



Whaikaha
Ministry of
Disabled People

Briefing to the Incoming Minister

In Confidence

February 2023



Te Kāwanatanga o Aotearoa
New Zealand Government

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Welcome

Whaikaha – the Ministry of Disabled People (Whaikaha) welcomes you to the Disability Issues portfolio. As the Minister for Disability Issues you will lead a new direction in how disabled people¹, tāngata whaikaha Māori² and their whānau are supported, and also the way society supports them to have greater choice and control over their lives.

The establishment of Whaikaha sees Aotearoa New Zealand continuing to take a lead role internationally in promoting the rights of disabled people³, tāngata whaikaha Māori and their whānau.

The disability issues portfolio will:

- meet Te Tiriti o Waitangi obligations – through partnerships with Māori about system transformation and pursuing equitable outcomes for tāngata whaikaha Māori
- transform how services are funded and provided to disabled people and their whānau who need support to live the lives they want
- tackle questions of equity and fragmentation across the disability system
- continue the shift from delivering disability support services under a medical model to a social model of disability that supports self-determination (reflecting a rights-based approach) and addressing environmental and social barriers
- influence how other government agencies reflect the needs of disabled people in the delivery of their policy and mainstream services.

This briefing provides background information on the key issues in this portfolio and the exciting new opportunities presented by the establishment of Whaikaha. This briefing outlines:

- our vision of the strategic direction Whaikaha will work towards to improve the lives of disabled people and their whānau in Aotearoa New Zealand
- the formation of Whaikaha, its functions and structures, financial appropriations and the hosting arrangement with the Ministry of Social Development (MSD)
- key upcoming matters requiring your attention
- the work underway to transform the disability support system, with the expansion of the Enabling Good Lives (EGL) approach nationally (refer to Appendix 11 for EGL background, vision and principles)
- how Whaikaha is working in partnership with disabled people and how the voice of disabled people is being built into our functions and approach
- the breadth and scale of the disability support services we provide (\$2 billion annually)
- individuals and groups you may wish to meet with as a priority.

Additional information in relation to your new portfolio can be provided as required.

¹ Disabled people is the inclusive term used for the purposes of brevity in this briefing when referring to a general group including tāngata whaikaha Māori, tāngata whaikaha, deaf people, Pacific disabled peoples and whānau.

² Māori disabled people

Disability in Aotearoa New Zealand and our foundations

In Aotearoa New Zealand, disabled people experience poorer wellbeing outcomes than other New Zealanders on almost any available metric. There are enormous variations in the experiences, needs and aspirations of disabled people, tāngata whaikaha Māori, Pacific disabled people, and their whānau. Within these population groups, it is tāngata whaikaha Māori who experience greater disadvantage than other disabled people in key outcome areas such as employment, education, and health.

The Statistics New Zealand (Stats NZ) June 2020 Wellbeing Survey indicated:

- 44 percent of disabled people rated their overall life satisfaction poorly (0–6 on a scale from 0 to 10), compared with just 15 percent of non-disabled people
- almost a third of disabled people gave a low rating for how worthwhile they felt their life was (30 percent), and 29 percent rated their family’s wellbeing poorly
- disabled people were among those with significantly higher levels of poor mental wellbeing.⁴ Further survey findings are in Appendix 5.

The 2013 Disability Survey demonstrated 1.1 million New Zealanders (24% of New Zealanders) identified as disabled.⁵ The causes of impairment vary greatly, including existing at birth, from injury, a health condition, or as a part of natural ageing.⁶ 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).

Supports for disabled people are commissioned, funded, or provided through various agencies, including Whaikaha, MSD, Te Whatu Ora (Health NZ), The Accident Compensation Corporation (ACC) and the Ministry of Education. Generally, disability support services provided by Whaikaha are for people under the age of 65. Te Whatu Ora provides supports for people over the age of 65, and ACC provides support for those who have an impairment as the result of an accident.

The number of people receiving disability support services provided by Whaikaha is growing faster than the general population. We expect this is likely to continue due to factors such as an ageing population, greater public awareness of available supports and improvements that make supports easier to understand and access.

On 1 July 2022, Whaikaha – Ministry of Disabled People was established. Whaikaha was established as a departmental agency, hosted by MSD. Whaikaha assumed responsibility from the Ministry of Health for a range of disability support services functions, and three EGL demonstration sites. The existing functions and responsibilities of the Office for Disability Issues, previously hosted in MSD, also became part of Whaikaha.

⁴ This is based on the WHO-5 Wellbeing Index which asks respondents about their experience of five positive aspects of subjective mental wellbeing. These include feeling cheerful, calm, and relaxed, and active and vigorous, waking up feeling fresh and rested, and whether they felt that their life was filled with interesting things.

⁵ This is the latest available data as the next Disability Survey is due to take place in 2023.

⁶ Impairment is the term used, rather than disability, as under the social model of disability, the disability lies in society not providing an environment that takes people’s impairment into account, not with the individual.

Roles and Responsibilities

Whaikaha reports to and supports your role as the Minister for Disability Issues. As Minister for Disability Issues, you have a leadership role to advocate for the rights of, and opportunities for, disabled people across all government portfolios. You also have a responsibility for the \$2 billion annual appropriation that ensures 43,000 disabled people receive disability support services from Whaikaha.

As Minister, you are responsible for leading the government's implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which provides another vehicle to drive cross-government work programmes and improve the lives of disabled people in Aotearoa New Zealand. Further detail on the UNCRPD is contained in Appendix 9.

Vision

We are working towards the New Zealand Disability Strategy's vision of Aotearoa New Zealand being a non-disabling society – a place where disabled people have an equal opportunity to achieve their goals and aspirations, and that all Aotearoa New Zealand will work together to make this happen. We lead a disability policy work programme covering strategic policy, stewardship, the ongoing transformation of disability support system, capability building for the wider government system to better serve our community and drive improvements in outcomes for all disabled people, tāngata whaikaha Māori and whānau.⁷

Whaikaha is committed to working in partnership with disabled people, tāngata whaikaha Māori and whānau. Along with the Government, we have obligations to consult with disabled people and tāngata whaikaha Māori and whānau under Te Tiriti o Waitangi, the UNCRPD, and the New Zealand Disability Strategy 2016-2026.

Improving the way disability support services and cross-government services are provided and removing current barriers (e.g. differing eligibility criteria and multiple assessment processes) are critical for achieving better outcomes for disabled people. However, better supports and services alone will not achieve equitable outcomes. Disabled people should encounter spaces, services and policies designed to meet everybody's needs, and people who understand and respect them.

Our establishment demonstrated the Government's commitment to take a bolder approach to the long-term transformation of the disability system. Transformation is needed to achieve equitable outcomes for disabled people across all the domains of their lives, including housing, education, employment, transportation, and community participation.

Whaikaha lifts the profile of disability across government. It will enable the co-creation of new structures and ways of working and signals a shift away from a medicalised and deficit-based model of disability to a social model of disability that specifies that individuals do not have disability – it lies in society and occurs when people with impairments are excluded from places and activities that many take for granted. This social model encompasses and enables a

⁷ SWC-21-SUB-0146 refers, 29 September 2021 paras 30 and 31

whole-of-life and strengths-based approach and works towards ensuring all disabled people can enjoy meaningful fulfilment of their fundamental human rights.

Forward work programme

We are currently focused on three key workstreams to meet the initial priorities of your portfolio. This includes:

- the continued establishment and consolidation of Whaikaha
- developing business case and expanding System Transformation
- continuity of and improvements to existing disability support services.

These workstreams support the initial priorities set out in your portfolio - establishing Whaikaha, rollout of the EGL approach and the Accessibility legislation. The Accessibility legislation is included within the transformation priority.

We have added a theme to reflect our day-to-day work and what we have achieved to-date, such as establishing and consolidating our organisation, and providing continuity and service improvement of disability support services.

Work to date

Since our establishment on 1 July 2022, Whaikaha has embraced our role as a system steward to champion better outcomes for disabled people. To date, we have achieved several key outcomes including:

- co-ordinated the 2022 Government delegation to the United Nation's examination of Aotearoa New Zealand's implementation of the UNCRPD
- engaged in the all-of-government COVID-19 response to strengthen the supports for disabled people, tāngata whaikaha Māori and whānau
- welcomed our permanent Chief Executive (appointed by the Public Service Commission)
- provided advice on disability issues to over 100 cabinet papers
- retained flexibility for individualised funding and carer support
- published of the third edition of the Aotearoa Autism Guidelines
- contributed to the Institutional Hearings of the Royal Commission of Inquiry – Abuse in State Care
- contributed to the ongoing Waitangi Tribunal Health Services and Outcomes Inquiry – Wai 2575.

Matters that require your early attention

The following provides an overview of key matters that we would like to discuss with you and further detail is provided throughout the briefing.

System Transformation: National Enabling Good Lives

We are preparing to send advice to you and the Minister of Finance, regarding the national operating model to draw down the contingency funding (\$100m) and implementation of the initial expansion of the transformed system. ^{Section 9(2)(f)(iv)}

Further information regarding the contingency funding is provided on page 9.

