



**DONALD
BEASLEY**
INSTITUTE



**Disabled Person-Led Monitoring
of the UNCRPD**

**My Experiences, My Rights:
Disability Supports and Services**

Preamble

Whakarakatira te tākata,

ahakoa ko wai, ahakoa nō hea.

Respect and treat all with dignity,

irrespective of who they are and where they come from.

Author: Donald Beasley Institute (DBI). The DBI is an independent charitable trust that conducts disability research and education. The DBI is committed to ethical, inclusive, and transformative research and projects that promote the rights of disabled people.

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Disclaimer: The Disabled People's Organisations Coalition (DPO Coalition) has made every effort to ensure the accuracy of the information in this report. However, it does not guarantee its accuracy and accepts no liability for any errors.

Kōrero Whakamārama: We apply the Kāi Tahu dialect when writing in te reo Māori, which includes Kāi Tahu specific words and replacing the 'ng' with a 'k'.

Tohu description: The DBI's tohu depicts the round shape of a wharerau, a temporary shelter once built at mahika kai sites (food gathering areas). The top of the wharerau sits above the earth with a rau (lined pit) below. As a place of shelter and story sharing, the wharerau reflects the DBI's commitment to working respectfully alongside whānau whaikaha to share and grow knowledge and understanding.

Project Artwork: Eve McCoy.

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1 Foreword

This research was commissioned by the Disabled People's Organisations (DPO) Coalition as part of our role monitoring the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in Aotearoa New Zealand.

As a Coalition, we always seek to engage researchers who use a Disability Rights Promotion International (DRPI) approach to undertake monitoring work on our behalf. The Donald Beasley Institute (DBI) is a world leader in this area, and we are so grateful to be able to work with them once again for this monitoring cycle. A huge mihi to the entire DBI team for their incredible work.

Disabled people, tākata whaikaha Māori, whānau hauā and tākata turi Māori, Pasefika disabled people, and their families, whānau, and aiga have, through this research, shared their collective experiences, knowledge and learnings of what it is and has been like to navigate disability supports and services through a tumultuous time. We see you, we thank you, and we will continue to champion what you have shared with us.

You can find more information about the work of the DPO Coalition here

<https://www.dpoc.org.nz/>

A handwritten signature in black ink, appearing to read 'Kera Sherwood-O'Regan', with a large, stylized flourish at the end.

Kera Sherwood-O'Regan
Current Chair
DPO Coalition

2 Whakarāpopototaka Mātua / Executive

Summary

This 'preamble' report provides the background to the disabled-led monitoring work carried out by the Donald Beasley Institute (DBI). In 2021, the Disabled People's Organisations Coalition (DPO) asked the DBI to do disabled person-led monitoring of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The DBI monitored disabled people's experiences of disability supports and services in Aotearoa New Zealand.

Selecting Disability Supports and Services as a Monitoring Topic

The New Zealand government signed and ratified the UNCRPD in 2008 and signed the optional protocol in 2016. Under Article 33.3, the New Zealand government must make sure that disabled people and their organisations are involved and participating in monitoring how the government is bringing the UNCRPD into reality. The DBI has been doing disabled-led monitoring of the UNCRPD since 2018. Previous monitoring cycles explored disabled people's experiences of housing and then health and wellbeing. Disability supports and services were identified as having an impact on housing and health and wellbeing. As a result, disability supports and services was chosen as the third topic to be monitored between 2022 and 2024.

The UNCRPD and Supports and Services

There is no specific article in the UNCRPD dedicated to disability supports and services, however, the following articles are relevant to this monitoring cycle.

- Accessibility - Article 9;
- Freedom from exploitation, violence and abuse - Article 16,
- Living independently and being included in the community - Article 19,
- Personal mobility - Article 20,
- Respect for family and home - Article 23,
- Education - Article 24,
- Habilitation and rehabilitation - Article 26,

- Participation in cultural life, recreation, leisure and sport - Article 30 (United Nations, 2006).

