



**Whaikaha**  
Ministry of  
Disabled People



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# Briefing to the Incoming Minister

## **In Confidence**

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November 2023



**Te Kāwanatanga o Aotearoa**  
New Zealand Government

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# Welcome to the Disability Issues Portfolio

Congratulations on your appointment. Whaikaha – Ministry of Disabled People welcomes you to the Disability Issues portfolio.

To support you in your role, this briefing provides information on:

- your role as Minister for Disability Issues and the scope of the Disability Issues portfolio
- an overview of the disability system including the rationale for establishing Whaikaha – Ministry of Disabled People
- work underway to transform the disability support system, including the expansion of the Enabling Good Lives approach to reach more disabled people, tāngata whaikaha Māori (Māori disabled people), their families and whānau
- key upcoming matters requiring your attention.

The appendices include the following background information:

- a summary of key acronyms used in this briefing (**Appendix 1**)
- key information about the structure of Whaikaha – Ministry of Disabled People, our leadership team and their contact details (**Appendix 2**)
- information about the appropriation you are responsible (**Appendix 3**)
- a summary of key individuals and groups you may wish to meet as a priority (**Appendix 4**)
- the Terms of Reference for the New Zealand Sign Language Board (**Appendix 5**).

This briefing is focused on giving you a comprehensive but high-level overview. We have also prepared more detailed briefings on the following aspects of your portfolio:

- the System Transformation work programme
- an overview of disability support services funded by Whaikaha – Ministry of Disabled People
- the legislative work programme
- the financial outlook for disability support services
- litigation concerning paid family carers
- the work programme on safeguarding and abuse.

I will discuss with you your preference for how and when you receive these briefings.

Brian Coffey (MNZM), the Chief Advisor to the Chief Executive will be available to you and your office to ensure our support to you as Minister works well for you. Brian will work to establish good systems and processes for the flow of information and advice between Whaikaha – Ministry of Disabled People and your office.

We look forward to working with you and discussing how we can support you, your priorities, and your responsibilities.



Paula Tesoriero MNZM

Chief Executive

Whaikaha – Ministry of Disabled People

# Scope of the Disability Issues Portfolio

## As Minister for Disability Issues

You have a leadership role to promote the rights of, and opportunities for, disabled people and tāngata whaikaha Māori across all government portfolios.

You are also responsible for the \$2.3 billion annual appropriation within Vote Social Development: Supporting Tāngata Whaikaha Māori and Disabled People. This includes funding for disability support services for approximately 50,000 disabled people and equipment modification for approximately 100,000 people. **Appendix 3** provides details of this appropriation.

As Minister for Disability Issues, you lead the direction in how disabled people<sup>1</sup>, tāngata whaikaha Māori<sup>2</sup> and their whānau are supported to have greater choice and control over their lives and to realise their full potential.<sup>3</sup>

You are the responsible Minister for Whaikaha – Ministry of Disabled People and are accountable to Parliament for the overall efficiency and effectiveness of the Ministry.

## The Disability Issues portfolio

The Disability Issues portfolio covers the following.

- Oversees the delivery of supports for the day to day lives of almost 50,000 disabled people under the age of 65 and equipment and modification supports for 100,000 people.
- Co-ordinates the government's response to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).
- Champions transformation in how disability supports are designed, funded, and delivered to disabled people, and their whānau, in line with the Enabling Good Lives vision and principles.
- Supports a shift from the "medical model" of disability towards a "social model" which sees a person as being disabled by society rather than their impairments. This model supports self-determination and focuses on

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<sup>1</sup> There is ongoing debate about the language used around disability, particularly in terms of identifying as a disabled person or as a person with a disability. 'Disabled people' was the agreed term in the 2001 New Zealand Disability Strategy developed by disabled people and is the generally accepted terminology in Aotearoa New Zealand.

<sup>2</sup> Disability, as described above, is not a Māori concept. Many tāngata whaikaha Māori view themselves as whānau and identify as Māori first. The removal of cultural and accessibility barriers to living this identity is a key issue for many tāngata whaikaha Māori.

<sup>3</sup> There are many different terms our communities use to identify themselves and disabled people and tāngata whaikaha Māori are just two of them. For the purposes of brevity, this briefing will use these terms when referring to a general group including tāngata whaikaha Māori, whānau hauā, Deaf people, Pacific disabled people and whānau.

reducing environmental and social barriers while also supporting the opportunity for (re)habilitation<sup>4</sup>.

- Stewards a more joined-up and effective cross-government disability system which is better equipped to promote equity for disabled people.
- Ensures disabled people, tāngata whaikaha Māori and their whānau are included in efforts to promote equity as experts in their own lives.
- Supports the Crown to meet its Te Tiriti o Waitangi/Treaty of Waitangi obligations through effective partnerships with, and interventions for, tāngata whaikaha Māori and their whānau.

## Appropriation responsibilities

The \$2.3b multi-category appropriation (MCA) *Supporting tāngata whaikaha Māori and disabled people* is part of Vote Social Development and funds Whaikaha – Ministry of Disabled People operations.<sup>5</sup>

The Chief Executive of the Ministry of Social Development (MSD) is the administrator of Vote Social Development and is responsible to the Minister for Social Development and Employment for the administration of the Vote.

Whaikaha – Ministry of Disabled People is a Departmental Agency hosted by MSD. In practice, the Chief Executive of Whaikaha – Ministry of Disabled People manages the MCA on a day-to-day basis. Whaikaha – Ministry of Disabled People broadly operates as its own Ministry, with MSD playing a role in providing financial assurance to the Government and sign-off from the MSD Chief Executive required as part of material financial matters (e.g., setting the annual budget).

The MCA includes departmental expenditure (costs for running the Ministry) and the Chief Executive of Whaikaha – Ministry of Disabled People is directly responsible for this to the Minister for Disability Issues. The MCA also includes non-departmental expenditure (costs incurred on behalf of the Crown for the provision of supports to disabled people) for which the Chief Executive of MSD

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<sup>4</sup> 'Habilitation' refers to a process aimed at helping people gain certain new skills, abilities, and knowledge. 'Rehabilitation' refers to re-gaining skills, abilities or knowledge that may have been lost or compromised as a result of acquiring a disability, or due to a change in one's disability or circumstances. Both habilitation and rehabilitation are recognized by the United Nations as a key part of the social model of disability, as ensuring effective rights for disabled people in practice requires both that social and environmental barriers are removed and that individuals and whānau can access effective (re)habilitation to support their inclusion in society. For example, if their language has been affected by an accident or supporting a disabled person to learn how to communicate when their impairment makes a non-standard form of communication more effective.

<sup>5</sup> Public Finance Act 1989, s7c(2)(c)(i) covers the departmental expenditure component. By mutual agreement, the Chief Executive of MSD can delegate financial management of the non-departmental expenditure to the Chief Executive of Whaikaha – Ministry of Disabled People.

(as Appropriation Administrator) is responsible to the Minister for Disability Issues.

## Legislation governing the provision of disability support services

The funding and delivery of disability support services sits within a legislative framework made up of the following statutes.

- **Pae Ora (Healthy Futures) Act 2022** – provides for the funding and provision of health and disability support services and establishes the Health Quality and Safety Commission. The Act also currently hosts the legislative basis for the New Zealand Disability Strategy 2013-2023.
- **Health and Disability Commissioner Act 1994** – promotes and protects the rights of health consumers and disability service consumers by establishing the Health and Disability Commissioner, a Code of Health and Disability Services Consumers Rights, a Consumer Advocacy Service, and investigations into complaints.
- **The Health and Disability Services (Safety) Act 2001** – promotes the safe and quality provision of health and disability services to the public, including by setting standards and auditing performance.
- **Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003** – provides a compulsory care and rehabilitation option for people with an intellectual disability who are charged with, or convicted of, an offence, to safeguard these individuals and provide a framework for the different levels of care. s9(2)(f)(iv)

# An overview of disability

## Disability in Aotearoa New Zealand

Disability has a complex history in Aotearoa New Zealand. Disabled people and tāngata whaikaha Māori have been targets of eugenics, excluded from society, and denied basic dignity and rights. The 'medical model' of disability holds that disability lies with the individual and that a disabled person needs to adapt or be cured to fit their environment and society. This model has informed harmful attitudes and practices towards disabled people in Aotearoa New Zealand and is outdated, although elements persist today.

Disabled people and tāngata whaikaha Māori have advocated for many years for a move away from the negative framing and medical model of disability. They have advocated for the right to be involved in work and decisions that affect them and their lives, and to be recognised as experts and leaders in their own lives and communities.

The New Zealand Disability Strategy (NZDS) adopts the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 'social model' of disability. This model encompasses a whole-of-life, strengths-based approach and aims to ensure all disabled people can enjoy meaningful fulfilment of their human rights to achieve their full potential. The social model recognises individuals have impairments<sup>6</sup>, but rather than the impairment disabling a person, the experience of disability occurs when:

- people with impairments are excluded from places and activities
- infrastructure and systems (the built environment) do not accommodate the diverse needs of all citizens
- there is a lack of willingness to make reasonable personalised accommodations for disabled people when effective universal design of environments and systems still do not meet a person's impairment needs
- information is not provided in accessible formats (e.g. New Zealand Sign Language)
- attitudes prevent people with impairments from participating in society on an equal basis with non-disabled people.

