

Submission to the Disability Support Services Bill

Waitaha Enabling Good Lives Regional Leadership Group

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About the Waitaha Enabling Good Lives Regional Leadership Group

The Waitaha Enabling Good Lives (EGL Regional Leadership Group represents disabled people, tāngata whaikaha Māori, Turi Māori, tagata sa'ilimalo, family/whānau/aiga, providers and other members of the disability community across Canterbury. Our work is guided by the Enabling Good Lives (EGL) principles, which recognise that disabled people and their families are the experts in their own lives and should have choice and control over the supports they receive.

Thank you for the opportunity to provide feedback on the Disability Support Services Bill.

Our overall position

The Waitaha Enabling Good Lives Regional Leadership Group opposes the Disability Support Services Bill (the DSS Bill or the Bill).

We believe the Bill in its current form will weaken the rights, choice, control and participation of disabled people, that it breaches the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and is not aligned with the principles of Enabling Good Lives (EGL).

We acknowledge the need for a legislative framework for Disability Support Services, and support redeveloping the Bill through processes that meet the active partnership obligations that the New Zealand Government has under Te Tiriti o Waitangi and the UNCRPD.

Context for disability support service reform

The Disability Support Services (DSS) Bill sits within a long history of disability reform in Aotearoa New Zealand, marked by a shift from institutional and controlling care models to a rights-based approach focused on enabling ordinary life outcomes. A rights-based approach is not merely a legal framework but a practical strategy to embed human rights into all aspects of governance, development, and social action. It prioritises participation, accountability, equality, empowerment, and legality; ensuring that policies and programmes are both ethical and effective in promoting human dignity and justice.

Earlier systems often forced families into limited choices: unsupported care at home, provider-assigned caregivers (if/when available), or placement in segregated, institutional

environments that restricted autonomy and participation. Official reviews, including the 1973 Royal Commission into Psychopaedic Hospitals and the Burns Report, identified these models as fundamentally breaching human rights. The true extent of the horrific abuse and torture perpetrated on around 250,000 people in institutionalised care was laid bare in the reports of the Royal Commission of Inquiry into Historical Abuse in State Care and in the Care of Faith-based Institutions published between 2020-2024. This legacy of harm demands more than reform; it requires a system that actively protects dignity and prevents such violations from ever occurring again.

To begin to address these issues, key legislation was enacted:

- New Zealand Bill of Rights Act 1990 – affirms fundamental rights
- Human Rights Act 1993 – prohibits discrimination
- Health and Disability Commissioner Act 1994 – promotes accessible, equitable services

Internationally, New Zealand's commitment to the UN Convention on the Rights of Persons with Disabilities (UNCRPD) (ratified in 2008) reinforces obligations to uphold disabled people's rights. Calls for reform were strengthened by the 2008 Social Services Select Committee Inquiry and growing advocacy from disabled people, families, and providers. From this context, Enabling Good Lives (EGL) emerged as a community-driven approach. EGL is based on the principle that disabled people and their whānau are experts in their own lives and should have choice and control over their supports, shaping a system focused on dignity, independence, and full participation.

In a 2021 Cabinet Paper called Disability System Transformation (the Paper), the Government agreed to a national implementation of EGL and explicitly stated that system fragmentation limits ordinary life, and that reform must increase choice and control. The Paper identified disabled peoples' leadership as central i.e. 'nothing about us, without us.' It also explicitly recognises that system reform must increase choice and control for whānau/family. This means that Cabinet had agreed that EGL is the framework for achieving ordinary life outcomes and fulfilling UNCRPD obligations.

EGL is built on a set of guiding principles that shape all decisions:

- Self-determination – people lead their own lives and decisions
- Beginning early – early support builds better long-term outcomes
- Person-centred – supports tailored to individual goals and strengths
- Ordinary life outcomes – focus on everyday life (home, work, community)
- Mainstream first – use community services before specialist ones
- Mana enhancing – respects dignity, culture, identity, and aspirations
- Easy to use – simple, flexible, accessible systems

- Relationship building – strong partnerships with whānau and communities

Since then, EGL has been considered so successful that countries around the world are looking to New Zealand's EGL model to modernise and transform their own systems. The 2022 report by the Committee on the Rights of Persons with Disabilities recommended the Government expedite the national rollout of the Enabling Good Lives programme.

