to meet the breadth of health and wellbeing needs of the diverse disabled population, including:
  - rights-based and cultural safety training to enable the workforce to identify their biases and training to eliminate ableism, racism, sexism, homophobia, transphobia and other forms of discrimination from the health system
  - training to develop workforce competencies regarding disabled people’s sexual health and reproductive needs and experiences of violence and abuse
  - support to recognise the expertise and skills of disabled people’s whānau, carers and supporters, including through specific training on informed consent and supported decision-making
- support whānau, carers and supporters to upskill to better meet the health and wellbeing needs of disabled people and to enter the formal health workforce if they choose, including through tailored training programmes
- remove barriers for disabled people to complete health care qualifications and enter the health workforce (This will better enable the disabled health workforce to build the careers they want and work safely and effectively within a team to support better health outcomes for other disabled people and their whānau. It will require the health system to change how it develops and recognises skills and capabilities and change the models of working that are funded or encouraged, as well as safe working environments and enabling workplace cultures.)
- remove barriers for Māori, including tāngata whaikaha Māori, to complete health care qualifications and enter the health workforce
- ensure there is a sustained commitment to recruiting and investing in a diverse disabled health workforce in all health entities, including tāngata whaikaha Māori and tagata sa’ilimalo workforces (This will require sustained commitment to designing services that work for disabled people and creating employment conditions that are mana enhancing for and attractive to disabled people.)
- support the wellbeing of the disabled health workforce by providing accessible materials, workplaces and accommodation on the job, including flexible employment models
- explore health system-funded respite options to provide wellbeing support for unpaid whānau, carers and supporters

- work alongside cross-agency partners and non-governmental organisations, in partnership with disabled people and their whānau, to support flexible working and childcare arrangements for carers and supporters of disabled people.

Links to other pae ora strategies

The themes in this priority area link to the following sections in the other pae ora strategies.

- **New Zealand Health Strategy:** Priority 3 – Valuing our workforce
- **Pae Tū: Hauora Māori Strategy:** Priority 3 – Growing the Māori health workforce and sector to match community needs
- **Te Mana Ola: The Pacific Health Strategy:** Priority 5 – Kau ngāue (Workforce)
- **Women’s Health Strategy:** Priority 1 – A health system that works for women
- **Rural Health Strategy:** Priority 5 – A valued and flexible rural health workforce

Priority 5: Increase the visibility of disabled people in health data, research and evidence as part of an active learning system

What we heard from disabled people and their whānau

> ‘The Crown does not know who identifies as tāngata whaikaha Māori as no data is collected that allows us to self-identify as who we are. Nor for that matter have tāngata whaikaha Māori, whānau hauā and Māori with lived experience of disability, as a group or population, had any meaningful opportunity to develop collective identity that might be measurable’ – Dr Tristram R. Ingham, Testimony in Wai 2575 (Ingham 2023)
>
> ‘Good-quality data and research on disability are essential to provide the basis for policy and program[mes], resource allocation and to better understand issues and solutions in providing health care for disabled people’ – Submission to the Health of Disabled People Strategy
>
> ‘It is very difficult to establish prevalence rates for the abuse of disabled people because of the lack of systematic data collection’ – Submission to the Health of Disabled People Strategy

Why this is a priority

The health system has a responsibility to improve health outcomes for disabled people, which requires improved understanding of the size and demographics of the diverse disabled population. There is a lack of up-to-date, detailed data on the diverse disabled population in Aotearoa New Zealand. There is a particular absence of data on self-identified disability, on communities within the broader disability population and that captures disability alongside other identity markers, such as ethnicity, gender and sexuality.

Improved data and research identifying the diverse disabled population makes their health outcomes and needs visible to the health system. This, in turn, enables the health system to monitor outcomes accurately and actively for disabled people; plan, target and fund services, research and workforce to meet their needs; and identify and address barriers contributing to differences in outcomes between disabled and non-disabled people. Robust data also enables accurate performance reporting, monitoring and evaluation of health entities in meeting the health and wellbeing needs of disabled people.

We have heard that monitoring system performance for Māori, particularly tāngata whaikaha Māori, and holding the system to account for upholding Te Tiriti requires further development. Effective monitoring requires quantitative and qualitative insights based in the voices of tāngata whaikaha Māori, whānau, hapū, iwi and Māori communities.

We must have unified, enduring data gathering systems that are accessible to disabled people and where privacy and security are paramount. This data will need robust governance and alignment with respect to Māori data sovereignty protocols.