This sees disability as arising from systems, attitudes, and structures rather than the individual with impairments.

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<sup>6</sup> An impairment refers to a limitation in function that prevents a person from carrying out certain tasks and functions in their daily lives without support. Examples of common impairments include deafness, blindness, or inability to walk. It is important to note that disablement occurs when a person with an impairment is not supported to participate on an equal basis with others and the social model places responsibility for this exclusion on systems, attitudes and environments – not the person.



A core reason for the establishment of Whaikaha – Ministry of Disabled People was to work across government to address these multiple barriers.

## The disabled population at a glance

There are an estimated 1.1 million disabled New Zealanders (24% of the population), based on data collected in the 2013 *Disability Survey*<sup>7</sup>.

Depending on the scale and type of an individual's impairment,<sup>8</sup> and the degree of support available to enable them to access services, they fit into one of three broader groups:

- people who require significant ongoing support from Government<sup>9</sup>
- people who can be adequately supported through a combination of minor or moderate supports and accessibility improvements<sup>10</sup>
- people with temporary impairments<sup>11</sup>.

Disability varies by demographic variables such as gender, ethnicity, and age. Women are more likely to be impaired due to disease, illness and ageing while men are more likely to be impaired because of accidents, injury, or existence of impairment from birth. Disability is more frequent among younger males and conversely more common among older females.

Of those who reported being disabled in the 2013 *Disability Survey*:

- 842,000 (72%) were European, with a disability rate of 25%
- 176,000 (15%) were tāngata whaikaha Māori, with a disability rate of 26%

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<sup>7</sup> The collection phase of the 2023 Disability Survey has started. The survey is expected to be completed by the end of 2023 with initial results available in late 2024. It is expected that the proportion of disabled people will grow due to population growth and an aging population.

<sup>8</sup> The causes of impairment vary greatly, including existing from birth, injury, a health condition, or as a part of natural ageing. In Aotearoa New Zealand, the most common cause of impairment for adults was disease or illness (42 percent). For children, the most common cause was a condition that existed at birth (49 percent).

<sup>9</sup> This group includes almost 50,000 people supported by DSS, 10,645 students receiving the Ministry of Education's Ongoing Resourcing Scheme, and 31,600 older people supported into residential care by Te Whatu Ora (Health NZ). This group receives the bulk of government investment.

<sup>10</sup> Includes 218,727 disabled people receiving a disability allowance, 100,878 receiving Supported Living Payments and receiving employment supports from the Ministry of Social Development and 43,000 Total Mobility clients supported by Waka Kotahi (New Zealand Transport Agency) and local councils.

<sup>11</sup> The common method used to identify disabled people in data does not sufficiently differentiate between people with permanent and temporary impairments, such as broken legs or concussions. There are also challenges related to people with periodic impairments, such as chronic pain or Post-Traumatic Stress Disorder, who are disabled but do not respond consistently to standard impairment questions.

- 60,000 (5%) were Asian, with a disability rate of 13%
- 51,000 (4%) were Pacific peoples, with a disability rate of 19%.

Disability is strongly correlated with age. In the 2013 *Disability Survey* there were:

- 95,000 disabled children (aged 0 to 14 years) with a disability rate of 11%
- 283,000 disabled adults (aged 15 to 44 years) with a disability rate of 16%
- 314,000 disabled older adults (aged 45 to 64 years) with a disability rate of 28%
- 370,000 disabled seniors (aged over 65) with a disability rate of 59%.

There are notable differences in the prevalence of disability across ethnic groups in different age brackets. Māori have the highest disability rates across the 0-14, 15-44 and 45-64 age brackets. More than two-fifths of Māori aged 45-64 are disabled, which is 1.5 times the disability rate of NZ Europeans in this age bracket. Pacific elderly (aged over 65) have the highest disability rates of 1.3 times the disability rate of NZ Europeans in this bracket.

Challenges related to disability frequently intersect with key issues for each of these groups. For example, the inability to acquire an affordable and accessible vehicle for young disabled people to travel around and be independent; or the need for New Zealand Sign Language (NZSL) interpreters with cultural capability to translate Māori concepts to enable Tūri Māori (Māori with lived experience of being Deaf or Hard of Hearing) to participate in their culture.

## Disabled people in Aotearoa New Zealand experience poorer outcomes

Disabled people experience poorer outcomes than non-disabled<sup>12</sup> New Zealanders on almost any available metric. The Statistics New Zealand (Stats NZ) June 2022 *Wellbeing Survey* indicated disabled people were *less likely* (emphasis added) than non-disabled people to report:

- *having excellent or very good health* – 44% of disabled people rated their health as fair/poor, compared to 14% of non-disabled people
- *having enough or more than enough money to meet daily needs* – 42% of disabled people reported having enough, compared to 46% of non-disabled people

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<sup>12</sup> The term 'non-disabled' is preferred over 'able-bodied' as the latter implies mana or status to not having a disability.

- *having not felt lonely in the last four weeks* – 42% of disabled people reported feeling lonely none of the time, compared to 56% of non-disabled people
- *no major problems (cold, damp, mould) at home* – 56% of disabled people reported their home is not damp, compared to 61% of non-disabled people.

Household Labour Force Survey data published in August this year indicates that disabled people have significantly lower labour market participation than non-disabled people – 44 percent compared with 85 percent. They also have significantly higher unemployment, and lower median wages and salaries. Of particular concern is that the percentage of young disabled people not in education, employment or training has risen to 44 percent, having dropped from 49 percent to 32 percent between 2020 and 2022.

*A Great Start? Education for Disabled Children in Early Childhood Education and Thriving at School? Education for Disabled Learners in Schools* was released by the Education Review Office in September 2022. The report highlighted:

- one fifth of disabled learners had been discouraged from enrolling at a local school and a quarter of disabled learners had been asked to stay at home
- secondary school disabled learners are two to three times more likely to be stood down or suspended than non-disabled learners
- one in four secondary school disabled learners also indicated that they were not supported to take the courses that interested them most
- more than a quarter of disabled learners do not feel accepted for who they are and almost a third do not feel they belong at school.

Tāngata whaikaha Māori, Pacific disabled people and other intersectional disabled populations experience greater disadvantage than other disabled people across most domains.

## Access to targeted disability supports across government

Specific supports for disabled people are commissioned, funded, or provided through various agencies, including Whaikaha – Ministry of Disabled People, MSD, Te Whatu Ora (Health New Zealand), Te Aka Whai Ora (Māori Health Authority), the Accident Compensation Corporation (ACC) and the Ministry of Education.

Supports for disabled people are fragmented and do not form a coherent system. Disabled people and their whānau report that the disability system is difficult to navigate, and that they would like to see a more consistent system that aligns with the social model of disability and, for tāngata whaikaha Māori and their whānau, is consistent with te ao Māori (the Māori world).

## Stewardship of disability across government

Responsibilities for enabling the full participation of disabled people and tāngata whaikaha Māori in our society are shared across the government agencies that deliver services and supports for New Zealanders (for example, health, education, transport). This recognises that the key barriers facing most disabled people relate to the accessibility of the services and supports available to all New Zealanders.

Health agencies, for example, are responsible for ensuring disabled people can enjoy the highest attainable standard of health.<sup>13</sup> As with specific disability supports, different agencies have adopted different approaches to ensuring equity for disabled people and this has led to inconsistencies across government.

Whaikaha – Ministry of Disabled People has a Cabinet-mandated role to lead and co-ordinate strategic disability policy across government. In practice, this requires us to reflect on priority issues across government and work with other agencies to ensure efforts are being made to improve outcomes for disabled people and tāngata whaikaha Māori and their families and whānau<sup>14</sup>.

Aotearoa New Zealand’s Independent Monitoring Mechanism for the UNCRPD<sup>15</sup> has noted that housing, education, and employment are among the most pressing issues for disabled people and Whaikaha – Ministry of Disabled People is prioritising its stewardship work to improve outcomes in these areas.

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<sup>13</sup> Article 25 of the UNCRPD requires state parties to “recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”.

<sup>14</sup> Importantly, this does not mean Whaikaha takes on responsibility for work by other agencies to promote better outcomes for disabled people. Improving health outcomes, for example, remains the responsibility of health agencies. We do, however, have a responsibility to establish settings that promote consistency and co-ordination between agencies. A good example of this is the Accessibility for New Zealanders Bill, which proposes to establish a system for identifying and making recommendations to remedy accessibility barriers across government.

<sup>15</sup> The IMM promotes, protects, and monitors implementation of the UNCRPD in Aotearoa New Zealand under article 33. The IMM consists of the Human Rights Commission, the Office of the Ombudsman, and the Disabled People’s Organisations Coalition. More information on the IMM and the key organisations within it can be found in **Appendix 4**.

