



This submission is made on behalf of the Foundation for Equity and Research New Zealand (FERNZ) Wellington Regional Community Action Groups (CAGs). It reflects discussions held during an online hui on 8 June 2026, as well as written feedback provided by CAG members.

We are Disabled People and Tāngata Whaikaha Māori from across the Wellington region. As recipients of Disability Support Services, we have direct experience of the disability support system and a strong interest in legislation that affects how supports are designed, funded, and delivered.

The views expressed in this submission are drawn from our lived experiences, discussions, and written contributions as People who are directly affected by decisions about disability support services.

The Foundation for Equity and Research New Zealand (FERNZ) is a kaupapa Māori-governed charitable trust with a strong focus on supporting Disabled People, Tāngata Whaikaha Māori, and other marginalised communities through lived-experience leadership, advocacy, community development, and systems change. FERNZ facilitates Community Action Groups (CAGs) across the Wellington and Waikato regions, building leadership among Disabled People and creating opportunities to identify issues, gather evidence from lived experience, develop community-led solutions, and advocate for positive systems change.

Disabled People are not a small minority. Approximately one in six New Zealanders identify as Disabled. The decisions made through this Bill will affect hundreds of thousands of people, their whānau, and their communities.

FERNZ is committed to the principles of equity, inclusion, accessibility, self-determination, and meaningful participation in decisions that affect our lives.

We are deeply concerned that the Disability Support Services Bill shifts disability support services away from the Government-endorsed Enabling Good Lives (EGL) vision and principles of self-determination, choice and control, person-directed support, and relationship building

We are particularly concerned that the Bill was developed without meaningful consultation, places increased expectations on families and whānau to provide support, creates a pathway for future income and asset testing, and gives decision-makers greater control over the supports we can access.

As one CAG member stated:

"It's being done to us as opposed to done with us."

We believe aspects of this Bill move away from a rights-based approach to disability support and risk undermining our independence, dignity, participation, and self-determination.

We are also concerned that aspects of the Bill treat us as passive recipients of support rather than as citizens with the same rights, responsibilities, aspirations, and decision-making authority as everyone else.

The Bill risks reinforcing outdated assumptions that others know what is best for us, rather than recognising our right to make decisions about our own lives. This approach is inconsistent with the dignity, respect, autonomy, and self-determination promoted through both the UNCRPD and EGL.

Consultation and Participation

Our primary concern is that this Bill was developed and introduced without meaningful consultation with Disabled People and disability-led organisations.

This would not be considered acceptable for other population groups.

Decisions affecting our lives should not be made without our direct involvement.

'Nothing about us without us' is a fundamental principle of disability rights and is reflected in New Zealand's obligations under Article 4(3) of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the EGL approach.

For many of us, the first time we became aware of the Bill was after it had already been introduced to Parliament.

In our view, this does not constitute meaningful consultation.

New Zealand signed the UNCRPD in 2007 and ratified it in 2008. Ratification means New Zealand has committed to ensuring that its laws, policies, and practices are consistent with the rights set out in the Convention.

Article 4(3) of the UNCRPD requires governments to closely consult with and actively involve Disabled People, including through their representative organisations, in the development and implementation of legislation and policy.

In practical terms, this means we must be involved in decisions about laws, policies, and services that affect our lives. Consultation should occur early enough to influence decisions, rather than after proposals have already been developed and introduced.

We should not first learn about legislation that affects our lives after it has already been introduced to Parliament. Consultation should occur before legislation is drafted and introduced, not after key decisions have already been made.

We have repeatedly been told that government wishes to work alongside us. Genuine partnership requires more than a submission process. We must be involved from the outset in identifying issues, developing solutions, shaping legislation, and evaluating the impacts of proposed changes.

Relationship building is a core EGL principle. Meaningful relationships are built through ongoing engagement, trust, transparency, and shared decision making. These principles are difficult to reconcile with a process in which those most affected were not meaningfully involved before the Bill was introduced.

In our view, the process followed for this Bill falls short of both New Zealand's obligations under Article 4(3) of the UNCRPD and the EGL principles of self-determination, mana enhancing, partnership, and relationship building.

