



In Confidence

Briefing for the Minister for Disability Issues

The new Ministry for Disabled People

Prepared by the Establishment Unit for the Ministry for Disabled People and Ministry of Health (Disability Directorate)

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Welcome

This briefing provides background information on the key issues in this portfolio and the exciting new opportunity presented by the new Ministry for Disabled People, which launches on 1 July 2022.

The establishment of the new Ministry is an important moment in the growth in the status of disability issues and disabled people in Aotearoa New Zealand.

As the inaugural Minister you will lead a new direction in how disabled people and their whānau are supported, and also the way society supports them to live good lives, with greater choice and control.

This background briefing outlines:

- the formation of the new Ministry, its functions and structures, financial appropriations and the hosting arrangement with the Ministry of Social Development (MSD)
- the breadth and scale of disability support services coming into the new Ministry (\$2 billion annually)
- the work ahead to transform the disability support system, with the expansion of the Enabling Good Lives (EGL) approach nationally
- new ways the Ministry will be working with disabled people in partnership and how the 'voice' of disabled people will be built into the functions and approach of the new Ministry
- key upcoming events and matters requiring your attention
- individuals and groups you may wish to meet with as a priority.

The Ministry of Health (Disability Directorate) and Establishment Unit of the Ministry for Disabled People can provide you with additional information in relation to your new portfolio as required.

Introduction

The new Ministry for Disabled People sees New Zealand continuing to take a lead role internationally in promoting the rights of disabled people¹. The new Ministry will provide you with the opportunity to:

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

The new Ministry will lead a disability work programme encompassing strategic policy, stewardship, the ongoing transformation of disability support services in line with an Enabling Good Lives (EGL) approach, and drive improvements in outcomes for disabled people and whānau. Once accessibility legislation is passed (expected to be enacted by 1 July 2023), the new Ministry will lead cross-government work to address accessibility barriers, guided by a Ministerial Accessibility Committee made up of, and representing, disabled people.

On 1 July 2022 the new Ministry assumes responsibility from the Ministry of Health for a range of disability support services functions, three regional sites² delivering on the EGL approach to the provision of disability support services. The Office of Disability Issues and its existing functions and responsibilities will also become part of the new Ministry from 1 July 2022.

s 9(2)(f)(iv)		

Disabled people is an inclusive term used for the purposes of brevity when referring to a general group including tangata whaikaka Maori, tangata whaikaha, deaf people and Pacific disabled peoples.

Christchurch site and MidCentral Mana Waikaha (managed by Ministry of Health) and Waikato site (managed by Ministry of Social Development)

Te Tiriti o Waitangi underpins the new Ministry

The new Ministry will become responsible for existing strategies that seek to give effect to the Articles of Te Tiriti o Waitangi – including Whāia Te Ao Mārama 2018–2022: The Māori Disability Action Plan.

The EGL approach is closely aligned to Whānau Ora, and the principles and processes of both give effect to rangatiratanga, enabling disabled people, tāngata whaikaha Māori me o rātou whānau to have control and make choices, and seeking to ensure equity of outcomes. As partnership arrangements are renewed and further developed by the new Ministry, partnership with Māori will be strengthened.

Partnering with the disabled community to drive transformation

Disabled people and whānau experience poorer wellbeing outcomes than other New Zealanders on almost any available metric. There are also enormous variations in the experiences, needs and aspirations of disabled people, tangata whalkaha Maori, Pacific disabled people, and their families. Tangata whaikaha Maori experience disadvantage greater than other disabled people in key outcome areas.

As well as working with Māori iwi and hapu and tāngata whaikaha Māori in addressing the transformation of the system, the new Ministry will be required to develop ways to listen to and understand the individual and collective voices of disabled people and their whānau, and partnering with the disability community in design, priority setting and delivery of supports.

s(9)(2)(g)(i)

Leadership and stewardship to improve the lives of disabled people

Improvements to way disability support services are provided are critical for achieving improved outcomes for disabled people. However, better supports and services alone will not put disabled people in control of their lives or create the significant shifts in wellbeing measures needed to achieve equity.

The principle of 'mainstream first' is a key part of the EGL approach and emphasised by the New Zealand Disability Strategy and United Nations Convention on the Rights of Persons with Disabilities. Disabled people should encounter spaces, services and policies designed to meet everybody's needs, and people who understand and respect them.

s 9(2)(f)(iv)		

Key demographics on New Zealand's disabled people 2020

The Minister for Disability Issues leads and advises across government on behalf of disabled New Zealanders, to ensure government services and policy consider their needs and interests. Promising progress is seen in employment and wellbeing but there is still much to do.



24% (1.1m)

of New Zealanders are disabled [2013 Census]

[The following data is from the Household Labour Force Survey, June 2020]

Among disabled people aged 18-64







experienced discrimination within the last 12 months (17% for non-disabled people)

reported having a house/flat with a major problem with heating (6% for non-disabled people)

reported not having enough money to meet every day needs (7% for non-disabled people)



of disabled people aged 18+ have no qualification (16% for non-disabled people)



of disabled people are satisfied with their lives

(compared to 86% for non-disabled people)



of disabled 15+ year-olds are employed, with 22% being underutilised (70% for nondisabled people employed, 12% underutilised)



of disabled people aged 18+ reported having poor overall mental wellbeing (7% for non-disabled people)

Timeline of key events and decisions

Dates	Description of Event and Activity	
23 June 2022	Ministerial Leadership Group on Disability Issues (Separate briefing will be provided to support your attendance)	
1 July 2022	Launch of the new Ministry for Disabled People (Information provided separately on this event)	
4 July 2022	Accessibility legislation to be considered by Cabinet Business Committee [MSD lead]. Introduction of Bill to House at end-July	
11-20 July 2022	Disability hearing of the Royal Commission of Inquiry into Historical Abuse in State Care and in the Care of Faith-based Institutions	
End of July 2022 -	Every six months participating government agencies provide progress reports about the work they are undertaking under the auspices of the Disability Action Plan 2019-2023 (DAP). Once a report is edited and checked and, finally, approved by the Disabled People's Organisations Coalition, a six-monthly DAP progress report is published on the Office for Disability Issues website.	
4 August 2022	In-cycle Office for Disability Issues Parent/Whānau/Family Network meeting	
23 and 24 August 2022 (Geneva time)	Examination of New Zealand's implementation of the Convention on the Rights of Persons with Disabilities by the UN Committee on the Rights of Persons with Disabilities, Geneva s 9(2)(ba)(i)	
August 2022	Crown accountability hearing of the Royal Commission of Inquiry into Abuse in State Care	
s 9(2)(f)(iv)	s 9(2)(f)(iv)	
22 & 27 June 2022	New Zealand Sign Language Board Nominations going through Appointments and Honours Committee (Cabinet 27 June)	
27 – 28 June 2022	Estimates (Select Committee)	
18 – 24 September -	International Week of the Deaf	
23 September 2022	International Day of Sign Languages	
7-8 October 2022	Blind Citizens Annual General Meeting and Conference, Invercargill	

14-18 November 2022	Waitangi Tribunal, Hearing Week 4
November/December 2022	s 9(2)(f)(iv)
November/December 2022 -	s 9(2)(f)(iv)
December 3 2022	International Day for Disabled Persons
End of January 2023	s 9(2)(f)(iv)
February 2023	Annual Review (Select Committee)