Legislation

Section 9(2)(f)(iv)

- [Redacted]
- [Redacted]
- [Redacted]
- [Redacted]

[Redacted]

[Redacted]

[Redacted]

Section 9(2)(h)

[Redacted]

Section 9(2)(f)(iv)

[Redacted]

[Redacted]

[Redacted]

Waitangi Tribunal Health Services and Outcomes Kaupapa Inquiry (Wai2575)

Section 9(2)(h)

[Redacted]

[Redacted]

[Redacted]

Royal Commission – Inquiry into Abuse in Care

Section 9(2)(h)

[Redacted]

[Redacted]

Finance and appropriations

Financial Responsibilities

The Minister for Disability Issues is responsible for the *Supporting tāngata whaikaha Māori and disabled people* appropriation that funds Whaikaha operations. This is a multi-category appropriation (MCA) established under Vote Social Development.⁸

The MSD Chief Executive is the administrator of Vote Social Development. They are responsible to the Minister for Social Development and Employment for the administration of the Vote.

As such, the MSD Chief Executive is responsible for the financial management, financial performance, and financial sustainability of Whaikaha. Delegations of responsibilities and agreements under the Public Finance Act 1989 can be made from MSD's Chief Executive to provide additional financial and reporting responsibilities.

Under the Public Finance Act 1989, expenses are able to be incurred for:

- departmental expenditure – the Chief Executive of Whaikaha is directly responsible for this to the Minister for Disability Issues
- non-departmental expenditure – as Appropriation Administrator the Chief Executive of MSD is responsible to the Minister for Disability Issues, who is the Appropriation Minister.

Practically, the Chief Executive of Whaikaha manages this appropriation on a day-to-day basis. However, this means that although Whaikaha broadly operates as its own Ministry, MSD plays a role in providing financial assurance to the Government and the sign-off of the MSD Chief Executive is required as part of material financial matters (e.g. setting the annual budget).

Appropriations

Disability appropriations of nearly \$2 billion annually in non-departmental expenditure and about \$58 million annually in departmental expenditure are made for our operations.

Whaikaha was established with:

- \$23.7 million of ongoing annual funding from the Budget 2022 initiative to establish Whaikaha, which also included additional one-off funding of \$7.9 million in 2022/23 and \$3.8 million in 2023/24
- \$19.9 million of annual funding transferred from Vote Health for staff and costs that moved from the Ministry of Health to Whaikaha
- \$7.4 million of annual funding transferred from Vote Social Development for staff and costs that moved from the MSD to Whaikaha.

Refer Appendix 2 for details of the MCA.

⁸ 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-department expenditure to you

Fiscal sustainability

Under Vote Health, the non-departmental expenditure appropriation for disability had a history of requiring top-up funding to avoid being unappropriated at year end. This reflects the demand-driven nature of the expenditure and continues to be a challenge for Whaikaha.

This was recognised by the Minister of Finance and the Minister for Disability Issues. They jointly directed⁹ that further work be undertaken to investigate and report back to them ahead of Budget 2024 on options for improving the fiscal management settings for DSS expenditure with a focus on options that:

- reflect the demand driven nature of the spend
- increase the transparency and accountability of expenditure
- provide a pathway for addressing key challenges to equitably funding clients and providers
- better manage spending growth fairly and sustainably for clients, the Crown, and providers
- supports strategic management of the spend.

This work is underway.

Contingency funding for implementing Enabling Good Lives (EGL)

As part of Budget 2022, there was a new initiative to extend EGL to more of the disabled population and their whānau, progressing towards a national rollout of the EGL approach beyond the current three sites (Christchurch, MidCentral, and Waikato).

\$100 million (over four years) has been set aside in a tagged contingency to support this

⁹ Report to Ministers of Finance, Disability Issues, Social Development and Employment, and Health – *Establishing the appropriation to fund the Ministry for disabled people and disability supports*, 24 March 2022.

work. This will provide for \$40.5 million in ongoing annual expenditure.

The Minister of Finance and Minister for Disability Issues have been delegated by Cabinet to jointly approve the drawdown of the operating contingency funding, with amendments to the final appropriation as necessary. Funding can be drawn down subject to the following:

- Ministers have agreed a clear and comprehensive operating framework for the transformed disability support system
- Ministers have agreed a clear and appropriately detailed plan to implement the transformed disability support system
- an explanation of how the contingency funding will be used to further the implementation and/or design of the transformed disability support system has been presented to Ministers
- a straightforward governance structure as well as advisory and partnership functions have been agreed
- key risks to the implementation and ongoing functioning of the transformed disability support system have been identified and options for mitigating these risks have been provided to Ministers.

Whaikaha is developing the material required so that Ministers are able to make decisions on the rollout and will be comfortable providing access to the contingency funding. Final decisions on the approach to expand EGL, including selecting priority populations and/or regions, are being finalised for your consideration.

Any contingency funding not appropriated will expire on 30 June 2024, unless Ministers agree to extend that date or otherwise rephrase the contingency. Further information regarding EGL is in Appendix 11.

Whaikaha

Whaikaha combines a significant service delivery responsibility with the stewardship role of a population Ministry. We were established on the premise that time is needed to succeed in the long-term transformation of the disability system. This is structured in three stages - establishment, consolidation, and transformation (noting there is overlap between the stages):

- **Core establishment and ongoing transition activities** (July to October 2022) – upon commencement, the disability support services functions and associated staff from the Ministry of Health, staff of the Office for Disability Issues and EGL sites transferred to Whaikaha. The key priority was the continuity of disability support services for disabled people, which has been accomplished
- **Consolidation** (July 2022 to December 2023) – this stage will see the development of our vision and strategy, in consultation with key partners. Existing services will continue, and we will develop and implement new functions and ways of working. The priority is to ensure the functional foundations and components are in place for our success and to support the work in leading disability system transformation
- **Transformation** (April 2023 onwards) – leading transformative change in partnership with disabled people, tāngata whaikaha Māori and whānau, and informed by the individual and collective voices of the disability community and the sector.

We expect to be a fully established Ministry by 30 June 2024. Once we are fully operational, we will lead further transformation of DSS, including identifying opportunities to consider how the EGL approach can be applied to other disability supports and other mainstream services across government. Our core responsibilities will be:

- wider leadership and stewardship of disability across government to improve the experience and outcomes of disabled people (and bringing accessibility and disability issues together)
- continued service delivery for disability support services and transformation of the disability support system.

Whaikaha is not responsible for all disability-related government policy development or supports. Our role is to support other government agencies in their work, as well as providing provide strategic leadership, stewardship, and coordination on disability issues across government.

People – Whaikaha Executive Leadership Team

 <p>Paula Tesoriero MNZM Chief Executive</p>	<p>Paula Tesoriero MNZM is the Chief Executive of Whaikaha. Paula was appointed to the role from 1 September 2022. An experienced Public Service leader, Paula’s most recent role was the Disability Rights Commissioner at the Human Rights Commission.</p> <p>Section 9(2)(a) [Redacted]</p>
 <p>Russell Cooke Deputy Chief Executive Performance and Governance</p>	<p>Russell Cooke joined Whaikaha on 1 July 2022. Russell was part of the team that established Whaikaha, leading the information and technology workstreams. Prior to this Russell was the Government Chief Privacy Officer, based in the Digital Public Service Branch in DIA.</p> <p>Section 9(2)(a) [Redacted]</p>
 <p>Amanda Bleckmann Deputy Chief Executive Operational Design and Delivery</p>	<p>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. Amanda brings a wealth of experience in commissioning, operational service design and delivery.</p> <p>Section 9(2)(a) [Redacted]</p>
 <p>Brian Coffey MNZM Acting Deputy Chief Executive Policy, Strategy and Partnership</p>	<p>Brian Coffey MNZM (Te Ātiawa ki Te Whanganui-a-Tara) is the Acting Deputy Chief Executive for Policy, Strategy and Partnership. Brian’s substantive role is the Director of the Office for Disability Issues (ODI). Mr Coffey has been involved in several government inter-agency initiatives regarding the disability sector.</p> <p>Section 9(2)(a) [Redacted]</p>
 <p>Marama Parore Kaihatū, Chief Advisor Māori</p>	<p>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.</p>

Organisational structure

Whaikaha has approximately 160 staff, with around half of these focused on service delivery. To recognise we are still establishing and consolidating, we are funded for an approximate level of 200 staff. Our Wellington office is currently accommodated in MSD’s national office at 56 the Terrace and we have regional offices around the country. We are seeking a permanent Wellington office accommodation and have released a Request for Information (RFI) to the market that outlines our requirements. This RFI is due to close mid-February at which time we will assess available options. The table below outlines our office locations, staffing levels and functions.