More recently, a refresh of the New Zealand Disability Strategy and The Disability Action Plan, along with consultation by Disability Support Services led to operational changes that are still being implemented by government.

New Zealand had previously been recognised and celebrated on a global stage for its significant contributions to the advancement of disability rights, with countries around the world looking to our EGL model to modernise and transform their own systems.

Our concerns

There has been a lack of genuine consultation and co-design

We are concerned that disabled people, whānau and the wider disability community were not meaningfully involved in the development of this Bill. The Government has acknowledged in the Regulatory Impact Statement for this Bill that full consultation with the disability community did not occur. This is inconsistent with both the EGL principles and the UNCRPD requirement that disabled people and their representative organisations are closely involved in decisions that affect them. A short select committee process cannot replace genuine partnership in the development of effective legislation.

We are also concerned that this legislation has not been developed in active partnership with whānau hauā Māori, tāngata whaikaha Māori, Turi Māori, iwi and hapū in alignment with New Zealand's responsibilities under Te Tiriti o Waitangi. We do not believe this Bill is consistent with the principles of Te Tiriti o Waitangi. We believe the absence of a specific Te Tiriti provision in this Bill is a breach of the Crown's obligations under Te Tiriti o Waitangi. A transparent and substantive analysis should be commissioned and published before this Bill proceeds.

Secondary legislation and future policy are not sufficiently guided by the proposed Bill

The Bill enables detailed rules governing Disability Support Services to be set through Ministerial programmes and Ministerial directions, forms of secondary legislation. This means rights, entitlements and policy settings are not clearly defined or protected in primary legislation and key aspects of the system and may be changed without full Parliamentary scrutiny or in co-design with the disability community. This is in direct contradiction to the objectives of this Bill which set out a purpose of creating a legislative

framework aiming to strengthen the disability support services system, improve consistency, fairness and transparency of decision-making and it does not provide the stability and security disabled people, whānau and carers need to plan supports and live their ordinary good lives.

Our communities have also expressed concern that this Bill enables 'means-testing' of funded disability support via Approved Ministerial programmes that establish income-based and asset-based criteria.

Under the UNCRPD, and the EGL Principles, access to support is a right and supports must enable full participation and ordinary life outcomes. We do not support the introduction of 'income-based criteria' or 'asset-based criteria' to determine funded disability supports or carer supports and we do not support these criteria being included in this Bill.

'Means-testing' funded disability support delivered through MSD, doesn't contribute to fair and consistent disability support. It only serves to widen disparities in the supports and cares disabled people receive from the different funding streams, creates potential for further safeguarding issues for disabled people, whānau and carers, creates additional administrative burden on disabled people and whānau, and increases the intrusion into their personal lives.

'Informal supports' are not a substitute for rights-and-needs-based funded disability supports.

We are concerned about the reference to 'families and whānau in the first instance' and the proposed application indicates a significant over-reliance on what is sometimes referred to by Ministry contracted providers as 'informal' or 'natural' supports.

This is a significant and regressive shift away from disability support based on an individual's needs, not on the availability, willingness, or capacity of family members to provide ongoing unpaid support. This approach echoes pre-deinstitutionalisation thinking, where families were expected to absorb system failures until they could no longer cope. We cannot return to a model that risks recreating the very conditions that led to institutionalisation and the horrific harm inflicted on disabled people as a result.

Disability support funding should always be determined by assessed need and desired outcomes and should not be contingent on the exhaustion of other avenues of funding, as this will lead to dangerous delays in timely disability support, is inaccessible and inequitable. The Bill implies that families, whānau and aiga are not already doing all that they can to meet the ordinary and additional needs of the disabled person/s they care about. It also implies that all disabled people have access to consistent, appropriate and safe support

from family. These implications are inaccurate, regrettable and have no place in legislative framework for disability support.

Our community has expressed concerns that a 'families in the first instance' approach will have the following impacts:

- Reduce the disabled person's privacy, autonomy, choice and control
- Restrict access to ordinary life opportunities for the disabled person
- Create unreasonable expectations of families
- Force whānau to further reduce or leave employment and/or education
- Increase unpaid care and financial hardship
- Trap disabled people and whānau in unsafe or unwanted living arrangements
- Negative shifts in the dynamics of familial relationships i.e. siblings, cousins, etc
- Increased isolation of disabled people and their whānau
- Create further inequities between paid external carers and unpaid family carers
- Restrict whānau rights to exercise choice and control over how much care they give, especially as they age
- Flow on impacts to health and wellbeing of disabled people and whānau
- Flow on impact to other public and social services i.e. health and mental health services

Description of DSS as a 'Contribution to care' but access to support is a right

The Bill also describes Disability Support Services as a 'contribution to care.'