## Key inquiries

Three inquiries are currently underway which will have significant findings and implications for disabled people and for the supports funded and delivered by Whaikaha – Ministry of Disabled People. These are:

- the Abuse in Care Royal Commission of Inquiry
- the Waitangi Tribunal Health Services and Outcomes Kaupapa Inquiry (WAI 2575) and
- the All of Government COVID-19 Royal Commission of Inquiry.

We will brief you separately on the issues being considered in these inquiries and the processes and timelines for a response by the Government.

# The Role and Functions of Whaikaha – Ministry of Disabled People

As noted, Whaikaha – Ministry of Disabled People (the Ministry) has a dual mandate made up of two broad roles.

- To lead strategic disability policy across government to better outcomes for disabled people and tāngata whaikaha Māori.
- To transform the disability system in line with Enabling Good Lives principles, starting with disability support services (DSS) funded by the Ministry, and to ensure the effective delivery of DSS.

A summary of each role can be found below.

## Stewarding Strategic Disability Policy

Beyond the disability support system, disabled people experience poor outcomes across a range of domains including health, education and employment.

Disabled people, tāngata whaikaha Māori, their families and whānau advocated for decades for disability to be treated as an issue separate from the health system and for the creation of a standalone disability ministry to tackle these issues. The 2022 Health and Disability System Reforms provided an opportunity to respond to this.

In October 2021, Cabinet agreed to establish Whaikaha – Ministry of Disabled People as a departmental agency, hosted by MSD, to lead change across government to improve outcomes for disabled people and to support the shift of DSS towards a social model of disability.

This meant administration of DSS functions and responsibility for the three Enabling Good Lives sites<sup>16</sup> would sit outside the health system.<sup>17</sup> In addition, these were to be delivered by an agency with a focus on driving improved outcomes for disabled people.

The Ministry combines a significant service commissioning and delivery responsibility with the cross-Government stewardship role of a population Ministry.

The establishment of Whaikaha – Ministry of Disabled People sees Aotearoa New Zealand as an international leader in promoting the rights of disabled people, tāngata whaikaha Māori and their whānau.

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<sup>16</sup> Enabling Good Lives sites are parts of DSS that operate in a manner more consistent with Enabling Good Lives. These sites are located in Christchurch, Waikato and MidCentral and have informed the development of and evidence base for ongoing transformation work. Detail on each of these sites can be found below.

<sup>17</sup> The Waikato demonstration was already provided by MSD outside the health system.

Whaikaha – Ministry of Disabled People has three key roles to lift the profile of disability across government and improve outcomes for disabled people and tāngata whaikaha Māori.

- Realising a partnership between government and disability communities as articulated in Te Tiriti o Waitangi/Treaty of Waitangi, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and the New Zealand Disability Strategy.
- Transforming the disability system in line with the Enabling Good Lives vision and principles, starting with the \$2.2 billion of DSS commissioned by the Ministry.
- Supporting other government agencies to incorporate disability perspectives and needs into their policies and services so they meet their responsibilities to disabled people and whānau in a consistent and joined-up way. We do this by:
  - leading and co-ordinating across government work on the progressive realisation of the UNCRPD, and the development and implementation of the New Zealand Disability Strategy and Action Plans
  - providing a disability perspective on Cabinet papers to ensure policy and services do not create difficulties for disabled people and enhance disabled peoples’ rights and opportunities
  - amplifying the voice of disabled people within government by sharing data and promoting effective engagement practices
  - providing secretariat support for the Ministerial Leadership Group on Disability Issues<sup>18</sup>, Disability Data and Evidence Working Group<sup>19</sup>, New Zealand Sign Language Board and other groups
  - responding to requests from agencies on policy work and participating in advisory groups
  - working with the Public Service Commission to lead the Papa Pounamu diversity and inclusion work programme for the Public Service
  - maintaining a disability nominations database connecting disabled candidates to State sector governance boards

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<sup>18</sup> Previous Ministers of Disability Issues have convened a Ministerial Leadership Group on Disability Issues that has met regularly with the Independent Monitoring Mechanism to discuss priorities and progress in relation to Aotearoa New Zealand’s response to the United Nations Convention on the Rights of Persons with Disabilities.

<sup>19</sup> The Disability Data and Evidence Working Group comprises officials, representatives from Disabled People’s Organisations and groups interested in disability research. The group is co-chaired by Whaikaha – Ministry of Disabled People and Statistics NZ.

## Transforming DSS to reflect the Enabling Good Lives approach

The current disability support system does not perform well for disabled people.

In 2008 the Social Services Committee undertook a cross-party review of supports for disabled people, including DSS, and found that the government supports for disabled people were fragmented across agencies and disability was often treated as a niche issue within said agencies and did not receive the attention required.

This review, combined with the aspirations of the disability community detailed in the Enabling Good Lives Vision and Principles, prompted and informed a new stream of work aimed at transforming DSS to provide more choice and control and better outcomes for disabled people and tāngata whaikaha Māori.

Responsibility for the effective delivery of DSS and the transformation of these supports is now a core function of Whaikaha – Ministry of Disabled People. More detail on efforts to transform DSS can be found below.

### Progress Towards Full Establishment

The establishment of Whaikaha – Ministry of Disabled People is being progressed in three parallel stages:

- Establishment and ongoing transition activities - January 2022 to October 2022
- Consolidation – July 2022 to July 2024
- Transformation – July 2023 onwards.

Since 1 July 2022, the Ministry has:

- appointed a permanent Chief Executive and leadership team
- established our organisational structure
- begun work on the legislative work programme<sup>20</sup>
- drawn down the \$73 million tagged contingency to enable expansion of the Enabling Good Lives approach to two further sites (this is discussed in more detail at page 25)
- initiated key transformation projects such as My Home, My Choice<sup>21</sup>
- led the Government delegation to Geneva for the 2022 United Nations Convention on the Rights of Persons with Disabilities examination and

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<sup>20</sup> More information on this can be found below and you will receive a briefing on this shortly.

<sup>21</sup> The My Home My Choice programme is working to transform the way people in residential services are assisted so they have more choice and control in their lives. This means ensuring a range of options are available for people who want alternatives to residential care, and increasing agency and citizenship for people who choose to live in residential services.



coordinated the Government's response to the Concluding Observations from UNCRPD

- released the High and Complex Needs Framework Strategy to support people with intellectual disabilities that have committed a crime
- established an initial set of partnership structures involving disabled people and tāngata whaikaha Māori and their families and whānau to guide key workstreams.

The disability community has high expectations of Whaikaha – Ministry of Disabled People and there is still much work to do to live up to these expectations and the mandate given to us by Cabinet.

## Our Three Pou

Three Pou (or pillars) provide the framework to guide how Whaikaha – Ministry of Disabled People works, behaves, what we value and our relationships with others.

- **Te Tiriti o Waitangi/the Treaty of Waitangi** – meeting Te Tiriti o Waitangi obligations by supporting the Crown to partner with Māori to transform the disability system and achieve equitable outcomes for tāngata whaikaha Māori.
- **Enabling Good Lives (EGL)** – disabled people and their whānau will have greater choice and control over their lives and supports and make more use of natural and universally available supports to realise their full potential.
- **United Nations Convention on the Rights of Persons with Disabilities** – an international human rights treaty that sets out what is required to implement existing human rights as they relate to disabled people. New Zealand was a leader in negotiating the Convention and ratified it on 26 September 2008.

## Partnership arrangements

Whaikaha – Ministry of Disabled People has a Cabinet-mandated role to lead a partnership between the disability community, Māori, and Government. As such, partnering with the disabled community and tāngata whaikaha Māori and their families and whānau is key to our work.

We are in the process of establishing six partnership structures. We will keep you updated on the implementation of these arrangements.

- *Transformation Management Board*: This Board provides governance for the transformation work programme as part of the Executive Leadership Team meeting cycle.
- *Strategic Advisory Group*: provides strategic advice on major work items including policy work, strategic intentions, Cabinet papers and the impact of change on the lives of disabled people.

- *Insights Alliance*: oversees the monitoring and evaluation of the Enabling Good Lives system transformation and the implementation of the Monitoring, Evaluation, Analysis and Learning framework.
- *Rangatahi / Youth network*: provides a forum for young disabled people to input to changes that will help them lead good lives.
- *Family / Whānau Network*: represents the interests of family and whānau in improvements to enable disabled people and tāngata whaikaha Māori to lead good lives.
- *Transformation project groups*: the first group, My Home My Choice, Nōku te kainga noho – Nōku te whakatau oversees and informs the design, implementation and evaluation of the project that supports people in residential services to have more choice and control over their lives.

## Voice Mechanisms

Our partnership role includes broader communities of disabled people and tāngata whaikaha Māori and their families and whānau<sup>22</sup> having a voice in what matters to them and knowing they can inform and influence decision-making.