Region	Location	Functions
Wellington	based in MSD National office	DSS and ODI services (70 staff)
Auckland	based at MSD Regional office, Ellerslie	DSS and ODI services (11 staff)
Hamilton	based in MSD Regional office	EGL site – front facing connector services (14 staff)
Palmerston North	based in a Needs Assessment and Coordination Service (NASC) building	EGL site – front facing connector services (37 staff)
Christchurch	based in ERO building	DSS services (5 staff)
	based at MSD leased office space in Eastgate Mall	EGL site – front facing connector service (17 staff)
Dunedin	based in MSD Regional office	DSS services (6 staff)

The diagram below sets out our initial structure as of 1 July 2022, and this broadly reflects our current structure. A review of our organisational design is being conducted to ensure we are fit for purpose. This is due for completion in late February 2023.

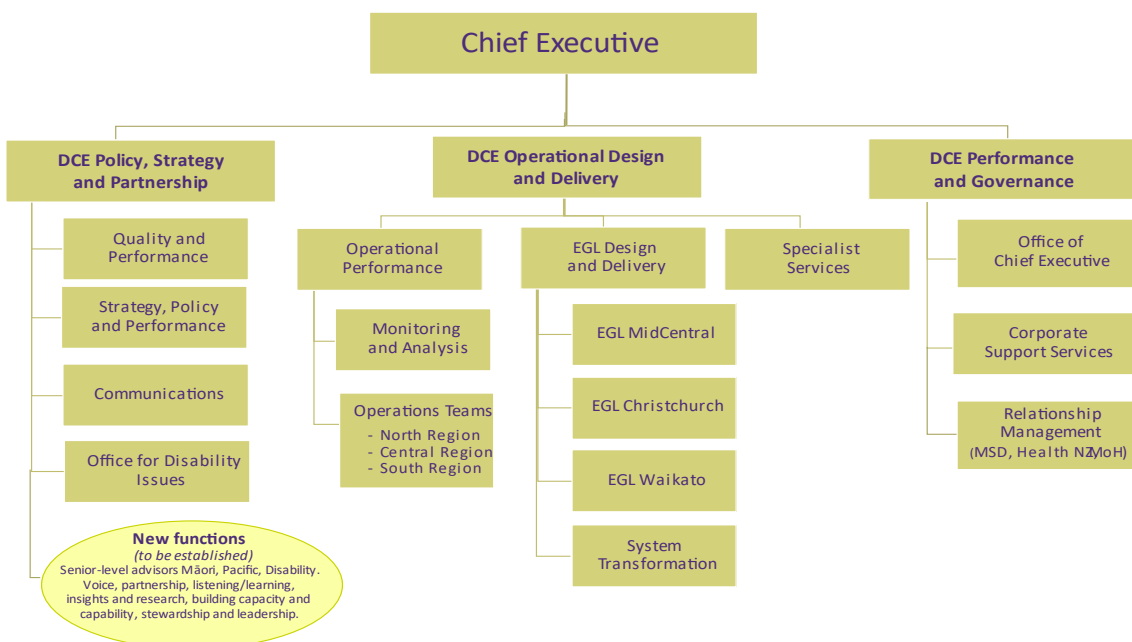


Figure 1. Initial organisational structure as at 1 July 2022

Departmental agency and host relationship

Cabinet agreed in October 2021 to establish Whaikaha in the form of a departmental agency hosted by MSD.¹⁰ The hosting arrangement enables Whaikaha to access MSD's established systems and corporate services.

As a departmental agency Whaikaha 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. The relationship between you and our Chief Executive will operate in the same as relationships between departmental chief executives and their respective minister(s).

Further support arrangements have been established with Manatū Hauora and Te Whatu Ora for aspects of managing the disability support services (DSS) that transferred to Whaikaha and are outlined in Shared Services and Service Level Agreements between the agencies. These agreements and arrangements to access information across agencies are evolving as Whaikaha consolidates its operations. All agreements will be reviewed in January 2024.

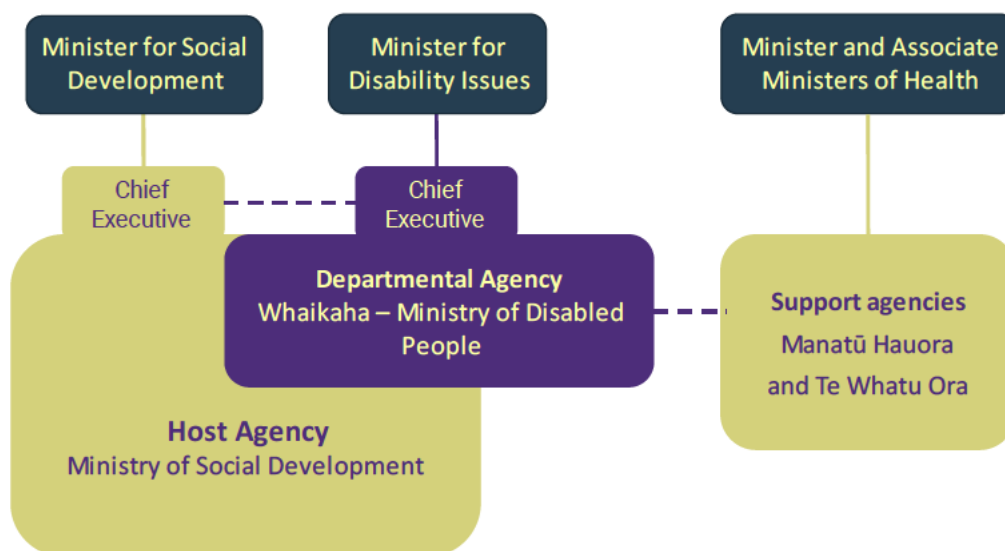


Figure 2. Departmental hosting arrangement

Strategic Framework

Cabinet agreed that Whaikaha will initially operate within MSD's strategic framework as we develop our own systems, processes, and capabilities. In our first 18 months we will develop our vision and strategy, in consultation with our key partners.

We are developing our own Statement of Intent expected in December 2023. Our section within MSD's Statement of Intent is attached for your information in Appendix 1.

¹⁰ CAB-21-MIN-0395, 4 October 2021

Partnership, Strategy and Policy Functions

Partnership and Voice

Working in partnership requires a high level of engagement so that they can inform decisions, help shape policy and services and improve living circumstances and outcomes – enabling good lives. This means Whaikaha will need to:

- give effect to Te Tiriti o Waitangi obligations
- consult with disabled people under the UNCRPD and the New Zealand Disability Strategy
- develop ways to listen to and understand the individual and collective voices of disabled people, tāngata whaikaha Māori and their whānau, and develop the most effective ways to partner with the different disability communities and with Māori
- provide disabled communities the opportunity to articulate the disability and broader issues they face and for their individual and collective voices to inform our understanding, knowledge base, policy, design, priority setting and delivery of support and transformation of the disability system. Whaikaha is also expected to be accessible to disabled people, tāngata whaikaha and whānau.

A key intention of Whaikaha is to recognise that disabled people, tāngata whaikaha Māori and whānau are experts in their own life experiences and on what they need to achieve better outcomes and enable good lives, and to give effect to these voices.¹¹

Our commitment to working in a tripartite partnership was integral to our establishment and remains of paramount importance. We continue to work closely with two groups that supported our establishment on 1 July 2022:¹²

- the Better Outcomes Partnership – membership includes tāngata whaikaha Māori, the wider disability community and officials from Whaikaha
- the Community Reference Group – members were drawn from the disability community representing tāngata Māori, youth disabled community, Pacific disabled peoples and whānau.

Work is underway to finalise our enduring partnership arrangements, which we expect to have confirmed in the first half of this year.

To give full effect to the voice of disabled people, tāngata whaikaha Māori and whānau, Whaikaha will listen to, advocate for and amplify their voices. Whaikaha will ensure the multiple voices are heard, that they are contextualised and made sense of, that they give rise to engagement and appropriate actions, and that the impacts the voices had are reported

¹¹ The 2019 Machinery of Government working group's *Mana, self-determination, and voice* paper outlines that the voice of the collective is just as important as the voice of the individual.

¹² The Better Outcomes Partnership was formerly titled the Establishment Unit Governance Group. The Community reference Group was formerly titled the Community Steering Group.

Strategic policy

Our strategic policy work is underpinned and influenced by the UNCRPD, Health Services and Outcomes Inquiry (Wai 2575) and the Royal Commission of Inquiry into Abuse in Care (Royal Commission).

The UNCRPD underpins all our strategic policy. The UNCRPD was ratified by the New Zealand Government in 2008 and promotes that more needs to be done for disabled people to achieve the same rights as non-disabled people. The UNCRPD human rights approach also affirms the need for State Parties' progressive realisation of equal rights and better life outcomes for disabled people.

The Waitangi Tribunal (the Tribunal) is currently conducting the Wai 2575 Inquiry and is hearing Stage Two Part 1 - Māori with lived experience of disabilities claims. Manatū Hauora and the Crown Law Office are leading for the Crown. The Policy Group leads our participation in this phase of the Inquiry and a final report from the Tribunal is expected in 2025.