This framing, again, reflects an outdated, residual model of support, where families hold primary responsibility and the state provides only supplementary assistance. Under the UNCRPD, and the EGL Principles, access to support is a right and supports must enable full participation and ordinary life outcomes, not merely contribute to care. Whānau support is one factor - not the foundation of the system and disability support is the provision of care required above and beyond usual care. Disabled people have the right to have disability support needs met in a dignified way and they should not have to forfeit familial relationships to maintain eligibility or access to the funded disability support they need.

In addition to the regressive framing of this Bill, it lacks the detail necessary to provide clarity on some proposed operational principles such as parameters to clearly define the resource and support 'an eligible person, their family, whānau, other culturally recognised family group and their community' is expected to have exhausted before they can be provided with DSS-funded disability support services. Nor does it provide detail to clarify what evidence an eligible person is expected to provide as proof of declined referral and/or non-existence of other publicly funded sources, of their own circumstances, or that of their family, whānau, other culturally recognised family group and the circumstances of their community in order to determine they have met the criteria for funded disability support services.

These principles and the lack of transparency are a cause for concern for our communities; indicating possible rollback of rights-and-needs-based funded disability support, an increased administrative burden and increased intrusion into personal lives disproportionate to provision of services. Detail of this significance cannot be left up to secondary legislation.

Individualised Funding should be retained and protected as a rights-based entitlement allocated to the disabled person on assessed need and not contingent on the availability or exhaustion of family, community, charitable, or informal supports. It also enables genuine choice, control, flexibility, and self-determination, allowing support to be arranged in ways that work in real life for disabled people and their families.

‘Everyday Life’ is not an ‘Ordinary Life’

The Bill states that disability support is intended to enable disabled people to live their ‘everyday life’. We are concerned that this language is a move away from an ‘ordinary life’ - a concept that is grounded in the history of enabling full citizenship, participation, and autonomy. The change to ‘everyday life’ lowers expectations and reframes support as a limited contribution rather than an investment in participation, citizenship and human rights. Disabled people should be supported to live ordinary lives with the same opportunities as everyone else to learn, work, participate in and contribute to their communities and pursue their aspirations. This is consistent with EGL and the UNCRPD. Anything less would be in breach of these.

DSS is framed as operating within a 'constrained funding environment' however, there is no analysis of how proposed changes will achieve a more sustainable outcome than an EGL / human rights-based system

The Bill places considerable emphasis on sustainability and operating within a constrained funding environment.

While responsible use of public funds is important, disability support should not be driven primarily by cost containment. New Zealand has obligations under the UNCRPD to progressively realise the rights of disabled people.

Funded disability supports are already allocated only to those who meet strict eligibility criteria.

The policy direction signalled in the Bill is not supported by clear evidence that the proposed changes will achieve better or more sustainable outcomes – for example – there has been no analysis suggesting that reducing or constraining supports will not create cost pressures elsewhere, such as increased demand on the health system and residential care facilities, greater reliance on income support, or higher long-term social costs associated with unmet

need.

In contrast, there is growing evidence from EGL demonstrations, that:

- investing in early, flexible, and person-directed support leads to better outcomes;
- increased choice and control can improve independence and participation; and
- effective support can reduce downstream costs across health, welfare, and crisis services.
- Individualised Funding allows disabled people and their whānau to design their supports so that they can live a good life.

Conclusion

The Disability Support Services Bill, as currently drafted, represents a significant shift backwards for disabled people and their whānau in Aotearoa. It reintroduces ideas and practices that past inquiries, Royal Commissions, and decades of reform have already shown to be harmful including an over-reliance on unpaid ‘informal supports’, lowered expectations for disabled people’s lives, and a system design that recentralises control rather than enabling choice.

This Bill does not reflect the rights-based approach affirmed through the New Zealand Bill of Rights Act, the Human Rights Act, the Health and Disability Commissioner Act, or the UNCRPD. Nor does it align with the Government’s own commitment to Enabling Good Lives as the successful framework for disability system transformation. This proven framework, developed in active partnership with disabled people, tāngata whaikaha Māori, whānau and providers, would be the blueprint of a disability support system, built with us – not for us, that is effective, sustainable and fiscally responsible.