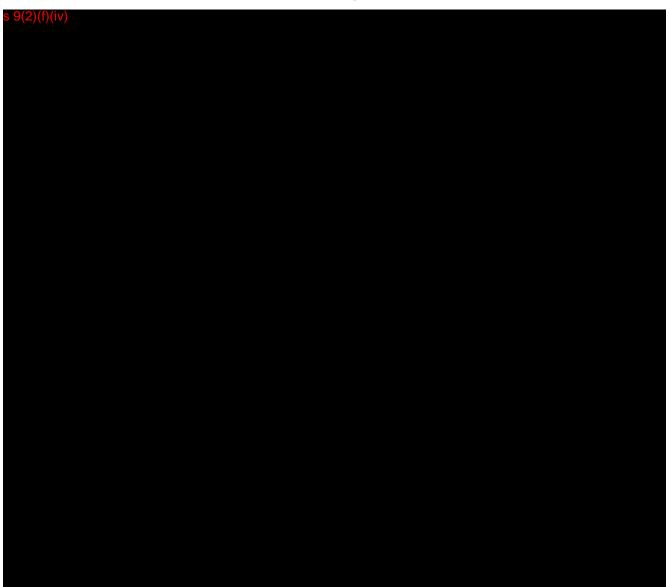


Establishment of the new Ministry for Disabled People

Functions and structure

The new Ministry will be a Departmental Agency hosted by MSD. The new Ministry has two key functions during the initial stages of its operation:

- ensuring continuity of support for disabled people while continuing the foundation and planning work for the transformation of disability support services
- facilitating leadership and stewardship of disability issues across government.



The new Ministry will combine a significant service delivery responsibility with the stewardship role of a population Ministry. It does not assume responsibility for disability supports, services and policies that are the responsibilities of other public sector agencies. The new Ministry's 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.

The key priority for establishment of the new Ministry has been the transfer of existing disability support services and related functions from Ministry of Health and ensuring the continuity of services for all existing clients from current providers. Further detail on the background on the establishment and the work programme to stand-up the new Ministry on 1 July 2022 is outlined in Appendix 1.

Three stages to the new Ministry's formation

The new Ministry needs time to complete its establishment, consolidate and stabilise, for it to be able to succeed in the long-term transformation of the disability system. This can be seen as three stages (with indicative timeframes):

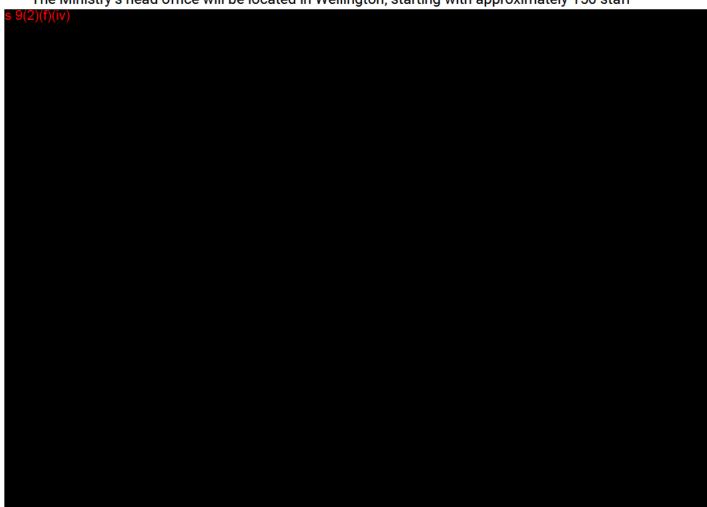
- Core establishment and ongoing transition activities 9(2)(f)(iv) - Upon commencement, the Disability Support Services functions and associated staff transfer from the Ministry of Health (including two EGL sites in Christchurch and Palmerston North), and the functions and staff of the Office of Disability Issues and EGL Waikato transfer from MSD. Ensuring continuity of services to disabled people is a priority. For its first eighteen months the Ministry will operate under MSD's statement of intent.
- Consolidation 9(2)(f)(iv) This stage will see the development of the Ministry's vision and strategy, in consultation with key partners. Existing services will be continued, and the Ministry 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 the Ministry's success and to support the work in leading disability system transformation.
- **Transformation** 9(2)(f)(iv) Leading transformative change in line with its own strategy and statement of intent, the Ministry's core responsibilities will be:
 - wider leadership and stewardship of disability across government to improve the experience and outcomes of disabled people and whanau (and bringing accessibility and disability issues together)
 - transformation of the disability support system (enable disabled person-directed support and the application of EGL principles³).

Transformation will be undertaken in partnership with disabled people and whanau, Māori iwi and hapu and tāngata whaikaha Māori, and informed by the individual and collective voices of the disability community and the sector.

The EGL principles are set out page 28

Organisational structure of the new Ministry

The Ministry's head office will be located in Wellington, starting with approximately 150 staff



The Ministry also has a regional presence. The table below outlines the location of the sites, staffing levels in those sites and their current functions.

Regional Sites for Ministry for Disabled People

Region	Location	Activities
Auckland	based at MSD Regional office, Ellerslie	Processing staff from DSS (11 staff)
Hamilton	based in MSD Regional office	EGL site – front facing connector services (14 staff)
Palmerston North	based in a NASC building	EGL site – front facing connector services (37staff)
Christchurch	based in ERO building	Processing staff from DSS (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	Processing staff from DSS (6 staff)

Departmental agency and host relationship

Cabinet agreed in October 2021 to establish the new Ministry in the form of a departmental agency hosted by the MSD⁴.



Ministerial relationship

As a departmental agency the new Ministry 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 the Chief Executive will operate in the same way as relationships between departmental chief executives and their respective minister(s).

Hosting Arrangements

The new Ministry is operationally autonomous, but the hosting arrangement enables the Ministry to access MSD's established systems and corporate services.

Support arrangements have been established with the Ministry of Health and Health NZ for aspects of managing the disability services that have transferred to the new Ministry and are outlined in Shared Services and Service Level Agreements between the agencies. 59(2)

Arrangements to access information across agencies will be supported by information sharing agreements that have been developed in consultation with the Office of the Privacy

Commissioner.

CAB-21-MIN-0395, 4 October 2021

Financial responsibilities

The Chief Executive of MSD is administrator for the Multi-Category Appropriation (MCA), for the Ministry for Disabled People's operations (with the Minister for Disability Issues being responsible for the appropriation). Under the Public Finance Act 1989, the Chief Executive is able to incur expenses against the multi-category appropriation established under Vote Social Development⁵. Specifically, for

- Departmental expenditure Chief Executive, Ministry for Disabled People is directly responsible to the Minister.
- Non-departmental expenditure MSD Chief Executive, as Appropriation Administrator, is responsible to the Minister.

As Appropriation Administrator, the MSD Chief Executive will be responsible for the financial management, financial performance and financial sustainability of the new Ministry. 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.

Corporate strategic framework

Cabinet agreed that the Ministry will initially operate within MSD's strategic framework until it while it develops its own systems, processes and capabilities. During its first 18 months the new Ministry will develop its vision and strategy, in consultation with key partners.

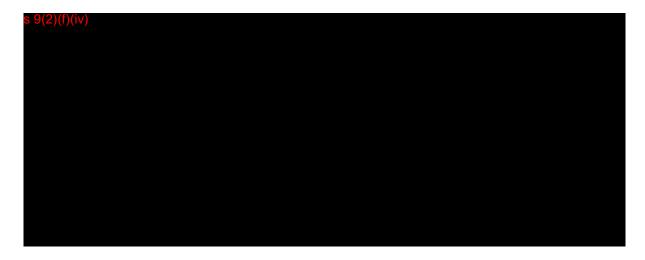
Finance and Appropriations

Disability appropriations of nearly \$2 billion annually in non-departmental expenditure and about \$45 million annually in departmental expenditure for the Ministry's operations have been established under a new MCA, Supporting tangata whaikaha Maori and disabled people.