Supports and Services in Aotearoa New Zealand

In Aotearoa, disability supports and services are provided by different government agencies depending on how a person became disabled, and age. For people born with disability, or if disability is caused by a health issue then Disability Support Services (DSS) provides disability support. DSS is currently funded by the Ministry of Social Development (previously the Ministry of Health and Whaikaha Ministry of Disabled People). If disability is caused by accident or injury, Accident Compensation Corporation (ACC) funds disability support. For people aged 65 years and over and people with psychosocial disabilities, disability support is funded by Health New Zealand. For disabled children within educational settings, the Ministry of Education provides various supports and services.

Disability Supports and Services

The laws that govern DSS include:

- Pae Ora (Healthy Futures) Act 2022,
- Health and Disability Commissioner Act 1994,
- The Health and Disability Services (Safety) Act 2001, and
- Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003.

Evolution of DSS

Disabled people have been asking for changes to DSS for over 30 years. In October 2021, the New Zealand government announced there would be a Whaikaha Ministry of Disabled People and DSS would move from the Ministry of Health to Whaikaha which happened in July 2022. The focus of Whaikaha was the national rollout of Enabling Good Lives and overseeing the UNCRPD within government policies.

On March 18, 2024, after a change in government, new Purchasing Guidelines and rules for Equipment and Modification Services (EMS) were announced to place restrictions on funding. An independent review of Whaikaha and DSS soon followed, and after the first part of the review, several recommendations were made. DSS was

then moved from Whaikaha to the Ministry of Social Development (MSD). Further announcements were made in September 2025 following the second part of the review. This included removal of purchasing guidelines and reinstated more choice and control for individualised funding (IF) users. However, it also meant that future funding allocation would be adjusted to how much the IF user had spent between June 2023 to June 2025.

Royal Commission of Inquiry into Abuse in State Care and HDC Report

The Royal Commission of Inquiry published its report on the historical abuse and neglect in care in July 2024. The report highlighted how disabled people were one of the main groups of people institutionalised during this period and experienced abuse and neglect, including physical, emotional, and sexual violence. Further to this, the Health & Disability Commissioner published their report about complaints made about residential disability support services, confirming disability abuse and neglect are still happening in smaller residential care settings within the DSS system.

The findings of both reports, emerging findings from this cycle of disabled person-led monitoring, and restrictions announced by the Government caused concern among the DPO Coalition and the monitoring team. This resulted in the current monitoring cycle being extended until 2025.

How to Read the Reports

The findings of this monitoring cycle have been presented in a series of reports rather than a single report. These are:

- Preamble
- Report 1: Whaikaha - Ministry of Disabled People
- Report 2: Consultation and Engagement
- Report 3: Disability Supports and Services
- Report 4: Enabling Good Lives
- Report 5: Summary of Recommendations

This preamble document has been designed to help set the scene for the Disabled Person-Led Monitoring of the UNCRPD in Aotearoa New Zealand - Disability

Supports and Services. Monitoring Reports 1-5 offer a generous, in-depth and thoughtful insight into a disability supports and services system that is fit for purpose, and should not be ignored.

3 Whakatakika / Introduction

In 2021, the Donald Beasley Institute (DBI) was commissioned by the Disabled People's Organisations Coalition (DPO) to conduct Disabled Person-Led Monitoring of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) on disabled people's experiences of disability supports and services. While this document is entitled 'preamble', it was written at the conclusion of the monitoring cycle for the purpose of capturing the context within which this research occurred. This includes: how disability supports and services was selected as a monitoring topic; supports and services within the UNCRPD; Disability Supports and Services in Aotearoa and the evolution of DSS; the Royal Commission of Inquiry into Abuse in State Care and Health & Disability Commissioner's 'Report on complaints to HDC about Residential Disability Support Services'; and an introduction to Reports 1-5.

4 Selecting Disability Supports and Services as a Monitoring Topic

In 2008, the New Zealand government became one of the first countries to sign and ratify the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD), and then its Optional Protocol in 2016. In doing so, the government agreed to progressively realise the human rights of disabled people as set out by the Articles contained within the Convention. Under Article 33.3, the New Zealand Government must ensure civil society (in particular disabled people and their representative organisations) are involved and participating in monitoring the Convention's implementation (United Nations, 2006).