We have included some recommendations for reworking this draft Bill but given the scale of the concerns and the risks of harm, we believe the most responsible path forward is to withdraw this Bill and begin again through a transparent, collaborative, and authentic co-design process with disabled people, tāngata whaikaha Māori, tagata sa’ilimalo, whānau, disabled peoples representative organisations, and the wider disability community.

A new Bill must uphold the principles of Enabling Good Lives, utilise needs-based Individualised Funding, protect human rights, and ensure that disabled people can live full, meaningful, ordinary lives with real choice and control.

Recommendations

We implore the Select Committee to reject the Bill in its current form and to:

- Ensure that the Disability Support Services Bill is redeveloped in partnership with disabled people, tāngata whaikaha Māori, tagata sa’ilimalo, whānau, carers,

providers, and representative organisations in alignment with Governments obligations outlined in the UNCRPD.

- Ensure that disability support legislation is a rights-based framework grounded in the Enabling Good Lives Approach and Principles and New Zealand’s obligations under Te Tiriti o Waitangi, the UNCRPD, UNDRIP, Human Rights Act 1993, and the New Zealand Bill of Rights Act 1990.
- Ensure any new legislation is developed in active partnership with whānau hauā Māori, tāngata whaikaha Māori, Turi Māori, iwi and hapū in alignment with New Zealand’s responsibilities under Te Tiriti o Waitangi and a transparent and substantive analysis of this Bill’s claim that it is consistent with the principles of Te Tiriti o Waitangi should be commissioned and published before this Bill proceeds.
- Ensure eligibility and funding standards are written into primary legislation and not left to ministerial programmes, directives or secondary legislation ensuring consistency and stability.
- Retain and protect Individualised Funding as a rights-based entitlement based on assessed need and not contingent on the availability or exhaustion of family, community, charitable, or informal supports.
- Remove the principle of “‘family’ ‘families’ ‘whānau’ ‘other culturally recognised family group/s’ ‘their community’ in the first instance” and the extensive list of people that are currently determined to be considered a family member to the eligible disabled person including but not limited to: spouse, civil union partner, or de facto partner, child, tamaiti whāngai, stepchild, or grandchild, sibling, half-sibling, or step-sibling, parent or step-parent, person who acts as a parent, grandparent, uncle or aunt, nephew or niece, first cousin, a member of eligible persons family, whānau, or other culturally recognised family group that has not been previously mentioned and is in a close relationship with the eligible person.
- Remove Ministers abilities to introduce ‘means-testing’, ‘income-based criteria’ and/or ‘asset-based criteria’ and/or any other eligibility or funding related settings to that end via Ministerial programmes, directives, secondary legislation and/or any other method.
- Require that any ministerial programmes, directives and/or secondary legislation are guided by and reflective of The New Zealand Disability Strategy and The

Disability Action Plan as per the Human Rights Monitor action UPR-2024-A060:
Continue to enhance protections for the rights of persons with disabilities.

- Require that any ministerial programs, directives and/or secondary legislation use Enabling Good Lives principles as the framework within which all decisions under the legislation must be made.
- Require that any ministerial programmes, directives and/or secondary legislation affirm Enabling Good Lives Approach and Principles, Te Tiriti o Waitangi, the UNCRPD, UNDRIP, Human Rights Act 1993, New Zealand Bill of Rights Act, the New Zealand Disability Strategy, the Disability Action Plan, New Zealand Sign Language Strategy, and the Atoatoali'o National Pacific Disability Approach and is required to reflect and implement the strategic visions set out within them.
- Retain, protect, and strengthen funded Respite support and Carer Support for whānau, and ensure these supports are further developed through active partnership in the forthcoming consultation with a focus on improving choice for whānau carers. This consultation must be meaningful, iterative, and inclusive of family and whānau, disabled people, and Disabled People's Organisations (DPOs), in line with New Zealand's obligations under the UNCRPD.

We look would welcome an opportunity to provide additional feedback throughout the development journey of this disability support services legislation.

Tēnā koe i tō wātea mai / Thank you for your time

Waitaha Enabling Good Lives (EGL) Regional Leadership Group

Waitaha EGL Disabled Core Group

Waitaha EGL Family and Whānau Core Group

Waitaha EGL Providers Core Group