The departmental funding appropriation includes funding from Budget 2022 to establish the new Ministry of \$106 million (over four years) and transfer of funding from Ministry of Health to cover the staff and overhead costs of \$78.4 million (over four years). Refer Appendix 2 for details of the MCA.

The new Ministry's appropriations were put in place within the short timeframes to establish the its financial framework. s 9(2)(f)(iv)

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.



Contingency funding for implementing Enabling Good Lives (EGL)

As part of Budget 2022 there is a new initiative to extend of EGL to more of the disabled population and their whānau and 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 work.

The Minister of Finance and you have been delegated by Cabinet to jointly approve the drawdown of the operating contingency funding, with amendments to the final appropriation as necessary. s 9(2)(f)(iv)



Addressing pressures in Disability Support Services

An additional \$704m was allocated through Budget 22 to address ongoing cost pressures over the next four years across disability support services.

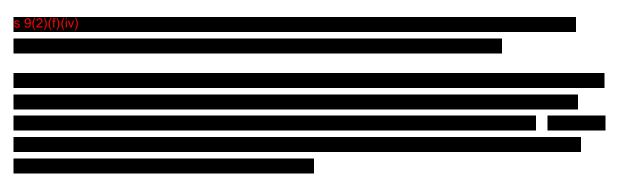


Name of the new Ministry pending

When Cabinet agreed to establish the new Ministry in October 2021, Cabinet authorised the Minister for the Public Service, the Minister for Disability Issues and the Minister of Health to determine its final name.

Discussions with the disability community identified that the name should have three components: te reo Māori, English and New Zealand Sign Language (NZSL) that should be developed independently of each other.

During the establishment work officials have engaged with the NZSL Board, and run engagement through the AmplifyU platform on the reo Māori and English name. The Unit also connected with Iwi chairs and convened hui with Māori members of the Community Steering Group and other tangata whaikaha Maori. The aim is for an English and reo Maori name for the new Ministry for the launch on 1 July. The NZSL name cannot be developed until the English and te reo name have been finalised.



The Ministry also has a domain name – 'whaikaha.govt.nz', which has been approved by the Department of Internal Affairs. Whaikaha means to have strength, ability and capability. Tāngata whaikaha is often used to describe disabled people.

Policy functions transferring to the Ministry

The Ministry of Health's disability directorate policy function and the Office of Disability Issues work programme and teams are transitioning into the new Ministry.

Policy work from the **Ministry of Health** includes strategic policy, operational policy relating to disability support services (DSS), and disability issues. s 9(2)(f)(iv)

The Office of Disability Issues (ODI) functions and responsibilities related to crossgovernment disability issues, the New Zealand Disability Strategy and Disability Action Plan, and New Zealand Sign Language Act 2006, and UN Convention on the Rights of Persons with Disabilities⁷ will transfer to the new Ministry.

ODI's work coming into the Ministry includes supporting cross-government progress on disability issues, including facilitating agency reporting against the Disability Action Plan, engaging with the International Monitoring Mechanism (IMM) which monitors New Zealand's actions in relation to the UN Convention and promoting effective engagement with the disability community. Other work includes capacity building within the disability sector (eg Nominations Database to lift diversity of board membership), advising on the experiences of disabled people to assist with the Royal Commission of Inquiry into Abuse in Care, and coordinating government-led actions to respond to the recommendations of the Disability Rights Commissioner's Inquiry into the Support of Disabled People and Whānau During Omicron.

s 9(2)(f)(iv)

The New Zealand Sign Language (NZSL) team (ODI) provides secretariat support for the New Zealand Sign Language Board, supports the Board's allocation of community grants and other activities to promote and maintain NZSL, and monitors the NZSL Strategy 2018-2023. The New Zealand Sign Language Act 2006 is currently administered by MSD, with the responsible Minister being the Minister for Disability Issues. \$ 9(2)(f)(iv)

Details on key disability strategies and upcoming legislative work programme are briefly outlined in Appendix 4.

⁷ CAB-22-MIN-104, 4 April 2022

s 9(2)(f)(iv)

Disability Support Services

Introduction

The purchase and delivery of disability support services for people with a long-term physical, intellectual and/or sensory impairments will be a key function of the new Ministry. The budget for provision of these services is approximately \$2 billion annually.

A wide range of services are funded ranging from equipment to support or retain independence, through to support with daily activities (eg shopping, transport, cleaning etc), through to access to community residential 24/7 support, as well as support to family caregivers (payment for care and respite support) so they can take a break from caring responsibilities.

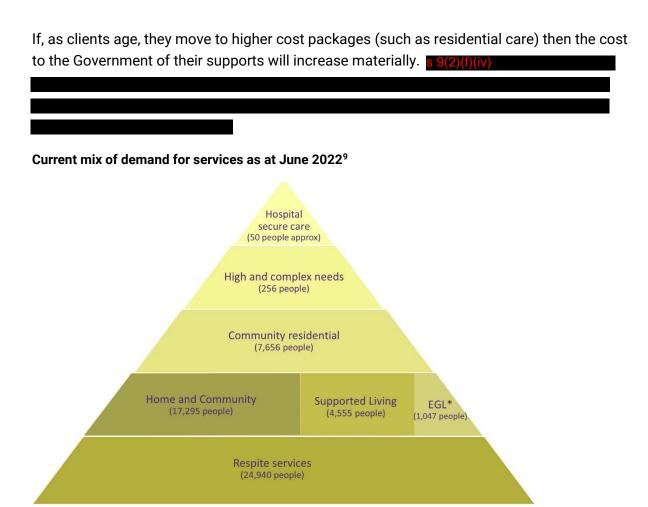
The number of people receiving disability supports is growing faster than the general population (growth rates of almost three percent per annum compared with around 1.6 percent in the general population) and we expect this is likely to continue. Potential drivers of this increase include greater public awareness of the ability to access disability support services, particularly for young people with autism. The population receiving Disability Support Services (DSS) is changing -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 spectrum disorder.

The mix of people who are current allocated funded disability support services:

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

The Ministry of Health currently provides ongoing supports for around 19,500 disability clients under 20 years of age. Although they make up around 44 percent of clients, only 12 percent of expenditure is on services for them. This likely reflects young people being supported through schools and their families/whanau and making up only a small percentage (around two percent) of the people in residential care.

Residential care costs around \$700 million per annum and supports around 7,000 clients. Most clients in residential care are 20 years of age or older, with the higher representation amongst those age 45 to 60 years. Service packages for clients in residential care are materially higher than for clients living in the community (reflecting the costs of services such as accommodation, food, specialist support, and day activities).



See Appendix 6 for an A3 of the key demographics of the disabled people funded by the Ministry of Health's disability support services.

Providers of Disability Support Services (DSS)

Disability support provider organisations consist of small to medium-sized organisations providing niche services to a small number of people and operating in only one or two regions, while others are large with nationwide service systems. Support can take place in communities, in workplaces, in people's homes or in accommodation facilitated by the disability support provider organisation.

These 751 current contracts have been transferred under the Public Service Act 2020 from the Ministry of Health disability directorate to the new Ministry from 1 July 2022. The Establishment Unit have engaged with providers of disability support services on the transfer of contracts to the new Ministry. s 9(2)(f)(iv)

⁹ 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.

s (9)(2)(g)(i)

A few providers have a

strong cultural perspective (for example, delivering for tangata whaikaha Maori and disabled Pacific peoples). Many providers also specialise in working with people with specific impairments (for example sensory, intellectual/learning disabilities, autism).