In addition, recommendations from the Royal Commission of Inquiry into Abuse in Care (Royal Commission) will help inform our future strategic policy work. The Royal Commission was established in 2018 to inquire into and report on agencies' responses to allegations of historical abuse towards children, young people, and adults at risk (including Deaf people and disabled people) in state care and faith-based institutions between 1950-2000. The Royal Commission's recommendations are expected to be released in mid-2023. Further detail on the UNCRPD, Wai 2575 and the Royal Commission is in Appendix 8 and 9.

Key strategies and action plans

Whaikaha has responsibility for several strategies and action plans:

- **New Zealand Disability Strategy (2016–2026)** – this represents New Zealand's approach for the progressive realisation of the UN Convention on the Rights of Persons with Disabilities. The current Strategy runs until 2026, and in 2024-2025, there will be the opportunity to consider with the disability community the strategic role and purpose of the Strategy and its mandate.
- **Disability Action Plan (2019–2023)** – 28 comprehensive, cross-government work programmes (underway or being planned) that have an explicit disability perspective and support the Strategy. It is expected that the 2023 update process will be a mechanism for confirming, reporting, and monitoring the progress against the UN committee recommendations.
- **New Zealand Sign Language (NZSL) Strategy (2018–2023)** – sets out the work required of the NZSL Board and government agencies to maintain and promote NZSL as an official language. This Strategy runs until 2023 and work to complete the refresh is scheduled to be completed in late 2023.
- **Whāia Te Ao Mārama: The Māori Disability Action Plan (2018–2022)** – supports tāngata whaikaha Māori and their whānau
- **Faiva Ora National Pasifika Disability Plan (2016–2021)** – outcomes and actions to support and improve the lives of Pacific disabled people of all ages and their

families. Some initial work co-designing and developing the new plan has been undertaken by the Pacific disabled groups with the refreshed plan expected to be completed in late 2023.

Whaikaha also has a contribution to make to relevant national strategies and plans under other portfolios.

- **Mahi Aroha Carers' Strategy Action Plan 2019-2023** - Carers are people who support a family, whānau, or aiga member with a disability, health condition, illness, injury, or addiction who needs help with everyday living. The Carers' Strategy is a partnership between government agencies and the Carers Alliance (~50 NGOs) to better recognise and support carers with information, programmes, and funding. The Carers' Strategy is led by the Minister for Social Development and Employment with MSD as the secretariat. Whaikaha is a member of the Carers' Strategy Working Group with other agencies such as MSD, Health and ACC.

Policy functions and work programmes

Our initial policy functions and work programmes were transferred from the Ministry of Health's Disability Directorate and the Office for Disability Issues on 1 July 2022. As a part of our consolidation stage, we are continuing to refine and develop our policy direction. Further information on our authorising environment and legislative work programme is contained in Appendix 10.

The policy work programme includes work to help progress disability support system transformation, ^{Section 9(2)(f)(iv)} [redacted] and working with other agencies to support key work programmes focused on disabled people such as the Ministry of Education's Highest Needs Review and the Ministry of Health's Health of Disabled People Strategy.

The Office for Disability Issues (ODI) functions and responsibilities include supporting cross-government progress and understanding of disability issues, coordinating and reporting on implementation of the UN Convention on the Rights of Persons with Disabilities, New Zealand Disability Strategy and the Disability Action Plan, engaging with the International Monitoring Mechanism (IMM) which monitors Aotearoa New Zealand's actions in relation to the UN Convention and promoting effective engagement with the disability community. Cabinet has noted that the Minister for Disability Issues, working with the Chief Executive, may agree to further changes to ODI to integrate its functions into Whaikaha.

New Zealand Sign Language Board and Programme Office

The New Zealand Sign Language (NZSL) office in ODI provides programme office support for the NZSL Board, supports the NZSL Board's allocation of community grants and other activities to promote and maintain NZSL, and monitors the NZSL Strategy 2018-2023.

In 2014, Cabinet established the NZSL Board as an independent advisory committee. You are responsible for making appointments to the NZSL Board.

The Board's purpose is to:

- promote and maintain the use of NZSL by ensuring the development, preservation, and acquisition of the language
- ensure the rights of Deaf people and NZSL users to use NZSL as outlined in the NZSL Act 2006
- provide expert advice to government and the community on NZSL.

You are responsible for approving the policy and criteria for the NZSL Fund. The NZSL Board funds community activities and ongoing activities and projects through the NZSL Fund, a fund of \$1.645 million for promoting NZSL. Ongoing activities and projects supported from the fund include NZSL week, the maintenance of the NZSL Dictionary, and multi-year programmes such as a Māori Deaf Development project.

Disability Support Services

Introduction

The commissioning and delivery of disability support services (DSS) for people with a long-term physical, intellectual and/or sensory impairment is a key function of Whaikaha. The budget for provision of these services is approximately \$2 billion annually.

Services are provided by a variety of organisations, from small providers to large nationwide service systems. The core services that are funded range from equipment to support or retain independence, through to support with daily activities (e.g., personal care, household management), through to residential 24/7 support, as well as supporting family caregivers (payment for care and respite support).

On any given day we commission DSS for over 43,000 disabled people, tāngata whaikaha Māori and whānau aged under 65 years. Annually we support over 95,000 people with equipment or modification services (all ages). The number of people receiving disability supports is growing faster than the general population and the population receiving DSS is changing – we expect this growth to continue.¹³ See Appendix 6 for the key demographics of the disabled people funded by DSS. The mix of people who are currently allocated DSS include:

- 42 percent have an intellectual disability as their principal disability (and many may also have a physical disability)
- 29 percent have autism as their principal disability
- 19.5 percent have a physical disability as their principal disability.

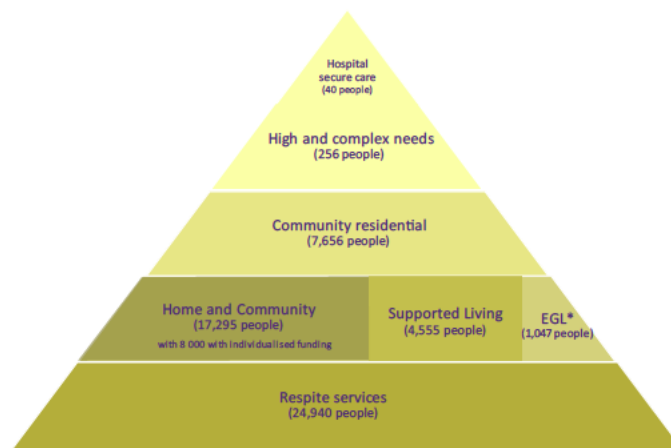


Figure 3. Approximate mix of demand for services as at June 2022.¹⁴

¹³ Growth rates of almost three percent per annum compared with around 1.6 percent in the general population. The median age has decreased (from 34 years in 2016 to 23 years in 2022), increased numbers of children (37 percent increase in 5–14 years), increased numbers of disabled people with high needs support (growing by 10 percent between 2016 and 2018) and increase in clients with intellectual disability and those with autism.

¹⁴ Data in this diagram is sourced from Appendix 6 and advice from Ministry of Health officials. Note that due the way data is allocated across different funded services, people accessing EGL may be counted in other categories. Currently there are approximately 3,900 disabled people accessing EGL services across three sites.

Key Matters in DSS

Residential services and bed capacity

There is a longstanding lack of suitable residential placement for disabled people under the age of 65 years in the Auckland region, and waiting lists around the country, particularly in Auckland, are growing. Given the ongoing shortages for suitable residential disability facilities, younger disabled people (aged under 65) may be inappropriately placed in aged residential care facilities. Work is underway to provide alternatives to aged care settings.

Budget 2022 disability support services cost pressures funding (\$176 million annually) will support provision of some increased bed capacity. However, pressure on specialised accommodation and the High and Complex Forensic Services will remain.

We are also investing in the infrastructure and support for the High and Complex Forensic Services in alignment with community aspirations for improving the wellbeing outcomes for people in secure or supervised care with an intellectual disability under the High and Complex Framework.

In 2023, we are leading residential reform through a partnership project with disabled people, tāngata whaikaha Māori, and whānau. This project will develop ways for people living in residential support services to choose where they live, who they live with and what they need to live their own good life.

Paid family care

Allowing people to pay their family members to provide support services is a policy issue with a long history in the health and disability sectors. There has been litigation, national and international criticism, and changes to legislation and policy.

Prior to 2012, the Ministry of Health and district health boards (DHBs) did not allow parents, spouses, and resident family members to be paid to provide support services for a family member. Following legal challenge, Cabinet agreed a limited family care policy that allowed some family members of people with high or very high disability support needs to be paid to provide Home and Community Support Services only. This was followed in 2013 by the introduction of Part 4A (family care policies) of the New Zealand Public Health and Disability Act 2000 to protect the Ministry and DHBs from further litigation.

In 2020, the current Government repealed Part 4A and agreed to eligibility changes. It was recognised at the time that further policy amendments would be required to remove remaining discrimination.

In June 2022, Cabinet agreed to further changes to extend the option of payment of family members to disabled people with low and moderate needs, and for a wider range of services. Cabinet noted that new policies would document the circumstances where it would not be appropriate for a family member to provide support services, such as where it would be contrary to the purpose of the support or would not achieve the person's goals/support plan or would cause harm to the person or the carer. Budget 2022 included additional funding of \$39


million over four years for Whaikaha to implement this policy change.