The Donald Beasley Institute (DBI) has conducted Disabled Person-Led Monitoring of the UNCRPD in Aotearoa New Zealand on behalf of the Disabled People's Organisations Coalition (DPO Coalition) since 2018, which contributes to the obligation set out by Article 33.3. The DBI is a national, independent, non-profit research organisation based in Ōtepoti Dunedin, Aotearoa. With a 42-year history and strong commitment to disability rights, disabled-led and inclusive research, the DBI was well-placed to undertake this important project.

While the Convention covers a wide range of human rights, disabled person-led monitoring in Aotearoa has traditionally focused on one topic per monitoring cycle. Between 2018 and 2020, disabled people's experiences of housing were investigated (Donald Beasley Institute, 2020a; 2020b). During this monitoring cycle, disabled people spoke about the intrinsic link between housing and health and wellbeing, which was then selected as the second monitoring topic (Donald Beasley Institute, 2022). From health and wellbeing, disability supports and services were identified as a significant factor affecting the progressive realisation of disabled people's housing and health rights. As a result, disabled people's experiences of disability supports and services was selected as the third monitoring topic, to be conducted between 2022 and 2024.

5 The UNCRPD and Supports and Services

While supports and services do not feature as standalone human rights within the UNCRPD, it is widely accepted that supports and services are crucial for the progressive realisation of disabled people's basic human rights. Outlined below are the Articles that were most relevant to this monitoring cycle, which include the New Zealand Government's responsibility to:

- take appropriate measures to ensure physical environments, transportation, information and communications, facilities and services are accessible for disabled people; identify and remove any barriers to accessibility; and provide appropriate forms of assistance and support to facilitate accessibility (Accessibility - Article 9);
- take appropriate measures to prevent exploitation, violence and abuse by ensuring appropriate forms of support for disabled people and their families and caregivers (Freedom from exploitation, violence and abuse - Article 16)
- take appropriate measures to facilitate the full enjoyment of the right to live in the community, with choices equal to others, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community (Living independently and being included in the community - Article 19),

- take effective measures to ensure personal mobility with the greatest possible independence, including facilitating access to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost (Personal mobility - Article 20),
- take effective measures to eliminate discrimination in all matters relating to marriage, family, parenthood and relationships, including by providing appropriate assistance to disabled people in their child-rearing responsibilities (Respect for family and home - Article 23),
- ensure that disabled people receive support within the general education system to facilitate their effective education (Education - Article 24),
- take effective measures to enable maximum independence and full inclusion by supporting participation and inclusion in the community and all aspects of society, including areas of habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services (Habilitation and rehabilitation - Article 26),
- take measures to ensure access to cultural materials in accessible formats, and recognising and supporting specific cultural and linguistic identities (Participation in cultural life, recreation, leisure and sport - Article 30) (United Nations, 2006).

6 Supports and Services in Aotearoa New Zealand

In Aotearoa, disability supports and services are provided by various government agencies based on the cause of disability and the life stage of a disabled person. The disability support provision for people who have a congenital disability or a disability caused by a health issue is Disability Support Services (DSS). During this cycle of monitoring the funding body and home of DSS moved from the Ministry of Health (MoH) to Whaikaha Ministry of Disabled People in 2022, and during an independent review, moved again, this time to the Ministry of Social Development (MSD) in 2024.

People who are under 65 years of age and whose disability is likely to continue for six months or more and result in a reduction of independent function may be eligible for DSS funding (Disability Support Services, 2024). Alternatively, supports and services for people who acquire their disability through accident and injury are funded by the Accident Compensation Corporation (ACC) (ACC, 2025). In addition, the supports and services of people aged 65 years and over and people with psychosocial disabilities are funded by Health New Zealand (formerly District Health Boards) (Health New Zealand, 2025). The Ministry of Education (MoE) also provides various supports and services for disabled children within educational settings such as Ongoing Resourcing Scheme (ORS) (Ministry of Education, 2025).

6.1 Disability Supports and Services (DSS)

In Aotearoa, DSS is defined within the Pae Ora (Healthy Futures) Act 2022 as goods, services, and facilities:

- a) provided to people with disabilities for their care or support or to promote their inclusion and participation in society and their independence; or
- b) provided for purposes related or incidental to the care or support of people with disabilities or to the promotion of their inclusion and participation in society and their independence (S.4, Ministry of Health, 2022).