Pricing of services

Providers have raised concerns about sustainability issues, relating to the pricing of services and the future cost of the disability support system. Providers continue to express concern that they are not sufficiently funded for the services provided, arguing 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 DHBs and ACC have been higher than those provided by the Ministry of Health (eg DHBs paid a higher rate for hospital level beds than the Ministry).

s (9)(2)(g)(i)

Role of co-ordinators and NASCs

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 whanau or careers to identify a disabled person's strengths, goals and support needs, and determine eligibility and allocate Ministry-funded support services (within the overall disability services budget). They can also assist with accessing other supports that might be needed.

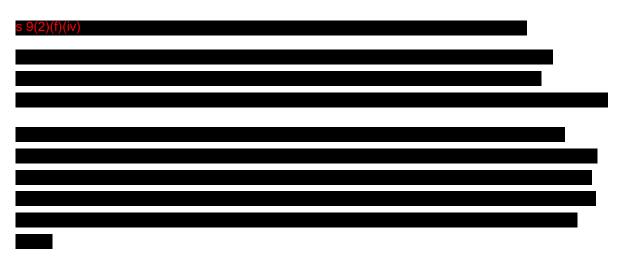
There are 14 NASCs located across New Zealand managing services for approximately 38,500 individuals (as at end-June 2021), with a total value of contracts of \$25 million annually. .

Over the past year NASC service demand has continued to grow and sector costs continue to rise, most notably sector recruitment and wage cost pressure and NASC services have been reporting an increase in service demand over the past two years. The majority of NASCs across the country are experiencing service demand gaps (for example Auckland NASC (Taikura Trust) has a current waitlist of 800 people, which is unprecedented).

High and complex needs framework (HCF) and Intellectual **Disability (Compulsory Care and Rehabilitation) Act**

About 200 to 300 people are supported under the High and Complex Needs Framework (HCF) at any time, with around 50 in hospital-level secure care units. The operations of the Framework will transfer to this Ministry immediately, but statutory functions under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (IDCCR Act) will remain in Ministry of Health until such time as any future decisions on changes to responsibility are made, and legislative changes are in place.

The commissioning, planning and funding functions for the HCF will transfer to this Ministry. These functions support the IDCCR Act and provide services for people subject to compulsory care orders.



Capacity of the high and complex needs framework (HCF)

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,

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 may be inappropriately placed in aged residential care facilities. s 9(2)(f)(iv)

Budget 2022 disability support services cost pressures funding (\$176 million annually) will support provision of some increased bed capacity, subject to competing cost pressures in disability support services. However, pressure on specialised accommodation and the HCF spend will remain.

Workforce Issues

The disability support sector employs an estimated 19,000 support workers (there are 61,500 support workers across the health and disability sector)¹⁰. The care and support workers are employed by providers contracted to the new Ministry, working in the homes of people who require care and assistance.

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 vears).11

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 adjustment¹². The new amended Act will extend the automatic expiry of the minimum pay sections until 1 January 2024. It 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. The Bill is expected to be introduced on 23 June 2022, and enacted by 1 July 2022.

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 disability sector.

The Ministry of Business, Innovation and Employment will shortly provide advice to the Minister of Immigration on a number of 'sector agreements' which provide special conditions for employing migrant workers for sectors that have particular needs. One of these is the Care Workforce Sector Agreement.

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, Department of Corrections,

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

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

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.

As Minister for Disability Issues, you are a lead Minister for the Care Worker Sector Agreement and will be expected to discuss the proposed agreement with the Minister for Immigration. A report concerning this Agreement is expected from the Minister for Immigration by the end of June 2022. Officials can provide further advice to support your engagement with the Minister of Immigration once proposals have been finalised.



Paid family care and role of disabled person as employer

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 legal action, 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. § 9(2)(h) Cabinet agreed a limited family care policy that allowed some family members of people with high or very high 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.

Budget 2022 included additional funding of \$39 million (over four years) for the new Ministry for paid family support. s 9(2)(f)(iv)

Some components for this policy will be delivered through the work to transform the disability support system based on the EGL approach, including appropriate safeguarding processes and supported decision making, that will mitigate the risk of abuse, particularly financial.

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, either: the disabled person employs the family carer (through several means) or the family member is employed through a disability support service provider.

There are a variety of options to pay a family member to provide disability support services when a disabled person manages their own budget (through the EGL approach), including employing a family member themselves or asking a nominated person to manage the employment process and budget, or payment to a family member as a contractor/selfemployed.

However, a disabled person who employs a family member to provide their support but lacks the capacity to fulfil the formal role of an employer, presents employment, legal and human rights challenges.

Budget 2022 included additional funding of \$111 million (over four years) for paid family support, with \$39 million for the new Ministry to deliver paid family support (as well as \$72 million for delivery by Health NZ). s 9(2)(f)(iv)



DSS Eligibility - Fetal alcohol spectrum disorder (FASD) issues

The Disability Rights Commissioner, Children's Commissioner and FASD advocacy groups have a been advocating for some years for DSS eligibility to be extended to those with a sole FASD diagnosis so that this group and their families can access DSS services and support.

Currently only people with FASD who also have a physical, sensory or intellectual disability or an autism diagnosis are eligible to be assessed to access DSS, with the exception of DSS child development services (CDS) which are available for any child with developmental delay.

In July 2021, the Minister of Health agreed to further work to explore what is required to improved access to DSS CDS and other DSS early interventions for children with FASD or suspected FASD. This work programme will transfer to the new Ministry.



Another aspect of active FASD-related work is contributing to the ongoing interagency implementation of the Ministry of Health-led FASD Action Plan 2016-2019. This includes regular participation in an interagency coordination group and governance group for new FASD initiatives (some involve CDS) and involvement in any future refresh of this Action Plan, which will require a cross-government approach.

Disability System Transformation – Enabling Good Lives

In 2007 a Social Services Select Committee Inquiry heard that people with disabilities 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. The Christchurch disability community and sector were invited to develop a proposal for demonstrating EGL in Canterbury. The second EGL pilot was established in Waikato in 2014.

In 2018, the Government endorsed the EGL vision and principles (as developed by the sector in 2011) as the basis for transforming the disability support system. Government also agreed to implement the EGL prototype in MidCentral DHB region from 1 October 2018.

Principles of EGL approach

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.

"Nothing about us without us", the longstanding international catch-cry of disabled people is a key feature of the EGL approach. This is reflected through EGL features at an individual level (such as, personal budgets, kaitūhono/connector working with disabled people to set goals and aspirations for their lives, and helping disabled people access the services they need). The EGL approach is also reflected with disabled people and their whānau working with agencies in partnership, governance, advisory and steering roles to inform how disability services and programmes are designed, monitored and evaluated, delivered and funded.

Current situation – Expanding EGL from three existing sites

Cabinet has agreed to transform disability support services using an Enabling Good Lives principles approach. It has also agreed to "roll out" the Enabling Good Lives model across Aotearoa/ New Zealand. The model will be based on lessons learned from the three demonstration / protype models based in Christchurch, Palmerston North and Hamilton.

The three existing sites have been operating for some time, however, none of them are developed to an extent that they could be "upscaled" to establish in other regions as yet. Each of the EGL sites have been developed at different times, 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 and older who are in receipt of the Ministry of Education Ongoing Resourcing Scheme (ORS) funding and support. Managed by Ministry of Health
- Waikato site in Hamilton was established in 2015 and allows for people to "opt-in" to the
 programme after they fit the criteria for DSS funding and has limited numbers of
 individuals they can support. Managed by Ministry of Social Development.
- MidCentral (Mana Whaikaha) in Palmerston North, where all DSS-eligible people in the region access the EGL approach. A NASC, "Enable", 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.