Some components for this policy will be delivered through the work to transform the disability support system, including appropriate safeguarding processes and supported decision making,

The role of a disabled person as an employer

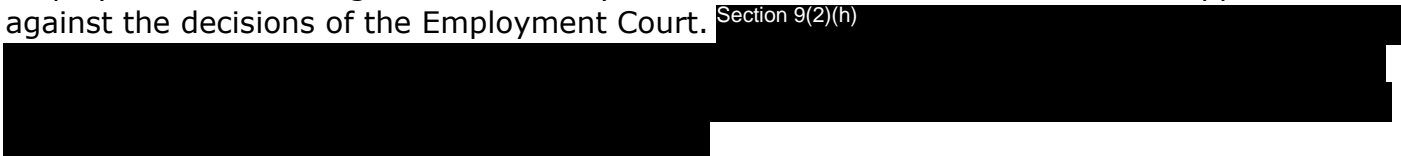

The process for disabled people to pay a family member to provide their support is currently through an employment arrangement. The disabled person employs the family carer (through several means), or the family member is employed through a disability support service provider.

Section 9(2)(h)



In 2021, an Employment Court decision found that the Crown is the employer of paid family carers as homeworkers in cases where disabled people may lack legal capacity to fulfil the employer role. Following this the Ministry of Health was a witness in a Court of Appeal case against the decisions of the Employment Court.

Section 9(2)(h)





DSS Eligibility – Fetal alcohol spectrum disorder (FASD) issues

Currently, people with FASD who also have a physical, sensory, or intellectual disability or an autism diagnosis are eligible to be assessed to access DSS. There are service and support gaps for people with FASD and those with a range of needs relating to their neurodevelopmental disabilities. Child Development Services (CDS) are available for any child with developmental delay.

For many years, advocates have been calling for improved support and services for those with fetal alcohol spectrum disorder (FASD) and their families, including extending eligibility for Whaikaha-funded DSS. The advocates represent a diverse range of interests, including the former Disability Rights Commissioner, Children’s Commissioner and FASD advocacy groups.

Section 9(2)(h)



Section 9(2)(h)

Section 9(2)(f)(iv)

Another aspect of active FASD-related work is contributing to the ongoing interagency implementation of the Manatū Hauora-led FASD Action Plan 2016-2019. This includes regular participation in an interagency coordination group and governance group for new FASD initiatives and involvement in any future refresh of this Action Plan, which requires a cross-government approach.

About Disability Support Services

Providers

Whaikaha contracts with disability support providers. These organisations provide support to a small number of people and operate in only one or two regions, while others are large with nationwide. Support can take place in communities, in people's private homes or in provider's residential facility.

There were 751 contracts transferred under the Public Service Act 2020 from the Ministry of Health Disability Directorate to Whaikaha on 1 July 2022. Administration and payment of our contracts and claims continue to be provided by Te Whatu Ora (under a shared services agreement) to ensure business coverage is maintained.

The current disability provider market is not as diverse as it needs to be and active stewardship on the part of government funding agencies is needed to address this. A few providers have a strong cultural perspective (for example, delivering for tāngata whaikaha Māori and disabled Pacific peoples). Many providers also specialise in working with people with specific impairments (e.g. sensory, intellectual/learning disabilities or autism).

Pricing of services

Providers have consistently raised concerns about sustainability and equity of pricing. Providers continue to express concern that they are not sufficiently funded for the services provided, stating that:

- wage and other costs are increasing faster than the Ministry is providing funding. Wages, the largest part of most providers' costs, are growing at around 2.5 percent per annum, as well wage pressures to attract/retain workers in the current competitive

labour market

- price increases provided by the Ministry of Health since 2016/17 have been few, provided to only some services (mostly residential care), and even those were lower than underlying inflation and wage pressures
- price increases provided by Te Whatu Ora (and before that DHBs) and ACC have been higher than those provided by Whaikaha (e.g., Te Whatu Ora pay a higher rate for hospital level beds than Whaikaha).

Section 9(2)(g)(i)

Needs Assessment and Service Co-ordination (NASC) service

Most of the services the Ministry funds are accessed via a Needs Assessment and Service Co-ordination (NASC) service. NASCs work with disabled people and their whānau or carers to identify a disabled person's strengths, goals, and support needs, and determine eligibility and allocate Ministry-funded support services. They can also assist with accessing other supports that might be needed.

There are 10 NASCs located across Aotearoa New Zealand supporting approximately 43,000 individuals, with a total value of contracts of \$25 million annually. Over the past 2 years NASC service demand has continued to grow. The majority of NASCs across the country are experiencing long waiting lists.

Workforce

The disability support sector employs an estimated 19,000 support workers (there are 61,500 support workers across the health and disability sector).¹⁵ The care and support workers are employed by providers contracted to Whaikaha or engaged through Individualised Funding.

The care workforce is predominately female (87%) and with high levels of part time workers. In terms of demographic profile, the surveyed workforce comprised 18% Māori and 9% Pacific Peoples, with the majority aged over 45 years (26% 45–54 years and 36% 55–64 years).¹⁶

Disability Workforce Strategy

Work is underway to develop a Disability Workforce Strategy to support a transformed disability support system.

Whaikaha will work with sector partners and the community to develop and publish a Disability Workforce Strategy that will frame how government can support the development of

¹⁵ There are 21,000 support workers in the Aged Residential Care sector, 16,000 in Home and Community Support Service sector, and 5,500 in mental health and addiction services. There are also support workers funded by ACC, Oranga Tamariki and Department of Corrections.

¹⁶ The New Zealand Care Workforce Survey 2019 Report, published by AUT New Zealand Work Research Institute, 2021, p 2-4

the disability workforce, with a focus on:

- defining what the current state is, what the future workforce needs to look like, and the critical shifts in workforce required to support ways of working consistent with the principles of EGL
- working with the education sector to ensure qualifications and/or experience and career pathways relevant to support the disability workforce as the system moves to increased personal control by disabled people
- working with the health sector to address the particular clinical and specialist disability workforce requirements which are issues in the current environment and will remain key components in the future, particularly for those under the High and Complex Framework and people with both disability and mental health issues
- developing capability and capacity for disabled people to lead and be part of the future disability workforce.

This Strategy will guide the design and purchasing of workforce development and training programmes and will provide guidance to support our advice and leadership in relation to settings for the disability workforce.

Pay equity

The Support Workers (Pay Equity) Settlements Act 2017 formalised the settlement of a legal claim that support workers were paid less than other workforces because the workforce is predominately female. The Act specified minimum hourly wage rates payable by employers to support workers from 1 July 2017. However, some sections of the Act expired on 1 July 2022, leaving no mechanism to maintain the gains made in wage rates for this workforce.

In April 2022, Cabinet agreed to provide additional funding to enable a minimum wage adjustment from 1 July 2022 for the support workers and in May 2022 agreed to amend the Act to provide a legislative mechanism to implement this minimum pay rate adjustment.¹⁷

In June 2022, the Government amended the Support Workers (Pay Equity) Settlements Act 2017 to provide a minimum wage rate adjustment for these workers to apply from 1 July 2022 and to maintain the training commitment and other provisions of the legislation.

This provides certainty for support workers on minimum wage rates, and allows time for the employers, unions, and funders to develop a sustainable longer-term solution to setting and maintaining pay rates and addressing pay disparities across the health and disability sector workforce.

Care Workforce Sector Agreement to support immigration by providers

The proportion of migrants in the care sector workforce has been growing due to domestic skill shortages, aging workforce, and growing demand for care workers across the health and

¹⁷ CAB-22-MIN-0218, 11 April 2022 and CAB-22-MIN-0189, 23 May 2022

disability sector. The Care Workforce Sector Agreement provides a pathway for migrant care workers to obtain work visas and a pathway to residence with lower wages than are required for workers in other sectors. In August 2022, the Government announced settings changes on sector agreements including the care workforce¹⁸. The new settings involve pay rates, standdown periods and relevant roles. These came into effect in October 2022.

As Minister for Disability Issues, you are a lead Minister for the Care Worker Sector Agreement and will be expected to discuss with the Minister for Immigration any relevant matters. Officials will provide support for any of these engagements.

High and Complex Framework (HCF)

The High and Complex Framework supports people under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 and other relevant legislation. It provides a diversionary pathway for people with an intellectual disability who are engaged with the criminal justice system towards more appropriate services with a strong rehabilitative focus.

About 200 to 300 people are supported under the High and Complex Framework (HCF) at any time, and currently there are 40 people in hospital-level secure care units. In all regions there are workforce and bed capacity pressures for specialised hospital accommodation for people with intellectual disabilities who require secure care and rehabilitation.

Whaikaha is responsible for the commissioning, planning, and funding functions of the HCF. The statutory and regulatory responsibilities for the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 remains with Manatū Hauora. Manatū Hauora has commenced the policy work to determine the long-term location of the statutory functions under the Act.