After so many years of not being at the table when decisions are about them are made, disabled people are working with Whaikaha – Ministry of Disabled People to create voice mechanisms that work for them. These include inviting us to join their meetings and creating sustainable mechanisms such as Memorandum of Understanding. The Ministry is working with disabled people’s networks to co-design face-to-face engagements to hear from communities in strategies and medium-term action plans.

In our stewardship role, and as we refresh the Disability Action Plan, we will work to improve cross-agency systems for gathering and analysing community voice to inform policy advice and services.

## Community Capability Building

A key function of Whaikaha – Ministry of Disabled People is to build the capability of disabled people, tāngata whaikaha Māori and their communities so that their voices are central to decision-making about how they are supported to live good lives.

The mechanisms that have developed around Enabling Good Lives illustrate how disabled people can provide regional leadership.

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<sup>22</sup> Tāngata whaikaha Māori, Pacific disabled people, disabled children and their families and whānau have historically been underrepresented in government engagements on disability issues. Whaikaha is progressing work to remedy these inequities both via this partnership stream and dedicated work alongside the development of key strategies including the refresh of the Disability Action Plan, Whāia Te Ao Mārama and the Pacific Disability Action Plan.

We have committed \$1 million to strengthen Regional Leadership Capability over the next year, and a similar sum to support national organisations to involve and hear from a wide range of disabled people.

This capacity and capability building will support disabled people, families and whānau to make decisions for themselves, make use of available resources, partner with government and advocate for themselves and their communities.

## Key Strategies and Action Plans

Whaikaha – Ministry of Disabled People is responsible for five strategies and action plans, all of which are due to be refreshed during this term of Government.

- **New Zealand Disability Strategy (2016–2026)** – The Pae Ora (Healthy Futures) Act 2022 requires the Minister for Disability Issues to determine a strategy for disability support services, called the New Zealand Disability Strategy. It provides the framework for the Government’s overall direction of the disability sector in improving disability support services. The current strategy is New Zealand’s vehicle for the progressive realisation of New Zealand’s commitments under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and runs until 2026. s9(2)(f)(iv)
- **Disability Action Plan (2019–2023)** – 29 comprehensive, cross-government work programmes that have an explicit disability perspective and support the implementation of the Disability Strategy. The current Action Plan is due for a refresh, and work to update the plan has commenced. s9(2)(f)(iv)
- **New Zealand Sign Language Strategy (2018–2023)** – sets out the work required of the New Zealand Sign Language (NZSL) Board and government agencies to maintain and promote NZSL as an official language. This Strategy expires at the end of this year.
- **Whāia Te Ao Mārama: The Māori Disability Action Plan (2018–2022)** – a culturally anchored approach to supporting tāngata whaikaha Māori and their whānau. The plan needs to be updated to reflect disability reform, and to strengthen delivery through actions underpinned by Te Tiriti o Waitangi. Whaikaha – Ministry of Disabled People is working with Te Ao Mārama Aotearoa and kaupapa Māori, tāngata whaikaha Māori and whānau hauā roopu to review and update the plan.
- **Faiva Ora National Pasifika Disability Plan (2016–2021)** – Whaikaha – Ministry of Disabled People is currently refreshing a National Pacific Disability Action Plan to drive improvements in Pacific disability wellbeing, with defined actions and accountability measures. s9(2)(f)(iv)

## Disability support services and System Transformation

A key function of Whaikaha – Ministry of Disabled People is the commissioning and delivery<sup>23</sup> of disability support services (DSS) for people with a long-term physical, intellectual and/or sensory impairment that arises before age 65<sup>24</sup>. This is supported by a \$2.2 billion annual appropriation.

We commission DSS for almost 50,000 disabled people, tāngata whaikaha Māori and whānau who are generally aged under 65 years. Annually we support around 100,000 people with equipment or modification services (all ages).

To be eligible to be assessed for DSS a person must:

- have an intellectual, sensory, or physical disability or Autism (or a combination of these); and
- their impairments are likely to continue for at least six months; and
- their impairments limit their ability to function independently, to the extent that ongoing support is required.

Disabled people receiving DSS span six impairment groups: Autism, Intellectual Disability, Neurological, Physical, Sensory, and Other.

The fastest growth in eligible disabled people receiving DSS is in the under 15 age group, and the Autism group. Both of these trends reflect the clarification in 2014 that people with autism are eligible for DSS. DSS eligibility criteria has not been substantively reviewed since 1994 and there is growing advocacy from disabled people to do so. The Ministry is in the early stages of scoping a review of eligibility.

Whaikaha – Ministry of Disabled People has around 800 contracts with 476 disability support providers. Some providers are small and only serve their local communities, while others deliver nationwide supports.

Core funded supports range from equipment to support to retain independence, through to support with daily activities (e.g., personal care, household management), through to 24/7 residential support, as well as supporting family

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<sup>23</sup> Whaikaha – Ministry of Disabled People does not provide supports directly. Supports funded by us are provided by third party providers and Te Whatu Ora administers and pays Whaikaha – Ministry of Disabled People contracts via a shared services agreement.

<sup>24</sup> If a person's impairment arises over 65, they are referred to Te Whatu Ora to receive support via the health of older people system. If a person turns 65 in the care of Whaikaha – Ministry of Disabled People, they will typically continue to receive that support until they are found eligible for supports via Te Whatu Ora. DSS and Te Whatu Ora NASCs will also be in contact to help ensure the person receives support that meets their needs.

caregivers (payment for care and respite support). Support takes place in communities<sup>25</sup>, private homes, and residential homes.

Most of the supports we fund are allocated via a Needs Assessment and Service Co-ordination service (NASC). NASCs work with disabled people, whānau and carers to identify a disabled person’s strengths, goals, support needs, and eligibility for DSS. They also assist with accessing other supports that might be needed. There are ten NASCs that operate across Aotearoa New Zealand.

## Enabling Good Lives and System Transformation

The Cabinet decision to establish Whaikaha – Ministry of Disabled People included a mandate for the Ministry to lead the long-term transformation of the disability system, starting with DSS.

In 2011, a disability sector working group produced a report on “Enabling Good Lives”, which recommended facilitation-based<sup>26</sup> transformation of the disability support system guided by the Enabling Good Lives vision and principles, set out below. These principles are intended to guide all interactions that any organisation or government agency has with disabled people.

Principle	Description
<b>Self-determination</b>	Disabled people are in control of their lives.
<b>Beginning early</b>	Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.
<b>Person-centred</b>	Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.
<b>Ordinary life outcomes</b>	Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.
<b>Mainstream first</b>	Disabled people are supported to access mainstream services before specialist disability services.
<b>Mana enhancing</b>	The abilities and contributions of disabled people and their families are recognised and respected.
<b>Easy to use</b>	Disabled people have supports that are simple to use and flexible.
<b>Relationship building</b>	Supports build and strengthen relationships between disabled people, their whānau and community.

<sup>25</sup> Support in communities refers to support outside a person’s residence, like assistance shopping or accessing local amenities.

<sup>26</sup> This stems from “Independent Facilitators” having a central role. They support people to plan for the life they are seeking and connect them to support that can assist them to create that life. There is a preference for accessing support available within the community before accessing disability support funding.

Since 2012, three Enabling Good Lives pilot/demonstration sites have been implemented. These build on a disabled person's strengths through:

- Connectors/Kaitūhono working alongside disabled people to develop plans for their life that is connected to the community. They support disabled people to build their life through connecting them to the community and to supports that are available to people generally (e.g., schools, other government services or local council services)
- disabled people seeking funding that can be used flexibly so that it supports them to build their life through complementing community-based support.

This approach contrasts with the current system which generally provides centrally designed and pre-determined supports in response to identified needs (meaning the focus is on what the disabled person cannot do, rather than on what they can and want to do).

The three Enabling Good Lives (EGL) sites are:

- EGL Christchurch - established in 2013 with a focus on young people aged 14 years and older in receipt of Ministry of Education Ongoing Resourcing Scheme funding and support. Enabling Good Lives Christchurch currently supports 800 people.
- EGL Waikato - established in 2015 and allows people to "opt-in" to the programme after they meet DSS eligibility criteria. Enabling Good Lives Waikato is a smaller-scale demonstration project and supports 600 people<sup>27</sup>.
- Mana Whaikaha - established in 2018 as a prototype of a transformed system in the MidCentral region (based around Palmerston North). All DSS-eligible people in the region can access support. Currently almost 3,000 people are supported by Mana Whaikaha.

Qualitative data gathered from each Enabling Good Lives site demonstrates positive impacts of the approach on the lives of disabled people, including:

- improved independence, self-confidence and personal development, expanded social networks, and opportunities to do things not possible under the previous system
- tāngata whaikaha Māori, Pacific disabled people and disabled children and young people reported increased uptake of and satisfaction with supports.

In 2021, Cabinet endorsed the Enabling Good Lives prototype in Mana Whaikaha as the basis for transforming the DSS nationally.

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<sup>27</sup> There is a waiting list to access the Enabling Good Lives Waikato demonstration, which is why only 600 people are served currently.