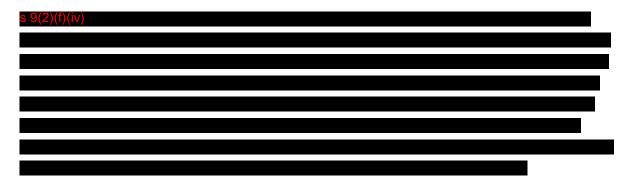
Any change process will need to involve EGL local regional leadership groups - to help build a shared understanding of the value of any proposed changes for improving outcomes at each site and supporting the ongoing evolution and expansion of EGL.

System transformation and implementation of EGL approach

Budget 22 has set aside \$100 million in contingency funding for the national implementation of the EGL approach to DSS. The disabled community has high expectations of this Ministry, and want to see demonstrable change in service provision, shared design of services, individualised funding, and the definition of disability to be addressed with urgency.

The Ministry of Health 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 of the new Ministry, in partnership with the

disabled community, to meet the contingency conditions and enable the approach to be upscaled from the pilot sites.



Evaluating the quality of services and support

MEAL (Monitoring, Evaluation, Analysis and Learning) is a framework which has been developed within the Ministry of Health in collaboration with disability community representatives. It is founded on the EGL principles - that disabled people are able to advise what is working and not working for them and advise on what services / support are needed for disabled people.



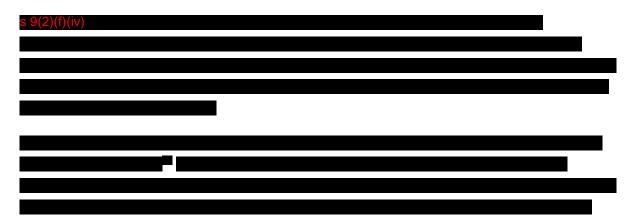
Opportunity to expand EGL to key regional sites

Once the drawdown of the Budget 2022 funding is agreed by joint Ministers, there are some immediate steps which could be taken to demonstrate the Government's ongoing commitment to expanding EGL sites.



Engagement, Partnership and Voice

A primary role of the Minister for Disability Issues is to lead and advocate for the rights of, and opportunities for, disabled people across all government portfolios. Engagement with the disability community occurs through a range of ongoing relationships, such as with the DPO Coalition, as well as one-off engagements with the community.



Governance and partnership arrangements

The October 2021 Cabinet paper¹⁴ states "Establishing a new Ministry will not in itself give disabled people a role in governance.... However, partnership with disabled people would be a 'top table' issue for the new Ministry, a key priority for the leadership team.".

During the new Ministry's establishment (from December 2021 to July 2022), partnership with disabled people was supported through a:

- Community Steering Group (CSG) role was to provide advice, guidance and support to the Establishment Director and Unit. The 12 members were drawn from the disability community, including five Māori members, one representing youth disabled community and one represents whānau, and two Pacific disabled peoples.
- Officials Steering Group (OSG) role was to provide advice, guidance and support to the Establishment Director and Unit to support achievement of the work programme.
- Governance Group (GG) role was to ensure the effective establishment of the new Ministry. Three members are tangata whaikaha Maori, three are from the wider disabled community, and three are Government officials.

These groups were tasked with guiding, supporting and endorsing elements of the work to set up the new Ministry and ensure it is ready operate on 1 July 2022 (noting that full operational capability will require additional time post-launch). A diagram of the governance structure is in Appendix One. Their Terms of Reference expire on 31 July 2022...

¹³ UNCRPD www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/

CAB-21-MIN-0395, 4 October. Refer to Cabinet submission SWC-21-SUB-0145, page 12

Decisions on the form and function of ongoing partnership arrangements will be the responsibility of the incoming Chief Executive to address. \$9(2)(f)(iv)

Other partnership and disability groups

You will have relationships with several groups that are supported through arrangements with the Ministry of Health and the Office for Disability Issues which are moving to the new Ministry. These groups offer you the opportunity to seek advice and input from disabled people at a national level on a range of issues.

Giving effect to the voice of disabled people

The new Ministry has an ambitious mandate - to drive better outcomes for all disabled people, lead cross-government strategic disability policy, deliver and transform Disability Support Services (DSS), and progress Disability System Transformation.

Cabinet has directed that, in delivering on this, the new Ministry give full effect to the voice of disabled people, tangata whaikaha Maori, and whanau. Voice is the views, needs and experiences of disabled people, tangata whaikaha Maori, and their whanau. It includes both individual voices and the voice of the collective. 15

Initial work has been done during the establishment phase to ensure the voice of disabled people can be embedded across all of the new Ministry's functions. The aim is that the Ministry is active in seeking to hear and contextualise voices and reflect them in its work programmes.

Community partners have made clear that the voice mechanism must be two way, with channels for input from the community into the Ministry's work programme, and the Ministry engaging with the community on issues and partnering on work. They have emphasised the need for independent community-based voice mechanisms to be supported by the Ministry. Further information on voice and how it might be developed and implemented to give effect to a partnership approach with disabled people is provided in Appendix 8.

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.

Key Contacts

Ministry of Health		
Deborah Kent	Acting Deputy Director-General Disability Directorate	s 9(2)(a)
Amanda Bleckmann	Group Manager, Disability Directorate	
s 9(2)(a)	Office of the Deputy Director- General, Manager	
s 9(2)(a)	Office of the Deputy Director- General, Advisor	
Ministry for Disabled Pe	ople Establishment Unit	MSD
Justine Cornwall	Director Ministry for Disabled People Establishment Unit	s 9(2)(a)
Mark Jacobs	Policy and Governance, Ministry for Disabled People Establishment Unit	

Appendix 1: Background on establishing the new Ministry

Review of disability support system resulted in new Ministry

In 2018 a machinery of government review was initiated to advise on the benefits, costs and risks of different options (including structural changes) for involving disabled people and their families/ whānau in the governance of the disability support system¹⁶.

The review was led by officials from MSD, in partnership with a working group of people from the disability community and officials from Ministry of Health and the Public Service Commission. This group worked together to define what success would look like, and then developed and tested options with the responsible Ministers (Health and Disability Issues).

In October 2021, Cabinet considered the outcome of the review and agreed to establish a new dedicated disability Ministry from 1 July 2022 (to align with the structural changes in the health sector). The Ministry will be established as a departmental agency, hosted by the Ministry of Social Development.

The new Ministry enabled the Government to demonstrate its commitment to the long-term transformative change to achieve equitable outcomes for disabled people across all the domains of their lives, including education, employment, transportation, and community participation.

The new Ministry also lifts the profile of disability across government, enabling the cocreation of new structures and ways of working, while signally a shift away from a medicalised and deficit-based model of disability, and instead a social model that encompasses and enables a whole-of-life and strengths-based approach. It also supports the EGL approach across a range of support services, embedding principles of choice and control for all disabled people¹⁷.

Establishment Unit's role in standing up the new Ministry

From March 2022, the Minister for Disability Issues has had day-to-day oversight of the disability system transformation and has been able to directly commission work relating to the design and development of the new Ministry by the Establishment Unit. Officials in the Establishment Unit will continue to report directly to you in the last few weeks leading up to the new Ministry 'going live'.