Disabled people and their whānau have told us that greater accountability is needed across the health system. This is to ensure that people can advocate for themselves and their whānau without fear of losing access to important services. They have also told us that the feedback loop between health agencies and the disability community needs to be improved so that disabled people and their whānau can see where and how their insights are leading to change to improve their health and wellbeing outcomes.

What it will look like in the future

We will have health data for disabled people and their whānau, including tāngata whaikaha Māori, that is meaningful, up to date and used to continuously improve the health system's ability to meet disabled people's needs. Accurate health data for disabled people will be reported regularly and used to inform commissioning and service design decisions.

Disabled people and their whānau will have authority over how their data is used within the health system and how health services are designed. The health system will ensure that disabled people, communities and organisations can determine the way health data for disabled people is collected, reported and interpreted for continuous quality improvement of health policies and services. Mechanisms to produce, manage, use and monitor data will include participation and leadership from, and respect for the rights of, disabled people, particularly tāngata whaikaha Māori. Health entities will regularly report on equity in health service provision and health outcomes for disabled people.

Disabled people and their whānau will have regular access to up-to-date, accurate and meaningful evidence and data relevant to their health and wellbeing needs. This includes access for tāngata whaikaha Māori to Māori health research and data. This evidence and data will be used for continuous health system improvement, to develop innovative solutions and to monitor progress in the health system.

There will be a specific focus on improved data collection for those who experience the greatest inequities within the disabled population. This includes tāngata whaikaha Māori, as well as tagata sa'ilimalo, disabled people from ethnic communities, disabled children and young people (including those in state care), disabled women, disabled people from Rainbow communities, people with intellectual and learning disabilities and people who are neurodiverse.

Disabled people and their whānau will play a leading role in planning, designing, implementing, monitoring and evaluating health services to best meet their own health and wellbeing needs. Measures of hauora for tāngata whaikaha Māori will reflect what is most important to tāngata whaikaha Māori and will consider mātauranga Māori practices and cultural expressions.

Health entities will report back to disabled people and their whānau regularly on how their insights are being leveraged to effect meaningful change.

What needs to change

Health entities need to:

- partner with disabled people and their whānau to collect robust, meaningful, timely and accurate data to be able to determine the health and wellbeing needs of disabled people and plan and monitor system performance (This includes commissioning and supporting the creation and maintenance of data frameworks and regularly reporting on accurate disaggregated data, such as ethnic-specific disability data and data on communities within the disabled population, particularly tāngata whaikaha Māori. Disaggregated data that maps to health data, including for rare and multiple coexisting conditions, will increase opportunities for service improvement.)
- support disability community-led research on the health and wellbeing needs and aspirations of disabled people and the interaction of disability with other identity markers (Priority populations for research include tāngata whaikaha Māori, people with self-identified disabilities, intellectually disabled people, neurodiverse people, people with disabling mental health conditions, people with chronic conditions, tagata sa’ilimalo, disabled people from Rainbow communities, disabled people from ethnic communities, disabled women, and disabled children and young people, including those in state care.)
- support research driven by Māori that evaluates the health and wellbeing needs and aspirations of tāngata whaikaha Māori
- enable regular, meaningful engagement and ongoing, reciprocal relationships with disabled people and their whānau, particularly with tāngata whaikaha Māori (This must include structures to ensure consistent feedback loops, so that disabled people and their whānau can see where and how their insights are leading to change.)
- regularly provide disabled people and their whānau with access to evidence and data
- provide appropriate monitoring and evaluation of equity of health care access, equitable quality of health care services and equity of health outcomes for disabled people and their whānau at all levels of the health system, including policy and service provision
- ensure all accountability and complaints mechanisms are timely, transparent, culturally safe, responsive and fully accessible to all disabled people and their whānau
- ensure health entities act to address inequities found in data, research and evidence between disabled and non-disabled people and within the disabled population.

Links to other pae ora strategies

The themes in this priority area link to the following sections in the other pae ora strategies.