In August 2023, Whaikaha – Ministry of Disabled People received approval to draw down a Budget 2022 contingency of \$73.7 million over four years, with outyear funding of \$40.5m from 2027/28.

The full transformation work programme is subject to future Cabinet policy and funding decisions.

The Ministry is working with the Social Wellbeing Agency to analyse data in the Integrated Data Infrastructure to better understand how the Enabling Good Lives sites have changed uptake and outcomes for disabled people receiving DSS. This work will give us a more detailed understanding of how uptake, cost and benefits of DSS might change if the Enabling Good Lives approach is rolled out across the country.

We have prepared a more detailed briefing on Enabling Good Lives and System Transformation, and proposals for the funding drawn down earlier this year.

## Matters requiring your early attention

This section provides an overview of matters that will require decisions in the coming weeks and months.

### Government Response to the United Nations Convention on the Rights of Persons with Disabilities Concluding Observations

In August 2022, the previous Minister for Disability Issues led a government delegation to participate in an examination by the United Nations Committee on the Rights of Persons with Disabilities of Aotearoa New Zealand's progress on disability rights.

The Government confirmed its response to the Committee's report in July 2023. Cabinet agreed to progress work on 51 of 60 Concluding Observations<sup>28</sup>. 9 Observations were noted as not to be progressed at this time.

Whaikaha is leading a process with cross-government agencies to develop high-level implementation plans towards the 51 Observations agreed.

The Minister for Disability Issues is currently due to report back to Cabinet by 1 December 2023 on progress with this work and to seek agreement on an appropriate monitoring mechanism. s9(2)(f)(iv)

### Appointments to the New Zealand Sign Language Board

You are responsible for making appointments to the New Zealand Sign Language (NZSL) Board and approving the policy and criteria for the \$1.645m NZSL Fund, which is used by the Board to support community activities and projects for promoting NZSL.

The NZSL Board Terms of Reference indicate the Board should generally have eight members, with a minimum of two members who identify as Turi Māori (Māori with lived experience of being Deaf or Hard of Hearing). All NZSL Board members must be NZSL users, with a majority of Board members being Deaf. A copy of the Terms of Reference can be found in **Appendix 5**.

The Board only has five members currently, two of whom, including the Board Chair, have indicated they will not seek to renew their appointment from 1 July 2024.

Appointments to the Board must be approved by the Cabinet Appointment and Honours Committee. We have commenced recruitment of new Board members and will provide you with recommendations for appointment in early 2024, alongside a Cabinet paper.


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<sup>28</sup> Note that the Concluding Observations from the UN Committee's examination of New Zealand reflect input provided by the disabled community in Aotearoa New Zealand, even though they are being presented by the UN Committee.



## Budget 2024

s9(2)(f)(iv)





### Paid Family Carers Litigation

The process for disabled people to pay a family member to provide support is currently through an employment arrangement. The disabled person employs the family carer, or the disabled person arranges for the family member to be employed through a disability support service provider.


In 2021, the Employment Court found that Manatū Hauora - Ministry of Health (now Whaikaha – Ministry of Disabled People) is the employer of two paid family carers where the disabled people were found to lack legal capacity to fulfil the employer role. The Crown has conceded that the disabled people being cared for in these cases do not have the legal capacity required to fulfil roles as employers, but has appealed to the Court of Appeal the finding that Whaikaha – Ministry of Disabled People (as the relevant Crown agent) should be considered the employer. A Court of Appeal decision is expected at any time in the next six months.<sup>29</sup>



s9(2)(h)


  


### Legislation work programme

s9(2)(f)(iv)

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<sup>29</sup> We have been expecting this decision since March 2023.

s9(2)(f)(iv)

## High and Complex Framework

The High and Complex Framework (HCF) supports people under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (the IDCCR Act) and other relevant legislation. It provides a diversionary pathway for offenders with intellectual disabilities who have been found unfit to stand trial on or be convicted of an imprisonable offence. This includes providing more appropriate supports with a strong rehabilitative focus. About 200 to 300 people are supported under the HCF at any time<sup>31</sup>.

Whaikaha – Ministry of Disabled People is responsible for the commissioning, planning, and funding functions of the HCF. The statutory and regulatory responsibilities for the IDCCR Act remain with Manatū Hauora (the Ministry of Health).

s9(2)(f)(iv)

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<sup>30</sup> This is a working title and subject to change.

<sup>31</sup> This number fluctuates daily as individuals either exit the service or are referred from the courts.

# Appendix 1: Key Disability Sector Acronyms

**CDS** – Child Development Services

**DSS** – Disability Support Services

**DPA** – Disabled Persons Assembly

**DPO** – Disabled Persons Organisation

**EGL** – Enabling Good Lives

**HCF** – High and Complex Framework

**IDCCR** – Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003

**IF** – Individualised Funding

**IMM** – Independent Monitoring Mechanism

**MEAL** – Monitoring, Evaluation, Analysis and Learning

**NASC** – Needs Assessment and Service Co-ordination

**NZDS** – New Zealand Disability Strategy

**NZDSN** – New Zealand Disability Support Network

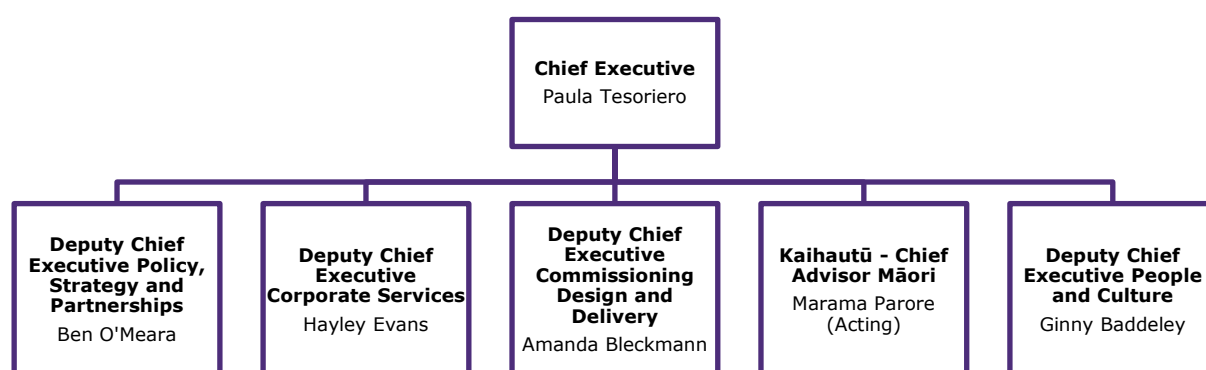
**ODI** – Office for Disability Issues

**TAMA** – Te Ao Mārama o Aotearoa Trust

**UNCRPD** – United Nations Convention on the Rights of Persons with Disabilities

## Appendix 2: Our Organisation and Leadership Team

Whaikaha stood up its refreshed organisation structure on 1 August 2023. That structure includes a Chief Executive with four Deputy Chief Executives (DCE) each leading their own Business Group and a Kaihautū – Chief Advisor Māori reporting directly to the Chief Executive. Our refreshed organisational structure diagram and a description of each of these Business Units and their Deputy Chief Executives is included below.



As a departmental agency Whaikaha – Ministry of Disabled People is an operationally autonomous agency within its host department, MSD, and is headed by its own Chief Executive, who is directly responsible to you as responsible Minister.<sup>32</sup> The relationship between you and our Chief Executive will operate in the same way as relationships between departmental chief executives and their respective Minister(s).

The Ministry's Leadership Team is listed below.

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<sup>32</sup> The hosting arrangement also enables Whaikaha to access MSD's established systems and corporate services.



Paula Tesoriero MNZM  
Chief Executive

Paula Tesoriero MNZM is the Chief Executive of Whaikaha and the first disabled Chief Executive of a Public Service Agency. Paula was appointed to the role from 1 September 2022 She is, a respected leader in the disability community as a Paralympian, and having been the Disability Rights Commissioner and Board member of various disability organisations.

Paula practiced law before entering the Public Service where she served in senior roles at the Ministry of Justice and Statistics New Zealand.

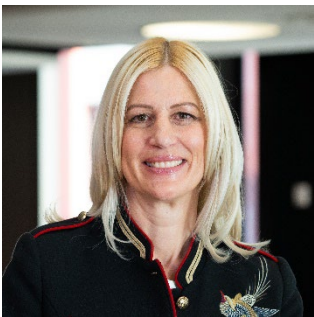
s9(2)(a)



Marama Parore  
(Ngāti Whātua, Ngāti Kahu, Ngāpuhi)  
Acting Kaihatū, Chief  
Advisor Māori

Marama Parore (Ngāti Whātua, Ngāti Kahu, Ngāpuhi) joined Whaikaha in January 2023. Marama has worked in the health sector for over 30 years in a range of organisations, both government and non-government. This includes as a nurse, an educator, a planner, designer, social marketer and Māori health Equity and Te Tiriti o Waitangi advocate.

s9(2)(a)



Amanda Bleckmann  
DCE  
Commissioning, Design  
and Delivery

Amanda Bleckmann joined Whaikaha on 1 July 2022 having previously worked in a range of roles within the Disability Directorate at the Ministry of Health for over three decades. Amanda brings a wealth of experience in commissioning, operational service design and delivery.

s9(2)(a)



Hayley Evans  
DCE  
Corporate Services

Hayley Evans is the Deputy Chief Executive, Corporate Services of Whaikaha. Hayley was appointed to the role from 2 October 2023. A lawyer by background, Hayley has held legal roles across the wider public service including most recently as Chief Legal Advisor for MSD and is also a keen student of NZSL.

s9(2)(a)



Ben O'Meara  
DCE Policy, Strategy and  
Partnerships

Ben O'Meara joined Whaikaha in March 2023. He has significant experience in policy development, leadership within a policy context, and advising Ministers on strategic and operational policy matters.