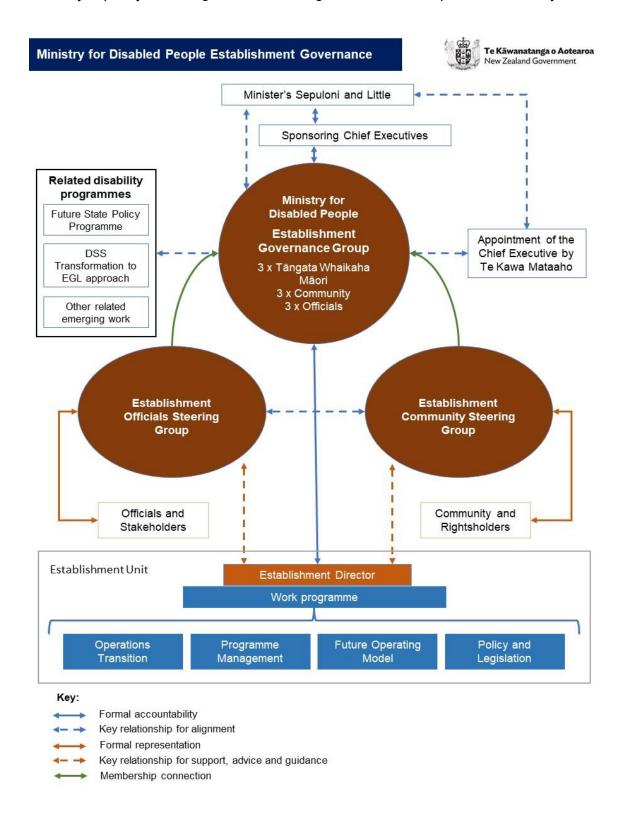
A key focus for governance of the Establishment Unit was to ensure there was appropriate engagement with disabled people, Pacific disabled peoples, tangata whaikaha Maori, and their families, and Māori as Treaty partners (including iwi leaders). The Chief Executive of

¹⁶ SWC-18-MIN-0029 refers, 4 April 2018

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

Social Development and Director-General of Ministry of Health are accountable for the establishment of the new Ministry.

The establishment governance structure was a new way of working - aligned to and supporting the new Ministry's foundational principles of formally involving disabled community representatives in a structure that would have previously only involved them in an advisory capacity. These governance arrangements remain in place until 31 July 2022.



Work programme to establish the new Ministry by 1 July on track

The Establishment Unit (EU) is responsible for ensuring that the new Ministry is operational from 1 July 2022 and can undertake all its critical functions. It is a team of 39 people dedicated to the operational readiness of the new Ministry.

The Establishment Unit's key objective is that there is no disruption in services to current clients.

As of 17 June, there are 9 working days before the new Ministry comes into effect. Status of the programme is 'stable' and Amber. It is expected this will remain the status through to 1 July unless significant issues arise¹⁸. There are currently no 'showstopper' issues or risks, and we expect to be able to meet our day one commitments.

Accommodation for the new Ministry

Accessibility was a key consideration for accommodation for the new Ministry. An exhaustive search for long term premises for the Ministry's national office indicated a need to accommodate it on an interim basis for 18-24 months. After detailed consideration of options, a short-term compromise of interim accommodation for the national office was confirmed as Level 4 of 56 The Terrace (hosted by Ministry of Social Development). This was subject to an accessibility audit by Barrier Free Trust, which provided 101 recommendations. Implementation of the highest priority 40 to 50 of these is well underway, following which most of the remaining recommendations will also be addressed.

Sites for the five regional locations have also been established, including Enabling Good Lives sites, and assessments have been done on some. It has been agreed that Full Barrier Free audits will be conducted on all regional sites as soon as possible post-1 July 2022.

People transfer

There are approximately 150 staff transferring to the new Ministry on 1 July 2022, and there are some vacancies that will be filled post-establishment. Engagement with staff in Ministry of Health and MSD on the transfer of functions and positions was undertaken in May and the day one structure has been confirmed. .

We are working to ensure that staff are welcomed to the new Ministry. On 1 July we will hold a powhiri in national office, which all regional staff will be invited to participate in online. Senior staff from MSD regions and from the Establishment Unit will support appropriate welcomes in each of the local sites. We have developed a 'concierge' approach (dedicated support both general and for ICT and systems in each site before and on launch day) to ensure a good Day One experience for transferring staff in both national office and all the regional sites.

For the past six months the Establishment Unit has tracked and reported progress against high-level milestones (key deliverables and activities) and a critical path. For the last 20 working days to 1 July a 20day plan is being used to track daily activities for readiness for Day One.

Appendix 2: Financial Appropriations

Multi-category Appropriation: Supporting tangata whaikaha Maori and disabled people

				\$ million		
Output type	Category	2022/23	2023/24	2024/25	2025/26	Total
Departmental (to run the Ministry)	Connecting people with supports and communities	5.10	5.10	5.10	5.10	20.39
	Stewardship of the disability system	46.52	40.73	\$38.22	\$38.50	163.97
	Establishing the new Ministry for Disabled People	1.35	0.54			1.90
Departmental Total		52.98	46.37	43.32	43.59	186.26
Non-Departmental (for disability support services)	Community-based support services	639.34	642.34	645.34	645.34	2,572.34
	Connecting and strengthening disability communities	65.00	65.00	65.00	65.00	259.99
	Early intervention support services	41.29	41.29	41.29	41.29	165.18
	Environmental support services	198.31	198.31	198.31	198.31	793.23
	Residential-based support services	1,012.84	1,012.84	1,012.84	1,012.84	4,051.34
Non-Departmental Total		1,956.77	1,959.77	1,962.77	1,962.77	7,842.08
Grand Total		2,009.74	2,006.14	2,006.09	2,006.36	8,028.34

The Ministry will need revised performance measures for the new MCA and its categories, for inclusion in the 2022/23 Supplementary Estimates¹⁹.

The Ministry's departmental expenditure for disability support services and associated functions has been transferred from the Ministry of Health (\$20m per year) to the MCA. However, work still needs to be completed to transfer funding relating to EGL Waikato and Office of Disability Issues (ODI) functions and staff transferring from MSD to the new Ministry. These funding transfers will need to be updated in October baseline update (OBU 2022) together with a wash-up of residual department expenditure funding for overheads and payment services from the Ministry of Health

Tagged contingency for EGL Implementation

			\$ million		
Vote: Ministry of Social development	2022/23	2023/24	2024/25	2025/26 & outyears	Total
Disability Support System Transformation – Implementation of the Enabling Good Lives approach					
Operating Contingency	14.60	17.50	27.40	40.50	100.00

The performance measures for the Ministry's MCA in 2022/23 Estimates reflect those for the corresponding appropriation in Vote Health in 2021/2022, and will need to be revised.





Appendix 4: Key Strategies and Legislation

Summary of key strategies for disability system

The Ministry for Disabled People inherits responsibility for several strategies and action plans, that transfer with the Office for Disability Issues (ODI) and Ministry of Health Disability Directorate, namely:

- New Zealand Disability Strategy (2016–2026) [ODI] This represents New Zealand's approach for the progressive realisation of the UN Convention of the Rights of Persons with Disability. 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) (ODI] Package of 28 comprehensive, crossgovernment work programmes (underway or being planned) that have an explicit disability perspective and support the Strategy. It is expected that most of the work programmes under this Action Plan will continue beyond 2023.
- New Zealand Sign Language (NZSL) Strategy (2018–2023) [ODI] Strategy 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 on the refresh will be commencing shortly.
- Whāia Te Ao Mārama: The Māori Disability Action Plan (2018–2022) [Ministry of Health] - supports tangata whaikaha Maori and their whanau and the commitments of the Ministry of Health to help achieve the goals in the plan.
- Faiva Ora National Pasifika Disability Plan (2016–2021) [Ministry of Health] out outcomes and actions to support and improve the lives of Pacific disabled people of all ages and their families. Some initial work has been undertaken by the Pacific disabled groups on refreshing the Plan.