Clause 8 – Family and Whānau Support

We are concerned by Clause 8 of the Bill, which states that families, whānau, and communities are expected to provide support where appropriate before additional Disability Support Services are provided.

This approach is inconsistent with the EGL principles of Self-Determination, Choice and Control, Person-Centred Supports, and Mana Enhancing.

We should be able to decide what supports we need and who provides those supports.

As one CAG member explained:

"It should be myself that's determining what is best for me and my life."

While family and whānau often play important roles in our lives, it should not be assumed that family support will always be available, appropriate, or desired. Family members may have their own health conditions, caring responsibilities, employment commitments, financial pressures, or other circumstances that limit their ability to provide ongoing support. Equally, some of us choose not to rely on family support and should not be expected to do so.

Disability support services should be based on our needs, aspirations, and choices, not assumptions about the availability of unpaid family care.

Another CAG member noted:

"I don't want to just have to rely on family or expect them to be supporting me or paying for my supports."

This comment reflects a broader concern raised during the hui that Clause 8 risks shifting responsibility for disability support away from government and onto families and whānau, regardless of whether that support is available, appropriate, or desired.

We are concerned that Clause 8 assumes family support should be relied upon before disability support services are available. This places the focus on family resources rather than on our aspirations, goals, and support needs.

This raises concerns under Article 19 of the UNCRPD: Living Independently and Being Included in the Community.

Article 19 recognises our right to live independently, make choices about our own lives, and participate fully in our communities. It requires governments to ensure we have access to the supports and services we need to live independently and have the same choices and opportunities as others.

Access to support should not depend on whether family members are available or expected to provide unpaid care.

We agree that family and whānau may be part of a person's support network, but they should not be treated as the default or primary source of support.

As discussed during the hui:

"Our family members shouldn't be expected to care for us. They should be involved in decisions about care, but they shouldn't be expected to be the primary caregiver."

Clause 11.3 – Income and Asset Testing

We strongly oppose Clause 11.3, which would allow disability support programmes to include income and asset testing.

Disability support is not a benefit. It exists to address the disability-related barriers and additional costs that many of us experience.

Support should be based on disability-related need, not on a person's income, savings, or assets.

Disability often comes with significant additional costs that non Disabled People rarely have to consider. These can include assistive technology, mobility equipment, guide dog care, specialist transport, home modifications, medical appointments, therapies, support services, and higher utility costs. Many of us face these expenses every day, regardless of whether we are employed or not.

The costs of disability are not limited to direct expenses. Many of us experience barriers to education, employment, and career progression. Family members may also reduce their working hours or leave employment altogether to provide support. The combination of higher costs and reduced earning opportunities means disability often carries a substantial economic impact throughout a person's life.

As one CAG member stated:

"I don't like anything that says income or asset testing."

Another CAG member described the provision as:

"a slippery slope going forward."

The possibility of future income and asset testing was one of the strongest concerns raised by CAG members.

Clause 11.3 creates a pathway for future policies that could undermine our financial security, independence, and autonomy.

Income and asset testing fails to recognise the additional costs and barriers associated with disability. It would create barriers to building financial security, discourage employment and savings, and undermine the independence that disability support services are intended to promote.

Clause 11.3 also appears inconsistent with the EGL principle of Self-Determination. We should be able to work, save, own assets, and build financial security without fear of losing access to essential supports.

It also raises concerns under Article 26 of the UNCRPD: Habilitation and Rehabilitation.

Article 26 requires governments to organise, strengthen, and extend services and supports that enable us to achieve and maintain maximum independence, full physical, mental, social, and vocational ability, and full inclusion in all aspects of life.

Access to appropriate supports is essential for participation in education, employment, community life, and other aspects of society. Supports should promote independence and inclusion rather than create additional barriers to participation.

Disability support services exist to create equity and remove barriers to participation. Access to essential supports should not depend on a person's income, savings, or assets.

Choice, Control and Self-Determination

A recurring theme throughout our discussion was the importance of having authority over decisions that affect our lives.