In his previous role at the Ministry of Education he was leading most of the Ministry's schooling-related policy advice, and the Ministry's system policy function. Ben's Policy career also saw him hold senior roles in local government and across other government agencies. He has experience working with operational leaders in a system leadership function.

s9(2)(a)



Ginny Baddeley  
DCE People and Culture

Ginny Baddeley joins Whaikaha as an experienced leader of People and Culture, most recently from Te Papa Atawhai | Department of Conservation where she was the Deputy-Director General People, and Chief People Officer.

She also has worked at a system level, including for Te Kawa Mataaho | State Services Commission where she was the Government Chief Talent Officer responsible for much of the early leadership, talent and career board establishment. At Department of Prime Minister and Cabinet she was the Director, National Security Workforce.

s9(2)(a)


## **Private Secretaries**

You will also have private secretaries in your office, who will act as the primary day to day contact between you and the Ministry. This relationship operates on a 'no surprises' approach and they will keep you updated on matters of interest within your portfolio.

The 'no surprises' approach also operates in the opposite direction and they will ensure that we are briefed on any matters that you may raise with Ministry officials to ensure they are prepared to offer you effective advice.

## **Appendix 3: Multi-category Appropriation: Supporting Tāngata Whaikaha Māori and Disabled People**

s9(2)(f)(iv)





s9(2)(f)(iv) [Redacted]

[Redacted]	[Redacted]	[Redacted]	[Redacted]	[Redacted]	[Redacted]
[Redacted]	[Redacted]	[Redacted]	[Redacted]	[Redacted]	[Redacted]
[Redacted]	[Redacted]	[Redacted]	[Redacted]	[Redacted]	[Redacted]
[Redacted]	[Redacted]	[Redacted]	[Redacted]	[Redacted]	[Redacted]

## Appendix 4: Priority groups to meet with

The following are key individuals and groups we recommend you meet as a matter of priority. Officials from the Ministry will work with your office to organise these engagements and provide appropriate support.

Group	Description
Independent Monitoring Mechanism (IMM)	<p>The purpose of the IMM is to promote, protect and monitor implementation of the Nations Convention on the Rights of Persons with Disabilities (UNCRPD), in Aotearoa New Zealand, under Article 33 of the UNCRPD. The IMM gives effect to its role by working collaboratively in partnership, and having a single united voice as the IMM on disability rights, and working with government agencies to monitor the Disability Action Plan and by bringing a disability perspective. It also reports to, and liaises with, the United Nations Committee on the Rights of Persons with Disabilities, as required.</p> <p>It consists of the Human Rights Commission, the Office of the Ombudsman, and the Disabled People’s Organisations (DPO) Coalition.</p>
Disabled Peoples’ Organisations (DPO) Coalition	<p>The Coalition is a group of seven disabled people-led organisations mandated under Article 4.3 of the Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which promotes active involvement by government agencies with representative organisations of disabled people which are governed by disabled people:</p> <ul style="list-style-type: none"> <li>• Association of Blind Citizens NZ;</li> <li>• Balance Aotearoa;</li> <li>• Deaf Aotearoa;</li> <li>• Disabled Persons Assembly NZ;</li> <li>• Kāpo Māori Aotearoa (not an active member);</li> <li>• Muscular Dystrophy Association; and</li> <li>• People First New Zealand Ngā Tāngata Tuatahi.</li> </ul>
Human Rights Commission	<p>The Human Rights Commission is Aotearoa New Zealand’s National Human Rights Institution. It is an independent Crown Entity operating under the Human Rights Act 1993 and has a range of complaints, advocacy, policy, research, and monitoring functions to achieve this.</p> <p>There are four Human Rights Commissioners, including Prudence Walker, Disability Rights Commissioner. The role includes:</p>

	<ul style="list-style-type: none"> <li>• making the Government’s COVID-19 response more equitable for disabled people;</li> <li>• shifting attitudes towards disabled people;</li> <li>• making the education system more inclusive for disabled children;</li> <li>• addressing violence and abuse against disabled people;</li> <li>• advocating for people with Fetal Alcohol Syndrome Disorder (FASD) to get access to disability support services; and</li> <li>• monitoring the implementation of the United Nations Convention on the Rights of Persons with Disabilities as part of the Independent Monitoring Mechanism.</li> </ul>
Office of the Ombudsman	<p>The Office of the Ombudsman is an office of Parliament, and the main roles from a disability perspective are to:</p> <ul style="list-style-type: none"> <li>• resolve complaints and investigate concerns about the administrative conduct of public sector agencies in relation to disabled people and/or disability issues;</li> <li>• monitor the implementation of the rights in the United Nations Convention on the Rights of Persons with Disabilities alongside the Human Rights Commission and Disabled Persons Organisations Coalition in the Independent Monitoring Mechanism; and</li> <li>• improve the conditions and treatment of disabled people in detention given a significant proportion of detainees are disabled. This also includes specifically monitoring intellectual disability and mental health facilities.</li> </ul> <p>The Office of the Ombudsman is led by Chief Ombudsman Judge Peter Boshier, a former Principal Family Court Judge and Law Commissioner, who has been in the role since 2015. The Chief Ombudsman is supported by about 150 staff across legal, monitoring and policy roles – including a team focused on progressing disability rights.</p> <p>In 2021, the Chief Ombudsman established a Disability Advisory Panel to inform his work in the area of disability rights. This provided access to timely and high-quality expert advice from New Zealanders with lived experience of disability, reflecting the mantra of the disability rights movement, “nothing about us, without us”.</p>
Health and Disability Commissioner (HDC)	<p>HDC is an Independent Crown Entity established under the Health and Disability Commissioner Act 1994. HDC is independent of providers, consumers, and government policy. Its jurisdiction is</p>

	<p>focused on quality of care, it does not extend to funding issues or service entitlement.</p> <p>HDC’s strategic objectives include protecting the rights of health consumers and disability services consumers under the Health and Disability Commissioner Act and Code and educating sector and consumers on those rights. It also seeks to improve quality in the sector and hold providers to account appropriately.</p> <p>HDC is focused on increasing disabled people’s awareness about their rights under the Code and ensuring that HDC is accessible and responsive to all people.</p> <p>HDC investigates disability support services-related complaints.</p>
National Enabling Good Lives Leadership Group	This group provides disability community and sector input into, and advice on, current and future initiatives involving transformation of the disability support system.
Tāngata whaikaha Māori groups	<p>These three groups have key partnership roles in supporting Whaikaha to deliver system transformation:</p> <ul style="list-style-type: none"> <li>• Te Ao Mārama Aotearoa;</li> <li>• Whānau Ora Interface Group; and</li> <li>• Kāpo Maōri Aotearoa.</li> </ul>
Mana Pasefika	Mana Pasefika is a network in the process of development, with the intention of becoming a national network of Pacific disabled people. Pati Umaga is the chair of Mana Pasefika.
New Zealand Disability Support Network (NZDSN)	NZDSN a network of not-for-profit organisations and some for-profit NGOs that provide supports to disabled people, mainly through contracts with government.
Parent, Family, Whānau Network	A network of grass-roots organisations who represent the shared lived experience of parents and whānau within the disability sector.
Faiva Ora Leadership Group	Faiva Ora is a community mandated Pacific advisory group to Whaikaha. They are the main stakeholder for providing the Pacific Voice to the Ministry.
New Zealand Sign Language (NZSL) Board	The NZSL Board is supported by the Ministry’s NZSL office and work to promote and maintain NZSL.

i. Lead Committee	A group made up of and representing disabled young people.
Carers Alliance and Carers New Zealand	The Carers Alliance (57 national not for profit organisations) aims for better support and recognition for family, whānau, and aiga carers and is the government’s partner for the NZ Carers’ Strategy. Carers NZ is the peak body for carers and the secretariat for the Alliance.
Home and Community Health Association	The Home and Community Health Association represents providers of home and community health services, and is the national voice that promotes and advances excellence, partnership and sustainability for the sector.

There are also key regional groups and groups that focus on specific impairments or health conditions that will be important to meet. As a priority we recommend you meet with the Enabling Good Lives Governance Groups and Regional Leadership Groups.