- **New Zealand Health Strategy:** Priority 4 – A learning culture
- **Pae Tū: Hauora Māori Strategy:** Priority 5 – Ensuring accountability for system performance for Māori health
- **Te Mana Ola: The Pacific Health Strategy:** Priority 3 – Soalaupule (Autonomy and determination)
- **Women's Health Strategy:** Priority 1 – A health system that works for women
- **Rural Health Strategy:** Priority 1 – Considering rural communities as a priority group

Part 4: Delivering our commitment to change

Turning strategies into action

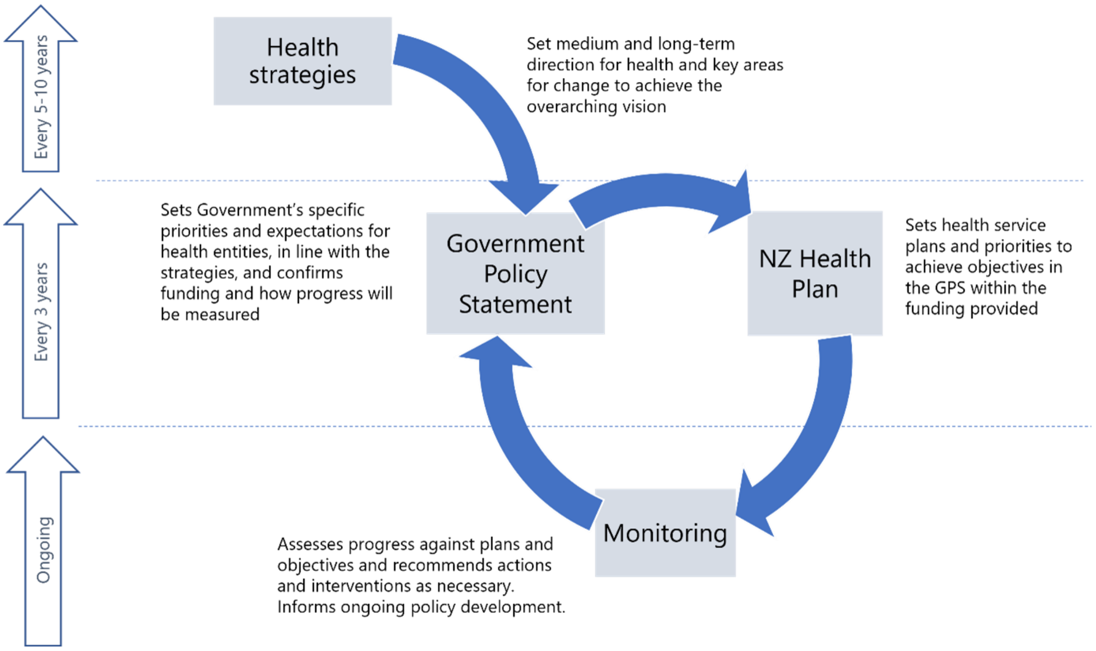
One of the objectives of the health system reforms is to better align and integrate the accountability arrangements that set direction and priorities for health agencies. The reforms put in place a new approach that aims to ensure clarity and coherence, from long-term strategic objectives to shorter-term priorities and expectations.

This new approach provides clear roles for key documents, underpinned by statutory requirements in the Pae Ora Act.

- Health strategies are intended to set a long-term (5 to 10 years) direction for improving health and identify priorities and opportunities for the health system. The strategies provide a vision and indicate the types of change necessary over the medium and long term. Strategies do not make commitments to particular actions or require health entities to undertake specific activities – instead, they describe potential choices and issues to be considered, to inform the decisions that the Government will make on what actions are taken forward and when. Health entities must take the strategies into account in carrying out their responsibilities.
- The Government Policy Statement (GPS) on Health sets out the specific priorities and expectations for the health system over a three-year period. It is the key document for Government to set its priorities, confirm actions for entities and funding for the health system and outline how success will be measured. The GPS will reflect the long-term direction of the strategies and include more detailed actions for health entities in the short term that work towards the strategy aims. The GPS is agreed by Ministers, and health entities must give effect to it.
- The New Zealand Health Plan (NZHP) is a three-year national service plan, that specifies the service priorities and areas for improvement that will achieve the Government's expectations in the GPS. The NZHP includes more detailed plans for health services, programmes and enablers that show how the health entities will meet priorities within the funding available. The NZHP is developed by health entities and approved by Ministers.

These documents work together to set a consistent direction for the health system, which is then developed into more specific actions and costed service plans that span a multi-year period, as shown in the figure below.

Figure 3: Relationships between health system direction-setting documents



Set medium and long-term direction for health and key areas for change to achieve the overarching vision

Sets Government's specific priorities and expectations for health entities, in line with the strategies, and confirms funding and how progress will be measured

Sets health service plans and priorities to achieve objectives in the GPS within the funding provided

Assesses progress against plans and objectives and recommends actions and interventions as necessary. Informs ongoing policy development.