DSS provision is governed by four pieces of legislation, including the Pae Ora (Healthy Futures) Act 2022, Health and Disability Commissioner Act 1994, The Health and Disability Services (Safety) Act 2001, and Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (Whaikaha Ministry of Disabled People, 2023). To access DSS, disabled people are assessed through NASCs (Needs Assessment and Service Coordination services), which are organisations contracted by the government to determine a person's eligibility for funded disability supports and services. NASCs work with disabled people to identify their disability support needs, before outlining what services are available and coordinating the provision of these to the person (Disability Support Services, 2025a).

6.2 Evolution of DSS

During this cycle of monitoring, the DSS system underwent significant changes. For more than three decades, disabled people had been asking for DSS to be reviewed and moved away from the Ministry of Health, and replaced with a simpler, more coordinated model of support based on the social and human rights models of disability (Palmer, 2020; Sullivan & Munford, 2010). Since 2011, disabled people have worked closely with government officials on the Disability System Transformation project, which was tasked with designing a disability support system that better suits the needs of disabled people (Ministry of Social Development, n.d). The outcome of this project was Enabling Good Lives (EGL).

In October 2021, shortly after the DPO Coalition selected DSS as the next monitoring topic, the New Zealand government announced the establishment of Whaikaha Ministry of Disabled People and the transition of DSS from the Ministry of Health (MoH) to Whaikaha, which occurred in July 2022. The primary focus of Whaikaha was the national rollout of Enabling Good Lives and overseeing the alignment between existing and emerging government policies with Articles contained within the UNCRPD (Ministry of Social Development, 2022). However, towards the end of this monitoring cycle, a change in government saw increased scrutiny on government spending, including that of Whaikaha and DSS (Upston, 2024). To avoid a budget blowout, on March 18, 2024, the Minister of Disability Issues introduced new Purchasing Guidelines and rules for Equipment and Modification Services (EMS) in an attempt to curb spending. An independent review of Whaikaha and DSS soon followed, led by three public officials (RNZ, 2024) who were not known to identify as disabled or have experience with disability communities. Findings from the first phase of the independent review were released in early August 2024, which included seven recommendations for the New Zealand Government:

1. Place a cap on disability support funding budget and reestablish monitoring and reporting requirements for Needs Assessment and Service Coordination organisations (NASCs), EGL demonstration sites and Equipment and Modification Services (EMS) providers.

2. Freeze current levels of funding for residential facility-based care for 2024/25, pending commissioning and completion of a detailed and urgent review of the contract and pricing models.
3. Take no action on a price increase for providers in 2024/25.
4. Establish an effective function within the Ministry to monitor the assessment and allocation performance of NASCs and EGL demonstration sites.
5. Update the assessment and allocation settings for individuals based on level of need.
6. Establish criteria for access to flexible funding and review the flexible funding guidelines to improve clarity and consistency.
7. Strengthen:
 - The departmental agency arrangement with the Ministry of Social Development, and
 - The shared services agreements with the Ministry of Social Development, Ministry of Health and Health New Zealand (Wevers et al., 2024, p. 7).

Importantly, while it was not articulated in the review's recommendations, the government also decided to move the functions of DSS from Whaikaha to the Ministry of Social Development (MSD) in September 2024 (Disability Support Services, 2025b). In September 2025, following the second phase of the review and public consultation, the Minister for Disability Issues made further announcements regarding changes to DSS assessments and allocations, and flexible funding, stating that in 2026:

- People will get more choice and control in their use of flexible funding.
- The purchasing guidelines will be removed.
- People who get flexible funding will be provided with a budget for them to manage within.
- People will get guidance to help manage their budget. This will make flexible funding easier to use.
- All NASCs around the country will do their assessments the same way. This is so their decisions on support are fairer and more consistent.
- Families and carers will be included in assessments (Disability Support Services, 2025c).

While it was claimed that disabled people should expect greater flexibility, choice and control over their funding, the message came with the caveat that existing flexible budgets will be reallocated based on how much the person spent between June 2023 and June 2025. This is an important detail, as many participants in this cycle of monitoring reported being unable to spend their budgets due to the March 18 restrictions and reductions, indicating that their future budgets are likely to be reduced. Further concerns have been raised about the redesign of NASC assessments and who is leading and informing this process. While the Minister's announcement was welcome news, scepticism amongst the disability community remains. As highlighted by one community leader, "It's a Catch 22 magical roundabout – it's a classic "yeah, nah"" (Wilkinson, 2025).