# Appendix 5: New Zealand Sign Language Board Terms of Reference



## Terms of Reference

for the

## New Zealand Sign Language Board

**Vision:** New Zealand Sign Language is a strong and vibrant language, recognised and embraced by New Zealand Society

Revised June 2022

\* Aspects of this Terms of Reference that may impact the operation of the NZSL Board will be reviewed annually, with a full review being conducted biennially.

## **Vision**

1. The New Zealand Sign Language (NZSL) Board (the Board) has a vision where:
  - NZSL is a strong, vibrant language, recognised and embraced by New Zealand society.
  - The right to use NZSL as a first or preferred language is acknowledged.
  - There are sufficient opportunities and resources for D/deaf people, their families and whānau, and other NZSL users to acquire and use NZSL.
  - NZSL is accessible and available to all NZSL users.

## **Principles**

2. The principles of the following legislation guide how the Board will work:
  - The New Zealand Sign Language Act 2006.
  - The Treaty of Waitangi.
  - The United Nations Convention on the Rights of Persons with Disabilities.

## **Approaches**

3. The following approaches guide how the Board will work:
  - The Board:
    - recognises that access to and the use of sign language is a human right for Deaf people as outlined in the United Nations Convention on the Rights of Persons with Disabilities and the NZSL Act 2006
    - recognises that Deaf NZSL users will lead the maintenance and promotion of NZSL
    - will work in partnership with the key government agencies, member organisations of the Disabled People's Organisations (DPO) Coalition which represent the Deaf community (i.e. Deaf Aotearoa), and other non-government organisations to implement the Board's NZSL Strategy and support government agencies to implement their own NZSL strategic plans and/or activities
    - will work in partnership with the Office for Disability Issues to include appropriate NZSL actions within the New Zealand Disability Strategy
    - will operate according to the principle of transparency, including through open communication, roles, responsibilities and areas of work.

## **Purpose**

4. The Board's purpose is to:
  - maintain and promote the use of NZSL by ensuring the development and preservation and acquisition of the language

- help ensure the rights of D/deaf people and NZSL users to use NZSL as outlined in the NZSL Act 2006 and United Nations Convention on the Rights of Persons with Disabilities and other relevant national and international legislation
- provide expert advice to government and the community on NZSL.

## **Roles and Functions**

### *Leadership*

#### 5. The Board will:

- lead the maintenance and promotion of NZSL
- be responsible for oversight of the NZSL Fund, and make recommendations on the allocation of funds from it to maintain and promote NZSL
- provide a national role and focal point of reference for government and support for NZSL
- provide leadership of the NZSL sector
- provide an expert voice on NZSL.

### *Advice*

#### 6. The Board will:

- advise on measures to give effect to NZSL as an official language, including advice on matters relating to the NZSL Act, and advice on the regulation of interpreting standards.
- provide centralised, expert, high level and systemic advice on NZSL across government agencies including providing advice on implementing the NZSL Strategy priorities, action plan, vision and purpose.
- refer enquiries/issues to other stakeholders or government agencies as appropriate.

### *Strategy and coordination*

#### 7. The Board will:

- set and keep current a five-year strategy and priority initiatives for the maintenance and promotion of NZSL, in consultation with government agencies
- engage with the Deaf community from time to time as required
- build key stakeholder relationships across public, private, and community sectors to achieve joint goals in relation to NZSL.



## *Monitoring*

8. The Board will:
  - monitor and report on key government activity supporting the five-year NZSL Strategy and priority initiatives
  - report to the Minister for Disability Issues annually, and as required, on matters relating to NZSL
  - provide input into other key monitoring reports as appropriate, for example, on the Convention on the Rights of Persons with Disabilities and the New Zealand Disability Strategy.
9. In supporting the Board to fulfil its monitoring requirements, the Ministries of Education, Social Development, Justice and Health, will report to the Board on their progress against the NZSL Strategy and priority initiatives annually, or as required.

## **Members**

### *Composition of the Board*

10. The Board will generally have eight members in total, all of whom will be NZSL users and a majority of whom will be Deaf. Membership may be extended to ten if this is required to achieve adequate diversity as described in paragraphs 11 and 12
11. The members will reflect the diversity of the Deaf community and NZSL users. It will include, at a minimum, two members who identify as Māori and one member nominated by the relevant Deaf community member organisation of the DPO Coalition (i.e. Deaf Aotearoa).
12. The Deaf Aotearoa Executive Board may nominate a candidate who is not employed by Deaf Aotearoa or on the Deaf Aotearoa Executive Board.
13. As far as possible membership will also have a gender balance, and reflect the perspectives of:
  - youth
  - families
  - older people
  - Pacific peoples, and other ethnic groups
  - people who use NZSL as their primary language, but do not identify as Deaf.
14. From time to time the Board will consult with experts from outside of the Board to ensure that broad perspectives regarding NZSL issues are achieved.

15. Senior managers, owners or others closely related to a Deaf Business may be excluded from Board membership or excluded from voting on funding decisions as recommended by the Office for Disability Issues.

#### *Skills and attributes required of members*

16. Desirable skills and attributes for Board members are:

- personal experience using NZSL
- a wide knowledge of NZSL users and a critical awareness of language issues in the community
- active linkages with the Deaf community, families with D/deaf members, and other NZSL users
- experience in governance
- a 'big picture' orientation, including an ability to think strategically and to prioritise
- an appreciation of practical measures to implement strategic priorities
- the ability to influence, without dominating
- an ability to work cooperatively as part of a group
- sound judgement
- sufficient competency in written English to deal with the complexity and volume of Board business.

### **Specific roles**

#### *Role of the nominee of a Disabled People's Organisation*

17. The Board membership includes a nominee of a relevant Deaf community member organisation of the Disabled People's Organisations Coalition.
18. Meeting the membership requirements of this Coalition gives assurance that the organisation is Deaf led, has national coverage and is a registered incorporated society. Currently Deaf Aotearoa is the only Disabled People's Organisation meeting this requirement. Deaf Aotearoa is also a member of the World Federation of the Deaf.
19. The Disabled People's Organisation nominee is a full member of the Board once appointed. All expectations apply as set out in this Terms of Reference and the Board Code of Conduct.
20. The Office for Disability Issues will work with the Disabled People's Organisation to identify suitable candidates for appointment based on the identified skills and experience required to balance the Board composition.

## *Roles, skills and attributes required of the Chair and Deputy Chair*

21. The Office for Disability Issues will hold, and make available to Board members, job descriptions for the roles of Chair and Deputy Chair.

22. In brief, the Chair's role is to:

- consult with the Board on all matters where guidance is required, or mandate is unclear
- set and manage the agenda for Board meetings
- manage meeting procedures and guide discussions, but not 'referee' disputes. The Chair may also contribute their own views to discussions
- promote and provide oversight of the Board's:
  - compliance with this Terms of Reference, and Board policies and processes
  - member compliance with its Code of Conduct
- lead on behalf of the Board:
  - liaison with the Office for Disability Issues' Secretariat
  - external relationships, as agreed by the Board
  - on-going evaluation and review, promoting a culture of continuous improvement
- provide support for Board members on request
- provide input for reports, correspondence and Ministerials on behalf of the Board and in liaison with the Office for Disability Issues.

23. The Chair:

*must have*

Board experience or be willing to receive training in this.

*should have*

- clear understanding of the roles and responsibilities of the Board within Government
- experience in working with government
- ability to attend additional meetings
- an ability to facilitate meetings and support members
- an ability to act as a credible spokesperson
- experience in managing a wide range of relationships, including Secretariat, community, and Ministerial relations.

24. The Deputy Chair's role is to:

- support the Chair in the execution of their role

- act in the place of the Chair in the absence of the Chair, on request from the Chair or in the case of a Conflict of Interest for the Chair.

25. The Deputy Chair will:

- have the ability to fully undertake the role of Board Chair.

26. The DPO nominee cannot be elected to the role of Chair or Deputy Chair.

## **Appointments**

### *Appointment to the NZSL Board*

27. The Minister for Disability Issues (the Minister) will recommend appointments to the Cabinet Appointments and Honours Committee after considering advice from a selection panel convened by the Office for Disability Issues.

28. Cabinet will be notified of the appointments to the Board.

29. Members of the Board may be removed if they:

- are adjudicated bankrupt
- have a conflict of interest that cannot be managed
- are convicted of a serious offence under the Crimes Act 1961
- are appointed to a permanent full-time position in the public service working on issues relevant to NZSL.

30. The Office for Disability Issues will convene a process to recommend to the Minister the person best suited to undertake the role of the Chairperson.

31. The Board may request co-option of replacement Board members when:

- a Board member resigns
- the Board appointment process does not recruit to all the Board member vacancies.

32. The Minister for Disability Issues may appoint co-opted members after considering advice from a selection panel convened by the Office for Disability Issues.

### *Term of office*

33. The standard term of office for each member of the Board is three years except for members appointed on its establishment, or as otherwise determined by the Minister.

34. The standard term of office for the role of Chair and Deputy Chair is three years. The term of office will be adjusted for either or both roles to provide at least six months overlap to support continuity.