Legislative work programme

Changes to the authorising environment

The DSS authorising environment is made up of both legislative and policy settings. Some of these settings may need to be changed to enable the roll out of an EGL approach to services.

Several Acts administered by the Ministry of Health concern the quality of disability support services, standards relating to them, and complaints about them:

The New Zealand Public Health and Disability Act 2000 (NZPH&D Act) and the Pae Ora (Healthy Futures) Bill 2021 provide for the **Health Quality and Safety Commission**. This Crown Entity is responsible for working with providers and consumers to promote higher quality health and disability support services.

- The Health and Disability Commissioner Act 1994 (HDC Act) provides the role of the Health and Disability Commissioner, who advises on a Code of Health and Disability Services Consumers Rights, and investigates complaints about breaches of those rights. The Act also puts in place a consumer advocacy service.
- The Health and Disability Services (Safety) Act 2001 (Safety Act) allows the Minister of Health to set standards relating to health and disability support services, and for auditing of performance against those standards.

Each of these Acts confers powers and responsibilities on the Minister of Health (and in the case of the Safety Act, Ministry of Health).

The relationship between the new Ministry and the Pae Ora Healthy Futures Act		
The new Ministry will be providing disability support services under the future Pae Ora (Healthy Futures) Act. (9)(2)(9)(1)		
However, the health system would continue to provide services for people who are not eligible for DSS (eg people with health or aged care-related support needs).		
Cabinet decisions that enable DSS authorising environment		
The current system is based on a number of Cabinet decisions. s 9(2)(f)(iv)		
s 9(2)(f)(iv)		
s 9(2)		
(1)(1V)		

9(2)(1)(10)
Accelerating Accessibility - Role for Ministry for Disabled People
The Government is introducing the Accessibility for New Zealanders Bill (the Bill) into the House in July 2022. This Bill will create an enabling framework focused on progressively dentifying, preventing, and removing barriers that disabled people and others face.
Cabinet agreed ²⁴ that the accessibility legislation will be administered by the new Ministry from 1 July 2023 and be responsible for it once it is enacted. Next year the Ministry will begin work for implementing the legislation 9(2)(f)(iv) including work to establish Ministerial committee, build relevant secretariat resources and staff, finalise terms of reference and appointment processes to the committee.
9(2)(f)(iv)
9(2)(f)(iv)
s 9(2)(f)
(iv)

²⁴ CAB-22-MIN-0104 on 4 April 2022

²⁵ S 9(2)(f)(iv)



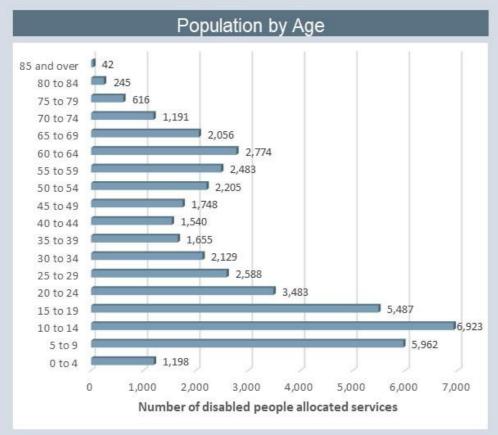




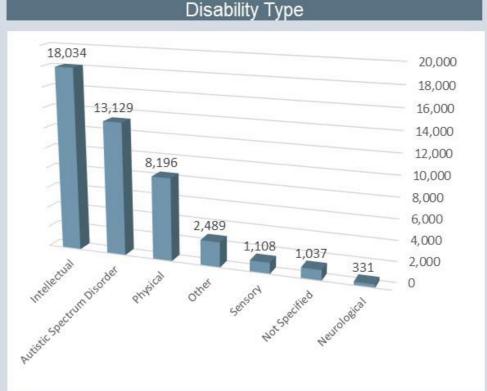
Demographics of Disabled People funded by the Disability Directorate 2021-2022 Financial year (YTD 12 June 2022)

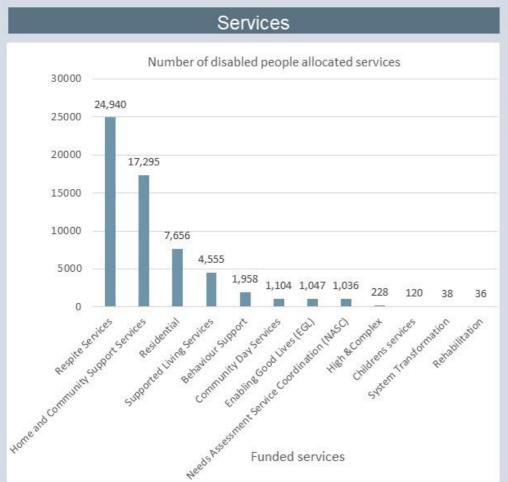
Total people allocated at least one disability service in 2021-22 financial year to date

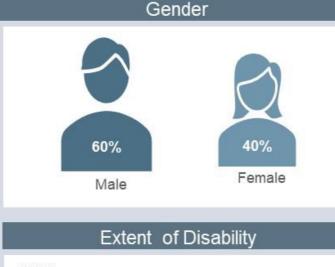
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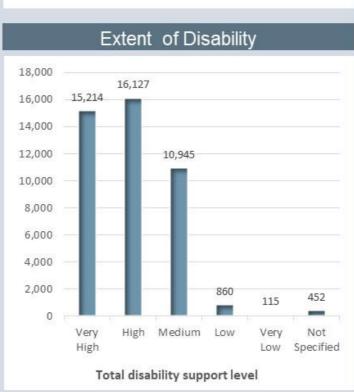


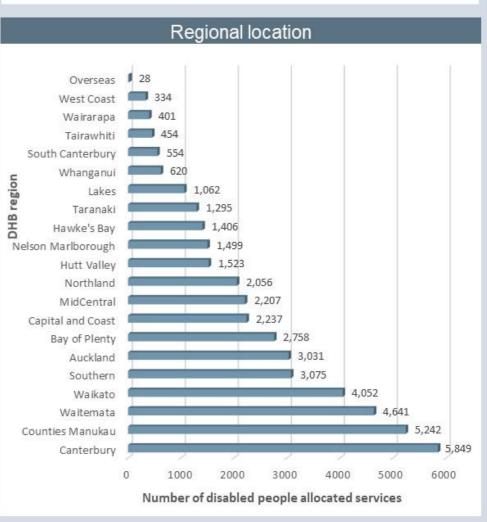












Appendix 7: Key oversight organisations with disability-related roles

The following is a summary of organisations – mainly independent Crown Entities – with disability-related roles.

As these organisations work to improve outcomes for disabled people in various ways. It will be important to establish relationships with them as the Ministry gets into its work. MSD gets input from these organisations as and when required.

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 confined to quality of care, it does not extend to funding issues or service entitlement.

HDC has 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. There is also a Director of Advocacy which is a separate statutory role. HDC does not have a separate Board or other governing body.

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.

Mental Health Commission

The Mental Health Commission (Commission) is an Independent Crown Entity established in February 2021 following a 2018 independent inquiry into mental health and addiction in which establishing a Mental Health and Wellbeing Commission was one of the recommendations.

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

The Commission's key objective is to contribute to better and equitable mental health and wellbeing outcomes for all people in Aotearoa New Zealand.

Human Rights Commission (HRC)

The New Zealand Human Rights Commission (Commission) is 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.