7 Royal Commission of Inquiry into Abuse in State Care and HDC Report

Also critical to the context of this monitoring cycle was the Royal Commission of Inquiry into Abuse in State Care and the Health & Disability Commissioner's 'Report on complaints to HDC about Residential Disability Support Services'. In July 2024, one of New Zealand's biggest Royal Commissions of Inquiry published its report on the historical abuse and neglect that occurred in State and faith-based institutions between 1950 and 1999. The report, 'Whanaketia - Through pain and trauma, from darkness to light', detailed the experiences of many disabled people who had received and engaged with disability supports and services, and highlighted how disabled people were one of the main groups of people institutionalised during this period. Many of them experienced extensive abuse and neglect, including physical, emotional, and sexual violence (Royal Commission of Inquiry, 2024). Relatedly, a further report published by the Health & Disability Commissioner documented complaints made about residential disability support services. This report confirmed that disability abuse and neglect are still occurring in smaller residential care settings within the DSS system (Health & Disability Commissioner, 2024).

The accumulation of historical and current evidence published by the RCOI and HDC, alongside emerging findings from this cycle of disabled person-led monitoring, raised concerns among both the DPO Coalition and the DBI monitoring team. The Government's simultaneous announcements of restrictions and reductions of disability supports and services in a bid to reduce spending, and subsequent responses to the independent review, risk further decreasing the quality of an already stretched and inadequate disability support services system. As a result of this evolving context, this cycle of monitoring was extended until 2025 to ensure that it included the perspectives of disabled people on some of the changes that were occurring.

8 How to Read the Reports

Unlike previous monitoring cycles, where findings have been presented in a single extensive report, this cycle of monitoring is presented across five shorter reports that can be read consecutively or independently. Each report details the methodology used to collect data, key findings, as well as recommendations contributed by disabled participants and their families, whānau, and close supporters. At the start of every report is an executive summary, which has been translated into alternative formats and languages (Te Reo Māori, NZSL, Easy Read, Braille, large print, plain text and audio). The reports and alternative formats can be found on the DPO Coalition's and DBI's websites. The published reports are as follows:

- Preamble
- Report 1: Whaikaha - Ministry of Disabled People
- Report 2: Consultation and Engagement
- Report 3: Disability Supports and Services
- Report 4: Enabling Good Lives
- Report 5: Summary of Recommendations

9 Kupu Whakamutaka / Concluding Remarks

This preamble document has been designed to help set the scene for the Disabled Person-Led Monitoring of the UNCRPD in Aotearoa New Zealand - Disability Supports and Services. It began by detailing how disability supports and services was selected as a monitoring topic and the presence of supports and services within the UNCRPD. Disability Supports and Services in Aotearoa are then explored, including the evolution of DSS, which occurred unexpectedly during this monitoring cycle. The Royal Commission of Inquiry into Abuse in State Care and the Health and Disability Commissioner's 'Report on complaints to HDC about Residential Disability Support Services' are then noted as having impacted monitoring participants' perspectives, before the sub-themes of Reports 1-5 are presented.

Providing a preamble for this monitoring cycle was essential to contextualise the responses contributed by participants in Reports 1-5. The development of Whaikaha Ministry of Disabled People, the pause on Enabling Good Lives, and the subsequent evolution of DSS during this monitoring cycle undoubtedly had a significant impact on the human rights, supports, and services experiences of disabled participants, as well as their family, whānau, aiga, and close supporters. While the government has indicated a positive shift in their intended approach to DSS in 2026 and beyond, it is unclear whether this approach will actively advance disabled people's human rights in a real and meaningful way. The findings of this monitoring cycle, therefore, remain relevant. While the government has praised itself for having "taken [disabled people's] feedback on board" (Upston, 2025), success can only be claimed when evidenced by future disabled person-led monitoring efforts. Until then, monitoring Reports 1-5 offer a generous, in-depth and thoughtful insight into a disability supports and services system that is fit for purpose, and should not be ignored.

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