35. At times, members of the Board may need to leave prior to the end of their term of office. In such cases, the Minister will consider recommendations from the selection panel to identify a suitable candidate for appointment to maintain the Board's mix of representation and background.

36. Any member may sit on the Board for a maximum of three terms (nine years) consecutively except for establishment members who, at the Minister's discretion, may sit for a consecutive period of up to nine years. All members wishing to be considered for a new term will need to complete the nomination process for reselection.

### **Expectation of members**

37. Members of the Board must ensure the Board acts in a manner consistent with this Terms of Reference and the priorities issued by the Minister for Disability Issues.

38. Board members will comply with all Board policies, including its Code of Conduct and Conflict of Interest Policy, and relevant legislation.

39. The Board will meet at least four times per year. The Board Chair may call additional meetings as required, within available budget.

40. Members may also be required to undertake work additional to attendance at Board meetings.

41. Members are expected to commit up to ten days a year on Board business, including attending meetings.

42. Members are expected to be able to travel to Wellington for all full meetings of the Board.

43. The Board Chair and Deputy Chair may be required to attend additional meetings from time to time.

44. Members are appointed as individuals with knowledge and expertise of NZSL. They are expected to understand and communicate the views of the user community but are expected to govern on behalf of all stakeholders.

45. The Board will operate collaboratively to achieve the Board's purpose, rather than pursuing individual views.

46. Individual Board members are expected to:

- attend, to the greatest extent possible, all meetings of the Board
- examine issues before the Board from a strategic viewpoint
- support a consensus decision-making approach.

47. Like all other NZSL Board members the Deaf Aotearoa nominee will bring their expertise, knowledge and experience to NZSL Board discussions and contribute to Board decisions based on the information presented to the NZSL Board. They are not expected to be a representative of Deaf Aotearoa or a delegate to the NZSL Board. This means that the relationship between Deaf Aotearoa and the NZSL Board, and giving effect to Article 4.3, is through the Chair and Deputy Chair of the NZSL Board (and/or delegated Board members as required) and through a Board to Board relationship.

48. Board members must publicly support and endorse all actions of the Board, even if they do not privately agree with them. This includes:

- recommendations on funding proposals
- work programme priorities
- the five-year NZSL Strategy, priority initiatives and strategies
- communications strategies
- advice to the Minister.

49. Where a Board member disagrees with a Board decision, they may:

- vote against the decision
- abstain from voting
- request that the Chair records their alternative view or objection in the record of the meeting
- raise the matter as an issue by using the Code of Conduct procedures.

50. In addition, the Deputy Chair of the Board is expected to assume the duties and powers of the Chair as delegated to them by the Board.

51. In addition, the Chair of the Board is expected to:

- facilitate meetings
- manage communications
- ensure the objectives of working with the Board are achieved
- build good working relationships with members, with the Minister, Government agencies, and the Deaf community.

52. A member may be removed from the Board if, in any 12-month period, in the sole opinion of the Minister, they have failed to attend sufficient meetings to appropriately take part in the Board's deliberations.

### *Remuneration, expenses and reimbursements*

53. Each Board member will be paid per day and pro-rata for a half day, for each day that they undertake work arising from their membership of the Board, including preparation for meetings. Remuneration will be in accordance with the Cabinet Office Circular Fees Framework for members appointed to bodies in which the Crown has an interest (the Fees Framework).

54. Board members will be paid allowances, if appropriate. Any allowances will be paid in accordance with Annex 1 of the Fees Framework.

55. All payments will be made by direct credit to the bank account nominated by the Board member.

### *Additional work*

56. Additional work may be requested from time to time by the Board.

57. Any payment for additional work must be agreed by the Office for Disability Issues, as the fee setting authority, in writing in advance before such work is undertaken.
58. Any additional work should relate to the governance role of the Board and should not cover activities that sit more properly with the Secretariat or are of a consultancy nature.
59. The key objectives for the additional work must be clearly specified and evaluated on completion.

### *Intellectual property*

60. Nothing will affect the rights of a Board member in the intellectual property owned by that member prior to entering this engagement or developed by the member other than in the performance of this engagement.

### *Confidentiality*

61. The Board will be presented with a range of information and papers on aspects of NZSL. Some of this information will be commercially sensitive or contain personal information about individuals.
62. Board members shall at all times comply with the Privacy Act 1993 and the Official Information Act 1982.
63. The Board will need to ensure there are no surprises for Ministers, by ensuring that all members follow agreed processes for sharing information. Under the “no surprises” policy, Ministers expect to be informed well in advance of any material or significant events, transactions and other issues relating to the Board that may be contentious or could attract public interest, whether positive or negative.
64. Other information can be shared and discussed more widely to gather feedback and ideas. These ideas can then be shared with the Board and government agency staff.
65. The Board will need to agree whether information is for sharing or to be kept private, subject to the Official Information Act 1982.
66. Members shall not disclose any confidential information obtained in the course of carrying out their role as a member of the Board.

### **NZSL Office**

67. The Board is supported by the NZSL Office within the Ministry of Disabled People (Office for Disability Issues).
68. The Board and NZSL Office will operate cohesively to ensure that objectives are successfully delivered. The Board may delegate responsibility to the NZSL Office for specified strategic objectives or for decisions when the Board is unable to make a decision.
69. The role of the NZSL Office is to:
  - support the Board to undertake its role

- act as a co-ordination and liaison point with government agencies in respect of the Board's monitoring and reporting duties as set out in this Terms of Reference
- monitor Board performance, including its impacts and effectiveness.

70. The NZSL Office provides the Board with:

- administrative support and contract management services
- policy advice
- the development and implementation of work programmes in line with the NZSL Strategy and as directed by the Board
- implementation of agreed measures to effectively maintain and promote NZSL.

71. The NZSL Office will confirm the Agenda for Board meetings with the Chair and Deputy Chair one month ahead of the meeting.

72. The NZSL Office will distribute papers for Board meetings to all Board members two weeks ahead of the meeting.

## **Governance**

73. The Board reports to the Minister for Disability Issues on government progress against the five-year NZSL Strategy and priority initiatives for the promotion and maintenance of NZSL.

74. The Board provides advice to the Minister for Disability Issues on allocation of the NZSL Fund.

75. To ensure the purposes of the Board are achieved, ODI will take responsibility for NZSL funding decisions for an agreed period of time and, if necessary, consult with the Minister, if the Board has difficulty forming a quorum because of conflicts of interest.

76. The Board receives input and advice from government departments and consults the Deaf community and the NZSL user community in developing the five-year NZSL Strategy and Action Plan.

## **Processes**

77. Meetings will follow an agenda and will normally be conducted in NZSL, or otherwise as agreed by the attending Board members. Interpreters will be provided as required for any meeting participants who are not conversant in NZSL.

78. Papers, and any NZSL translation of these, are to be circulated for Board members' consideration in advance of the relevant meeting, where possible.

79. Where a potential conflict of interest arises, papers may be withheld from specific members.



80. All members can be present and vote on strategic priorities however if any conflict of interest is identified must remove themselves, according to the current policy, when the Board discuss specific contract requirements and funding allocation.
81. Consideration of issues and related decisions can be made outside of formal meetings, as required, through processes agreed by members and confirmed by the Office for Disability Issues.
82. Where the Office for Disability Issues does not agree with a Board decision, it:
  - will raise this with the Chair in the first instance
  - may raise the difference in views with Ministry of Disabled People Officials for consideration
  - may provide alternative advice to the Minister.

#### *Sub-committees*

83. The Board may agree to establish subcommittees, such as for Finance.
84. Subcommittee membership selection will prioritise the relevant skill set required, and where possible will seek to include a membership balance as set out in this Terms of Reference under 'Composition of the Board'.
85. The Board may delegate decision-making authority to a subcommittee for specified aspects consistent with the NZSL Strategy. Without such delegated authority, a sub-committee may only make recommendations to the Board for consideration.
86. Any subcommittee will report to the Board on all meetings, decisions and recommendations.
87. A record of all actions and decisions agreed at Board meetings and sub-committee meetings will be kept and confirmed and made available to all Board members prior to the next Board meeting.

#### *Quorum*

88. The Board quorum shall be half plus one of Board members present.
89. The sub-committee quorum shall require all members vote.
90. Where a quorum is not possible, such as due to Conflicts of Interest, the Board may agree to:
  - delegate a specified mandate to a sub-committee to make a recommendation to the Board
  - nominate the NZSL Office as a voting participant to meet quorum requirements
  - delegate a specified mandate to the NZSL Office to make a decision.

## **Board performance**

91. The Board is required to report to the Minister for Disability Issues annually on progress in implementing the NZSL Strategy, and any other matters relevant to the Board carrying out its role.
92. The Director, Office for Disability Issues, is responsible for monitoring the effectiveness of the Board, including its processes, impacts and effectiveness.
93. The Director, Office for Disability Issues, will commission biennially an independent review of the Board, including the NZSL Office function.



# Whaikaha

Ministry of  
Disabled People



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for NZSL  
name