The EGL vision recognises us as experts in our own lives. Support systems should strengthen independence, choice, and control, not create additional barriers or restrictions.

As one CAG member stated:

"We have right to have our own lives to do what we want."

This reflects the principles of Self-Determination and Choice and Control that sit at the heart of EGL and are reinforced by Articles 19 and 26 of the UNCRPD.

Several provisions within the Bill risk reducing our ability to direct our own supports and make decisions about our lives.

We are also concerned that aspects of the Bill treat us as passive recipients of support rather than as citizens with the same rights, responsibilities, aspirations, and decision-making authority as everyone else.

The Bill risks reinforcing assumptions that others know what is best for us, rather than recognising our right to make decisions about our own lives. This approach can be experienced as infantilising and is inconsistent with the dignity, respect, autonomy, and self-determination promoted through both the UNCRPD and EGL.

Too often, disability policy has been designed around what others think Disabled People need rather than what we identify as important for our own lives. The EGL approach was developed to move away from that thinking by recognising that we are the experts in our own lives and should be at the centre of decisions that affect us.

We believe disability support services should enable us to exercise the same freedom, choice, and control over our lives that non-disabled people expect as a matter of course.

Ministerial Powers and Future Decision-Making

We are concerned that the Bill gives significant discretion to Ministers and government agencies to determine how disability support programmes operate.

While flexibility may be necessary, we are concerned that important decisions about eligibility, supports, and programme design could be made without sufficient transparency or meaningful involvement from Disabled People and disability-led organisations.

We are particularly concerned that significant decisions affecting eligibility, supports, and service delivery could be made through programmes, regulations, or ministerial decisions without the same level of scrutiny and public accountability that would accompany changes made through primary legislation.

This creates a risk that future changes affecting our access to support could occur without adequate consultation, transparency, or public debate.

This concern is particularly relevant given the lack of consultation that occurred prior to the introduction of this Bill. If Ministers are given broad powers to make future decisions, there must also be robust requirements for consultation and engagement with Disabled People, Disabled People's Organisations (DPOs), and disability-led organisations.

The EGL principles of Self-Determination, Mana Enhancing, Partnership, and Relationship Building require us to be active participants in decisions that affect our lives. These principles should apply not only to how disability support services are delivered, but also to how future decisions about those services are made.

We believe decisions that affect our rights, supports, and opportunities should not be made about us without us.

Any significant changes to disability support programmes, eligibility criteria, or service delivery arrangements should require meaningful consultation with Disabled People, DPOs, and disability-led organisations before decisions are made.

Strong consultation requirements would help ensure transparency, accountability, and public confidence in future decision-making, while also helping New Zealand meet its obligations under Article 4(3) of the UNCRPD.

Recommendations

We recommend that:

1. The Government pause further progress of the Bill until it has fulfilled its obligations under Article 4(3) of the UNCRPD by undertaking genuine consultation and co-design with Disabled People, Disabled People's Organisations, disability-led organisations, and other affected communities.
2. Clause 8 be removed or substantially amended so that family and whānau support is not treated as a prerequisite for receiving Disability Support Services.
3. Clause 11.3 be removed from the Bill and Disability Support Services remain based on disability-related need rather than income, savings, or assets.
4. The Bill be amended to ensure consistency with New Zealand's obligations under the United Nations Convention on the Rights of Persons with Disabilities, particularly Article 4(3) (Participation and Consultation), Article 19 (Living Independently and Being Included in the Community), and Article 26 (Habilitation and Rehabilitation).
5. Any significant changes to disability support programmes, eligibility criteria, or service delivery arrangements should require meaningful consultation with Disabled People, Disabled People's Organisations, and disability-led organisations before decisions are made.
6. The legislation should explicitly recognise the right of Disabled People to exercise choice, control, and self-determination in decisions affecting our lives and supports.

Disability support legislation should strengthen our rights, independence, participation, dignity, and self-determination.

In its current form, we do not believe this Bill achieves that objective.

We should be active partners in the design of the legislation, policies, and services that affect our lives. Nothing about us without us.