This new approach provides a clear pathway for translating strategies into action and monitoring the impact of strategies and the performance of agencies. The role of health strategies is critical to providing the long-term vision and priority areas that inform decisions in the other documents.

As the Government determines the first three-year GPS, for 2024–2027, and in subsequent cycles, the strategies will be turned into clear expectations and actions that will provide the opportunity to achieve the changes set out.

Monitoring outcomes

The health strategies set a direction for achieving pae ora | healthy futures for all New Zealanders and include goals to eliminate health inequities and improve outcomes. Monitoring progress towards this vision requires a long-term approach to measuring key health outcomes.

The GPS will set requirements for measures and indicators that will be used to monitor the progress of the health system and individual entities in achieving these goals. These measures will combine more enduring and long-term outcomes that are intricately linked to the strategies, as well as more specific measures that reflect three-year priorities and help drive action in certain areas. They will support Manatū Hauora, in its stewardship role, to track delivery of the strategies and report on impacts over time.

Ensuring high-quality data will be essential to monitoring outcomes. This is particularly the case for monitoring inequities between population groups, which require a breakdown of data to make comparisons and develop insights.

The current health data sets contain numerous gaps, both for disabled people and their whānau and services (for example, primary and community health care), that will need to be addressed through purposeful, targeted data and analytics plans to ensure that the intended impact of the strategies can be appropriated monitored for all groups (see priority 5 for more detail).

Ongoing evaluation

In addition to monitoring the intended outcomes of the strategies to check on the success of their delivery, it is also important to ensure ongoing evaluation of the strategy direction itself to make sure it remains appropriate.

Over the coming years as the strategies are developed into firm actions in the GPS and NZHP and then implemented, it will be necessary to invest in ongoing research and evaluation to continue to build our understanding of the direction and evolve it where needed. This may include:

- evaluating the impact of the Pae Ora Act, the effectiveness of its implementation and lessons for the health system structure
- evaluating the new accountability approach, the roles of strategies, the GPS and NZHP and the effectiveness of their delivery and alignment in achieving health system goals
- evaluating the process undertaken to develop the health strategies, to draw insights on the benefits of different engagement approaches, analysis and development.

We will develop these evaluation areas further to help us refresh the approach to research across the health system.

Finalised Health of Disabled People Strategy

After we have published this provisional strategy, we will undertake further targeted engagement with the disability community. This will help us further shape the identified priority areas. We expect to publish the finalised Health of Disabled People Strategy once we have completed the targeted engagement process.

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Appendix: Definition of pae ora for Māori

Pae ora is a holistic concept that includes three interconnected elements: whānau ora, mauri ora and wai ora. Pae ora provides a platform for Māori to live with good health and wellbeing in an environment that supports them to flourish and thrive as Māori.

The concept encourages everyone in the health and disability system, as contributors to Māori wellbeing, to work collaboratively, to think beyond narrow definitions of health and provide high-quality and effective health services. Pae ora affirms holistic Māori approaches – strongly supporting solutions that are led by Māori and Māori models of health and wellness. Pae ora recognises the desire of Māori to have control over their future health and wellbeing.

Whānau ora	Whānau ora is a fundamental philosophy for creating strong, healthy and empowered whānau. A strong, healthy and empowered whānau can make the most significant difference to intergenerational Māori health and wellbeing. Whānau empowerment is shaped by access to quality information and advice, necessary resources, healthy living, a sense of agency and self-determination, and a conviction that the future can be created not simply endured.
Mauri ora	Mauri ora seeks to shift the mauri (or life force) of a person from one that is languishing to one that is flourishing. A strong, flourishing mauri requires interventions, services and treatments that foster healthy lifestyles, increase knowledge and power, strengthen identity, encourage self-management and restore dignity. Mauri ora has a spiritual dimension that recognises culture as a determinant of good health.
Wai ora	Wai ora acknowledges the importance of Māori connections to whenua (land) as part of the environments in which we live and belong and the significant impact of these environments on the health and wellbeing of individuals, whānau, hapū, iwi and Māori communities. An environment that is compatible with good health reflects the need for Māori to have access to resources (that is, good housing, safe drinking water, clean air, healthy food) and to live in environments that support and sustain a strong, flourishing mauri and a healthy and empowered whānau.