Four Human Rights Commissioners, including a Disability Rights Commissioner, Paula **Tesoriero** – a lawyer by training and former senior public servant – has been in the role since 2017. Her current priorities include:

- 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. Recent examples of this include the Ombudsman's 2020 A Matter of Urgency report in which he found that the rights of disabled parents in relation to the removal of newborn babies were not visible in Oranga Tamariki policy or practice and his investigation into the Ministry of Health's facilities and services for people with an intellectual disability supported under the High and Complex Framework.
- 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, by providing access to timely and high-quality expert advice from New Zealanders with lived experience of disability, thereby reflecting the mantra of the disability rights movement, "nothing about us, without us".

Independent Monitoring Mechanism (IMM)

The purpose of the IMM is to promote, protect and monitor implementation of the UNCRPD in New Zealand under Article 33 of the UNCRPD.

It is made up 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.

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 bringing a disability perspective. It also reports to, and liaises with, the United Nations Committee on the Rights of Persons with Disabilities, as required.

Appendix 8: Giving effect to the voice of disabled people

A key intent of the new Ministry is that it give full effect to the individual and collective voices of disabled people, tangata whaikaha Maori, and whanau, and the wider disability community.

Disabled people are experts in their own lives and should make the decisions that affect them (a realisation of 'nothing about us, without us'). At an individual level, EGL approaches that put the disabled people at the centre are a reflection of Voice. At a collective level Voice mechanisms should ensure disabled people and their whanau have an impact on government policies and operations. Better outcomes for disabled people and whānau will be achieved because policies and solutions are informed by the views and needs of those they impact.

Aside from the drive to give effect to Voice, Government has obligations to consult with disabled people under Te Tiriti o Waitangi, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and the New Zealand Disability Strategy (NZDS).

Significant work previously undertaken with the disability community has emphasised the importance of voice, and some of the actions and structures required. In particular the Machinery of Government (MOG) working group's 2019 report Mana, Self-determination, and Voice focused on the need for effective independent voice mechanisms to be built and supported.

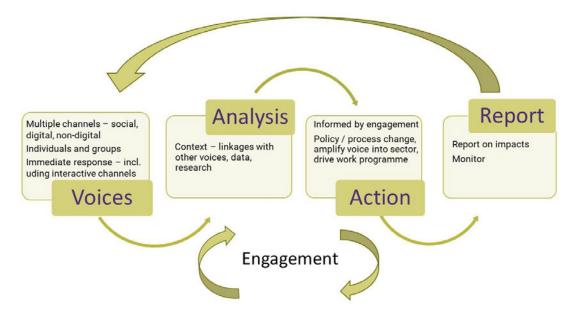
Voice will be part of the 'way we do things' at the Ministry

The explicit focus on Voice in the new Ministry is new. During the establishment phase the focus of the EU has been to consider how to build Voice mechanisms into the Ministry and its operations, and to identify the initial parts of an ongoing work programme to fully establish a voice function and realise the intent.

To give full effect to the voice of disabled people the Ministry will need to ensure the multiple voices of disabled people and their whānau 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. (See diagram below.)

Engagement, partnership, accountability and transparency are key features.

Cycle for hearing and responding to voices of disabled people



Voice to develop over time

To date, the EU has put in place several channels to enable engagement - these include online engagement platform AmplifyU, a Facebook page, an 0800 line, a general email enquiry address and complaints arrangements. The Ministry will need to establish further channels, processes, and approaches (eg social media, websites, online engagement platforms, hui/wananga/face-to-face engagements, roadshows, and complaints mechanisms).

Community-led, grassroots and independent voice mechanisms are seen as a prerequisite for voice. The Community Steering Group has emphasised the need for resourcing to support capability and capacity development and to maintain independent voice mechanisms in the community. They consider the Regional Leadership Groups and Core Groups in EGL sites, that have developed locally and organically, examples of independent local voice mechanisms. s 9(2)(f)(iv)

They also see the community-developed and endorsed evaluation model of Monitoring Evaluation Analysis and Learning (MEAL) as a key opportunity for disabled people's voices to be central to decisions. s 9(2)(f)(iv)

The new Ministry will work with the community to plan for the long term development of Voice.

Appendix 9: Commonly used acronyms

Abbreviation	Description
CSG	Establishment Unit Community Steering Group
CDS	Child Development Services
CYWS	Child and Youth Wellbeing Strategy
DAP	Disability Action Plan 2019-2023 (under the NZDS)
DEAP	Disability Employment Action Plan (Working Matters)
DDEWG	Disability Data and Evidence Working Group
DPCW Act	Disabled Persons Community Welfare Act 1975
DPO Coalition	Disabled People's Organisations Coalition
DSS	Disability support services
DST	Disability system transformation
DIAS	Disability Information Advisory Services
EGL	Enabling Good Lives
EGL GG	Enabling Good Lives Governance Group
EGL RLG	Enabling Good Lives Regional Leadership Groups
EU	Establishment Unit
FASD	Fetal alcohol spectrum disorder
FFC	Family Funded Care
FOLG	Faiva Ora National Leadership Group
GG	Establishment Unit Governance Group
HDC Act	Health and Disability Commissioner Act 1994
HDSS Act	Health and Disability Services (Safety) Act 2001
HCNF	High and Complex Needs Framework
HCHN	Home and Community Health Network
HCSS	Home and Community Support Services
IDCCR Act	Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003

IF	Individualised funding
IIDL	International Initiative for Disability Leadership
IIMHL	International Initiative for Mental Health Leadership
IMM	Independent Monitoring Mechanism
LSAP	Learning Support Action Plan
MEAL	Monitoring, Evaluation, Analysis & Learning
MLGDI	Ministerial Leadership Group on Disability Issues
MOG	Machinery of Government (review, Working Group)
NAATI	National Accreditation Authority of Translators and Interpreters
NASC	Needs Assessment and Service Co-ordination
NSDA	National Disabled Students' Association
NEGL	National Enabling Good Lives Leadership Group
NZDS	New Zealand Disability Strategy 2016-2026
NZDSN	New Zealand Disability Support Network
NZPH&D Act	New Zealand Public Health and Disability Act 2000
NZSL Act	New Zealand Sign Language Act 2006
NZSL Board	New Zealand Sign Language Board
NZSL Strategy	New Zealand Sign Language Strategy 2018-2023
ODI	Office for Disability Issues
OSG	Establishment Unit Officials Steering Group
RCS	Residential Care Subsidy
RSS	Residential Support Subsidy
TAMA	Te Ao Mārama Aotearoa (Trust)
UNCROC	United Nations Convention on the Rights of Children
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNDRIP	United Nations Declaration on the Rights of Indigenous Peoples
WAI 2575	Waitangi Tribunal Health Services and Outcomes Inquiry
WOIG	Whānau Ora Interface Group

Te reo terms used in disability system

Reo Māori kupu	English meaning
Hauā (not preferred or endorsed - it is deficit- based)	Disabled, lame, invalid
Hauātanga	Disability, impediment
Hunga hauā	Disabled people, lame people
Kāpō	Blindness, Blind person
Tāngata whaikaha (preferred term – it is strengths-based)	Used to refer to 'Disabled people'
Tāngata whaikaha katoa	All Disabled people
Tāngata whaikaha Māori	Māori Disabled
Tāngata whaikaha Māori me ō rātou whānau	Disabled Māori and family (plural)
Tāngata whaikaha Māori me tōna whānau	Disabled Māori and family (singular)
Tāngata whaikaha me ō rātou whānau	Disabled people and family
Tāngata whaikaha me tōna whānau	Disabled person and family
Turi	Deafness, deaf person
Whaikaha	(verb) to have strength, be strong enough. (modifier) disabled – a usage created within the Māori disabled community