Due to the separation of the statutory functions from the commissioning functions of the HCF, a Memorandum of Understanding (MOU) has been agreed between Manatū Hauora and Whaikaha. The MOU sets out the arrangements for the ongoing operation of the Act and an agreed joint workplan.

¹⁸ <https://www.immigration.govt.nz/about-us/media-centre/news-notifications/details-of-sector-agreements-for-specific-aewv-occupations-announced>

Appendices

Appendix 1: Statement of Intent

The following text is our section contained within MSD's Statement of Intent 2022-2026.¹⁹

Whaikaha – Ministry of Disabled People

The establishment of Whaikaha – Ministry of Disabled People (Whaikaha) enables the diverse experiences of disabled people, tāngata whaikaha Māori, Pacific disabled peoples, their families, whānau and carers²⁰ to be better recognised and understood. It is also an opportunity to begin transforming the government system so disabled people, tāngata whaikaha Māori and whānau have equal opportunities to achieve their goals and aspirations.

Currently many disabled people, tāngata whaikaha Māori and whānau face significant barriers in achieving ordinary life outcomes. Disabled people's voices have not been heard in a fragmented system that lacks clarity of focus and leadership. Establishing a new ministry and beginning national implementation of the Enabling Good Lives approach (EGL) are significant milestones for the disability community.

Whaikaha has three key functions during the initial stages of its establishment and consolidation:

- ensuring continuity of support for disabled people, tāngata whaikaha Māori and whānau while furthering the work on the transformation of disability support services
- facilitating leadership and stewardship of disability issues across government
- maintaining the trust and confidence of disabled people, tāngata whaikaha Māori and whānau.

In undertaking these functions, Whaikaha will work in partnership with disabled people, tāngata whaikaha Māori and whānau.

As a Departmental Agency of the Crown, Whaikaha is a Te Tiriti o Waitangi partner committed to supporting and enabling Māori, whānau, hapū, iwi and communities so that tāngata whaikaha Māori me ō rātou whānau realise their aspirations, and to embedding Te Tiriti o Waitangi into the way Whaikaha will work with and for Māori.

Whaikaha will combine a significant service delivery responsibility with the stewardship role of a population Ministry²¹. Whaikaha cannot and should not assume responsibility for disability supports, services and policies that are the responsibilities of other public sector agencies. Its role is to support other government agencies to hear and respond to the needs and

¹⁹ <https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/corporate/statement-of-intent/2022/statement-of-intent-2022-2026.pdf>

²⁰ For the purposes of brevity these groups are collectively abbreviated to 'disabled people, tāngata whaikaha Māori and whānau'

²¹ For example, the Ministry for Pacific Peoples or the Ministry for Women.

perspectives of disabled people, tāngata whaikaha Māori and whānau in their work and to provide strategic leadership and co-ordination across government.

These are significant responsibilities and Whaikaha's work has just begun. It is important that Whaikaha has the time it needs to consolidate and stabilise its functions, so it can progress longer term transformation of the disability support system. This can be seen as three stages:

- **Establishment** – Upon commencement, the Disability Support Services' functions and associated staff, including Mana Whaikaha and Enabling Good Lives Christchurch, transferred from Manatū Hauora. At the same time, the functions and staff of the Office for Disability Issues and Enabling Good Lives Waikato transferred from MSD. Ensuring continuity of services to disabled people is a priority. Aspects of Whaikaha, such as some corporate functions including accommodation, have been established on an interim basis. Engagement to ensure the voices of disabled people, tāngata whaikaha Māori, whānau and their communities are reflected in Whaikaha's work will continue to be developed as a priority.
- **Consolidation** – The incoming Chief Executive will begin to develop Whaikaha's vision and strategy in consultation with key partners. Existing services will continue and Whaikaha will develop and implement its new functions and ways of working. The priority is to ensure the functional foundations and components are in place for Whaikaha's success and to support the work in leading disability system transformation.
- **Transformation** – Leading transformative change will be a core responsibility for Whaikaha, including:
 - wider leadership and stewardship of disability issues across government to improve the experience and outcomes of disabled people, tāngata whaikaha Māori and whānau
 - transformation of the disability support system (enable disabled person-directed support and the application of EGL principles).

Transformation will be undertaken in partnership with disabled people, tāngata whaikaha Māori and whānau, with Māori (including iwi and hapū), and informed by the individual and collective voices of the disability community as well as input from the sector.

These priorities sit at the centre of Whaikaha's purpose and are its major accountabilities to the disability community and government.

MSD's Statement of Intent 2022 – 2026 provides a broad base for Whaikaha to begin to deliver on the goal of disabled people's full participation and inclusion across multiple facets of their lives. The Government recognises Whaikaha will need to develop objectives and performance measures across broad areas of wellbeing and government priorities which are valued by disabled people, tāngata whaikaha Māori and whānau.

The first 18 months of operation will enable Whaikaha to engage in partnership with disabled people, tāngata whaikaha Māori and whānau on its strategic path and on the development of measures of progress with relevant agencies.

Appendix 2: Financial Appropriations

Multi-category Appropriation: Supporting tāngata whaikaha Māori and disabled people

As at the October Baseline Update (OBU 2022) Whaikaha has the following appropriation:

Output type/Category	2022/23	2023/24	2024/25	\$ million 2025/26 and outyears	Total over four years
<i>Departmental (to run Whaikaha)</i>					
Stewardship of the disability system	53.2	48.4	45.7	45.9	193.2
Connecting people with supports and communities	5.1	5.1	5.1	5.1	20.4
Departmental Total	58.3	53.5	50.8	51.0	213.6
<i>Non-Departmental (for disability support services)</i>					
Residential-based support services	1012.7	1012.6	1012.6	1012.6	4050.5
Community-based support services	654.2	657.2	660.2	660.2	2631.8
Environmental support services	198.3	198.3	198.3	198.3	793.2
Connecting and strengthening disability communities	65.0	65.0	65.0	65.0	260.0
Early intervention support services	41.3	41.3	41.3	41.3	165.2
Non-Departmental Total	1971.5	1974.4	1977.4	1977.4	7900.7
Grand Total	2029.8	2027.9	2028.2	2028.4	8114.2

[Redacted]

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

Appendix 3: Key stakeholders and relationships

Your portfolio shares a strong mutual interest with Ministers whose portfolios focus on other population groups including portfolios for Māori Development, Whānau Ora, Pacific Peoples, Women, Family Carers, Diversity, Inclusion and Ethnic Communities, Youth, Children and Rural Communities.

There are also strong connections to the portfolios of the Minister of Health, Minister for Social Development and Employment, Minister of Education, Minister of Justice, Minister of Housing, Minister for Building and Construction, Minister for Economic Development, and the Minister for Prevention of Family and Sexual Violence.

The following are key individuals and groups that we recommend you meet with as a priority. Officials from Whaikaha will work with your office to organise these engagements.

Group	Description
<p>Disabled Peoples' Organisation (DPO) Coalition:</p> <ul style="list-style-type: none"> • Association of Blind Citizens NZ • Balance Aotearoa • Deaf Aotearoa • Disabled Persons Assembly NZ • Kāpo Māori Aotearoa (not an active member) • Muscular Dystrophy Association • People First New Zealand Ngā Tāngata Tuatahi 	<p>The Coalition is a group of disabled people-led organisations that are mandated under Article 4.3 of the UNCRPD which promotes active involvement by government agencies with representative organisations of disabled people which are governed by disabled people.</p>
<p>National EGL Leadership Group</p>	<p>Jade Farrar, Chair.</p> <p>This group provides disability community and sector input into, and advice on, current and future initiatives involving transformation of the disability support system.</p>
<p>Key tāngata whaikaha groups:</p> <ul style="list-style-type: none"> • Whānau Ora Interface Group • Te Aō Mārama • Kāpo Māori Aotearoa 	<p>These three groups will have key partnership roles in supporting Whaikaha deliver system transformation.</p>
<p>NZ Disability Support Network</p>	<p>Peter Reynolds leads this key network for providers of disability support services</p>

Parent, Family, Whānau Network	<p>Rebekah Graham, Chair.</p> <p>Relatively new community-driven network, initiated by its current Chair, bringing together those who support and care for disabled people so that these voices can be heard by government.</p>
Pacific Advisory Group (Faiva Ora Leadership Group)	<p>Kramer Hoeflich, Chair</p> <p>Faiva Ora is a community mandated Pacific advisory group to Whaikaha. They are the main stakeholder for providing the Pacific Voice to Whaikaha.</p>
New Zealand Sign Language Board (NZSL)	<p>Rhian Yates, Chair and Catherine Greenwood, Deputy Chair.</p> <p>The NZSL Board is supported by the Whaikaha NZSL office and work to promote and maintain NZSL.</p>
Parliamentary Champions for Accessibility Legislation:(PCAL)	<p>PCAL is a cross-party group of Parliamentarians committed to ensuring Aotearoa New Zealand has accessibility legislation that is fit for purpose.</p>
i.Lead Committee	<p>Sonia Thursby, CEO, Yes Disability.</p> <p>National network representing disabled youth. They hold national conferences to discuss key issues for young disabled people.</p>
Carers Alliance and Carers New Zealand	<p>The Carers Alliance (50 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. Carers NZ CEO, Laurie Hilsген.</p> <p>Co-chairs of the Alliance, Catherine Hall (CE of Alzheimers NZ). Janine Stewart (General Manager Programmes, IHC).</p>

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 EGL Governance Groups in MidCentral, Waikato and Christchurch, as well as the Regional Leadership Groups associated with the three EGL sites given their role

Appendix 4: Key oversight organisations with disability-related roles

The following is a summary of oversight organisations – mainly independent Crown Entities – with disability-related roles. These organisations work to improve outcomes for disabled people in various ways, and it will be important to establish relationships with them.

Health and Disability Commissioner (HDC)

The Health and Disability Commissioner (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 focused on quality of care, it does not extend to funding issues or service entitlement.

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

Commissioner Morag McDowell, formerly a Coroner and Crown Prosecutor, leads the organisation with the Executive Leadership Team of an Aged Care Commissioner (as of March 2022), three Deputy Commissioners, three Associate Commissioners, a Director of Proceedings, and a Corporate Services Manager.

Rose Wall, the Deputy Commissioner, Disability, is focused on increasing the awareness of disabled consumers about their rights under the Code and ensuring that HDC is accessible and responsive to all people.

Human Rights Commission (HRC)

The New Zealand Human Rights Commission (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.

There are four Human Rights Commissioners, including a Disability Rights Commissioner (this role is currently vacant). Our Chief Executive, Paula Tesoriero previously held the Disability Rights Commissioner role since 2017. The role included:

- making the Government's COVID-19 response more equitable for disabled people
- shifting attitudes towards disabled people
- making the education system more inclusive for disabled children
- addressing violence and abuse against disabled people
- advocating for people with FASD to get access to disability support services
- monitoring the implementation of the UNCRPD as part of the Independent Monitoring Mechanism.

Office of the Ombudsman

The Office of the Ombudsman is an office of Parliament, and the main roles from a disability perspective are to:

- resolve complaints and investigate concerns about the administrative conduct of public sector agencies in relation to disabled people and/or disability issues
- monitor the implementation of the rights in the UNCRPD alongside the Human Rights Commission and Disabled Persons Organisation Coalition in the Independent Monitoring Mechanism
- 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.

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.

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”.

Mental Health Commission

The Mental Health Commission (Commission) is an Independent Crown Entity established in February 2021, based on recommendations following a 2018 independent inquiry into mental health and addiction. The Commission's key objective is to contribute to better and equitable mental health and wellbeing outcomes for all people in Aotearoa New Zealand.

Hayden Waro is the current Chair and is the Chief Executive of Tui Ora, a Māori development organisation and health and social service.

Independent Monitoring Mechanism (IMM)

The purpose of the IMM is to promote, protect and monitor implementation of the 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.

It consists of the **Human Rights Commission, the Office of the Ombudsman, and the Disabled People’s Organisations (DPO) Coalition** – a group of Disabled People’s Organisations who have a mandate to work in partnership with government under Article 4(3) of the UNCRPD.

Appendix 5: Statistics New Zealand wellbeing survey - June 2020

About the data

Stats NZ collected this information as part of a wellbeing supplement added to the household labour force survey in the June 2020 quarter. The supplement included a selection of questions from the general social survey, which was delayed until April 2021 due to the COVID-19 pandemic.

Additional survey indications include:

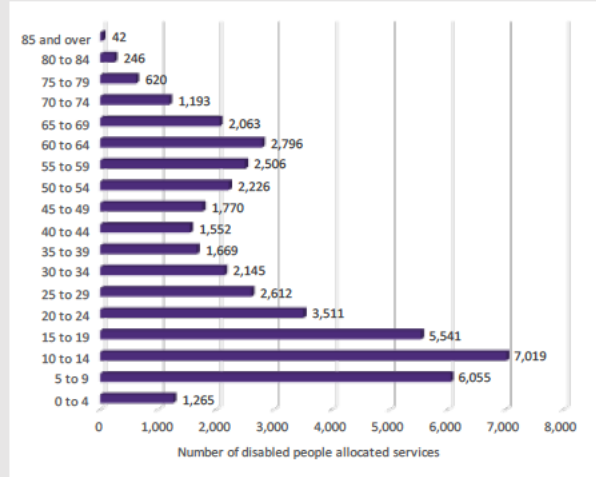
- in addition, one in nine disabled people reported feeling lonely most or all of the time (12 percent). This was three times the rate of non-disabled people (3.9 percent).
- disabled people were less likely to feel safe when walking alone in their neighbourhood, more likely to experience discrimination, and reported lower levels of trust when compared with non-disabled people.
- almost a quarter of disabled people do not have enough money for everyday needs.
- many disabled people also face financial difficulties. Twenty-three percent of disabled adults under 65 felt they did not have enough money to meet their everyday needs. This dropped to 6.5 percent for non-disabled people of the same age.
- when looking at all sources of income combined, the median income for disabled people was \$400 a week, compared with \$900 for non-disabled people. This median is calculated using all incomes reported in the survey (including wages and salaries, self-employment earnings, and government transfers such as benefits or ACC payments) and it includes people who have no income at all.
- disabled people were far less likely than non-disabled people to be employed, and those who were employed were less likely to work full time.
- the employment rate for disabled people (aged 18–64) was 39.9 percent, less than half the rate for non-disabled people in the same age bracket (81.4 percent). Twenty-seven percent of disabled people with a job worked part time (fewer than 30 hours a week), compared with 17 percent of non-disabled people.
- employed disabled people were more likely to report low levels of perceived job security than employed non-disabled people. Of those who were working, 17 percent of disabled people thought there was a high or almost certain chance they would lose their job in the next 12 months, significantly higher than 6.7 percent of non-disabled people.
- the median weekly earnings for disabled people being paid a wage or salary was \$936. This compares with \$1,080 for non-disabled people. The median hourly earnings for disabled people were \$25.00, which is \$2.40 less than the hourly median for non-disabled people.

Appendix 6: DSS demographics

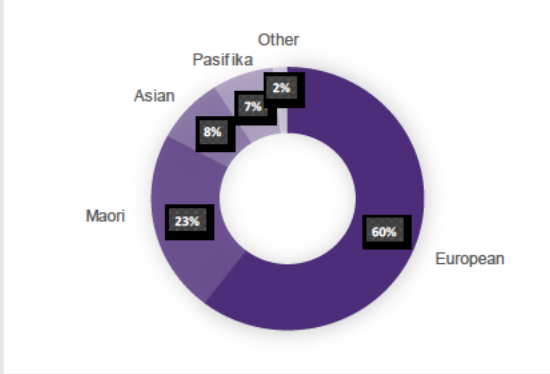
Demographics of disabled people allocated disability supports in 2022

Total people allocated at least one disability service in the 2022 calendar year **46,262**

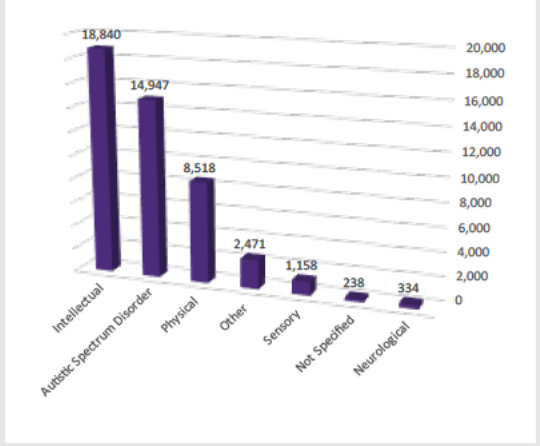
Population by Age



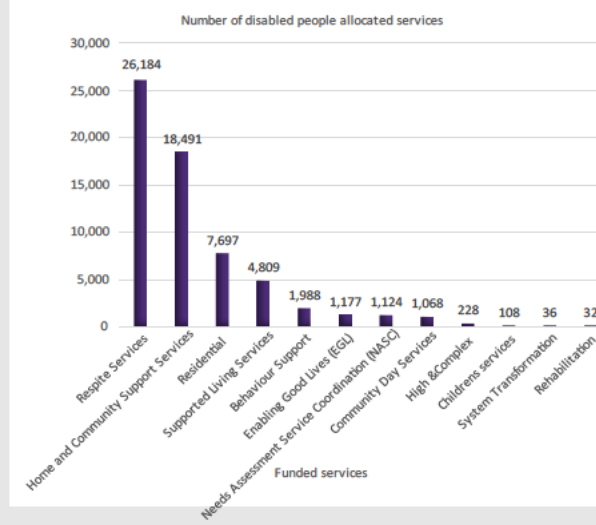
Ethnicity



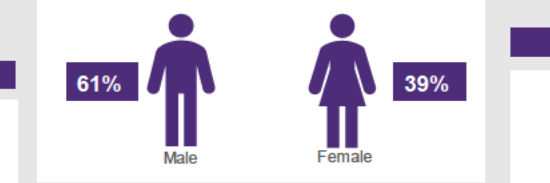
Disability Type



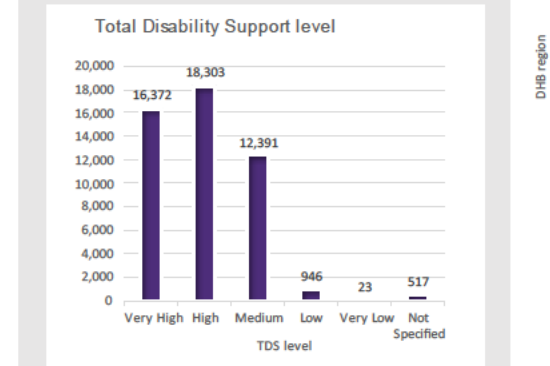
Services



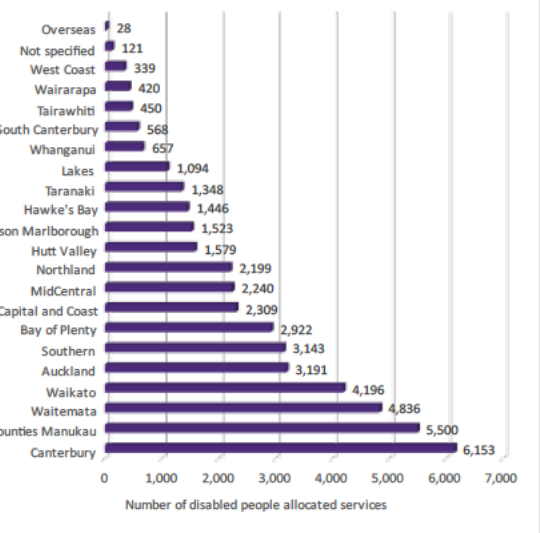
Gender



Extent of Disability



Regional location



[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

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Appendix 9: United Nations Convention on the Rights of Persons with Disabilities

The UNCRPD consists of 50 articles which focus on specific areas of life, including the rights to education, having a family, emergency responsiveness, choosing where you live, non-discrimination and decision-making.

The New Zealand Government submitted its latest report to the United Nations in March 2019. The United Nations Committee's periodic review of New Zealand's implementation of the Convention was planned for 2019 but was significantly delayed, in part due to COVID-19, and has yet to be re-scheduled.

In August 2022, the Minister for Disability Issues led a government delegation of senior officials to Geneva in August to participate in an examination of Aotearoa New Zealand's progress on disability rights.

This examination was undertaken by 18 independent experts in disability rights who comprise the United Nations Committee on the Rights of Persons with Disabilities (the UN Committee). The UN Committee identified 60 recommendations (referred to as Concluding Observations) which span the responsibilities of many Ministerial portfolios and associated agencies.

The Committee's observations are very important for government to further consider and act on what more government can do to realise the rights of disabled people in Aotearoa New Zealand.

Section 9(2)(f)(iv)

Appendix 10: Authorising environment and legislative work programme

Authorising environment

The authorising environment for disability support services is made up of both legislative and policy settings. Implementing the EGL approach to government supports nationally (including to DSS) may require some amendments to, and/or designing new, legislation and policies to provide the authority to act in support of the EGL approach.

These Acts confer powers and responsibilities on the Minister of Health (and in the case of the Safety Act, Ministry of Health) and concern the quality of disability support services, standards relating to them, and complaints about them including:

- **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
- **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. Section 9(2)(f)(iv)

Any changes to the DSS authorising environment that may be desirable to reflect the creation of Whaikaha must consider the relationship between disability and health services, noting that the health system continues to provide services for people who are not eligible for DSS (e.g., people with health or aged care-related support needs). Section 9(2)(f)(iv)

DSS Cabinet decisions need to be reviewed

The disability support system is based on a number of historical Cabinet decisions. Further policy work is required to identify whether any of these historical decisions need to be rescinded or amended to enable the implementation of services based on an EGL approach. Many previous Cabinet decisions relate to means testing and the use of needs assessments. Most of these decisions are from the 1990s and have not been updated since.

In agreeing to the establishment of Whaikaha and the national implementation of the EGL approach to support, Cabinet did not amend or update the previous decisions establishing

DSS. Cabinet agreed that in the initial phase of national implementation decisions should be consistent with decisions made in 2018 on Mana Whaikaha²²:

- the eligibility criteria should be the same as the current eligible population for DSS with the clarification that all children with significant developmental delay but no confirmed diagnosis, regardless of age, are eligible for early intervention support
- means testing for household management should not apply to people who have a flexible personal budget
- means testing for household management should continue to apply while people continue to receive a NASC-allocated package during the transition period.

Legislative work programme

Section 9(2)(f)(iv) [Redacted]

- [Redacted]
- [Redacted]
- [Redacted]
- [Redacted]

[Redacted]

Disability System Bill

Section 9(2)(f)(iv) [Redacted]

[Redacted]

²² SWC-18_MIN-0108

Section 9(2)(f)(iv)

Disabled Person-Directed Support Funding and Employment Arrangements Bill

Section 9(2)(f)(iv)

Section 9(2)(h)

Accessibility for New Zealanders Bill

The Government introduced the Accessibility for New Zealanders Bill (the Bill) into the House in July 2022. The purpose of the Bill is to create an enabling framework focused on progressively identifying, preventing, and removing accessibility barriers that disabled people and others with accessibility needs face. It establishes a new ministerial advisory committee alongside new functions for the Minister for Disability Issues and the Whaikaha Chief Executive.

The Bill is currently at the Select Committee stage. While Cabinet agreed²³ that Whaikaha will be responsible for the Bill once it is enacted, MSD is leading the Bill's passage through the House.

Whaikaha and MSD will work together to provide you with advice in due course on the future of this Bill.

²³ CAB-22-MIN-0104 on 4 April 2022

Amending the New Zealand Sign Language Act 2006

Section 9(2)(f)(iv)

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Appendix 11: System Transformation – Enabling Good Lives

Background

In 2007 a Social Services Select Committee Inquiry heard that disabled people often felt they had little control over the services they received, and funding was relatively inflexible.

In 2011, a review by a group of people from the disability sector produced a report “Enabling Good Lives” – with disabled people to have greater choice and control over their supports and their lives.

In September 2012 the Ministerial Committee on Disability Issues agreed that fundamental change to the disability support system was needed.

In 2018, the Government agreed to implement the EGL prototype in MidCentral DHB region and endorsed the EGL vision and principles, developed by the sector in 2011, as the basis for transforming the disability support system.

Expansion of the EGL model will be based on lessons learned from the three demonstration/prototype in Christchurch, Palmerston North, and Hamilton. The three existing sites have been operating for some time. Each of the EGL sites started at different times, operated in different ways and managed by different agencies, to trial different approaches:

- Christchurch site was established in 2013 with a focus is on young people aged 14 years and older who are in receipt of the Ministry of Education Ongoing Resourcing Scheme (ORS) funding and support.
- Waikato site in Hamilton was established in 2015 and allows for people to “opt-in” to the programme after they meet the criteria for DSS funding and has limited numbers of individuals they can support.
- MidCentral (Mana Whaikaha) in Palmerston North, where all DSS-eligible people in the region can access the EGL approach. Mana Whaikaha manages all the administration and financial functions for this site and provides a range of support options depending on the participant’s need and their support preferences.

Budget 2022 set aside \$100 million in contingency funding for the expansion of the EGL approach. The disabled community has high expectations of Whaikaha, and want to see demonstrable change in service provision, shared design of services, personal budgets, and eligibility for DSS to be addressed with urgency.

Whaikaha has been working with representatives of the disability community on some of the elements that will be required for national transformation, but further system and operating model design will be required, in partnership with the disabled community, to meet the contingency conditions and enable the approach to be upscaled from the pilot sites.

Vision

The vision for EGL is that disabled people and their families will have greater choice and control over their lives and supports and make more use of natural and universally available supports. Disabled people will be able to say things like “I have access to a range of support that helps me live the life I want and to be a contributing member of my community”, and I have real choices about the kind of support I receive, and where and how I receive it”.²⁴

The government will get better value for the funding it provides because the new approach will generally provide better quality of life outcomes, less money spent on provider premises and more on support.

Principles

The principles underpinning this vision are set out below:

Principle	Description
Self-determination	Disabled people are in control of their lives.
Beginning early	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.
Person-centred	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.
Ordinary life outcomes	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.
Mainstream first	Disabled people are supported to access mainstream services before specialist disability services.
Mana enhancing	The abilities and contributions of disabled people and their families are recognised and respected.
Easy to use	Disabled people have supports that are simple to use and flexible
Relationship building	Supports build and strengthen relationships between disabled people, their whānau and community.

²⁴ Further information on the EGL vision is at <https://www.enablinggoodlives.co.nz/about-egl/egl-approach/vision/>



Whaikaha
Ministry of
Disabled People



Te Kāwanatanga o Aotearoa
New Zealand Government