Submission to the Social Services and Community Committee on the Disability Support Services Bill

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1. Key points and recommendations

IHC does not support the passing of this Bill in its current form and submits that the Select Committee should make recommendations to amend the Disability Support Services Bill as follows:

1. More time should be allowed for disabled people to have their say on this Bill.
2. Explicitly recognise the rights of disabled people under the UNCRPD in the Bill.
3. Strengthen the purpose clause by including autonomy, participation, inclusion, dignity, and self-determination.
4. Remove or amend language that positions disability support primarily as a contribution to care.
5. Require mandatory consultation with disabled people, Māori, whānau, representative organisations, and service providers before Ministerial Programmes are established or amended.
6. Require publication of impact assessments, including UNCRPD, equity, and Te Tiriti analyses.
7. Establish independent oversight arrangements for Ministerial Programmes.
8. Require regular reporting to Parliament on the Disability Support Services (DSS) Programme operation and outcomes.
9. Provide clear review and accountability mechanisms where Programmes are ineffective, inequitable, or inconsistent with the purpose of the Act.
10. Ensure future Programme development is transparent and subject to appropriate public scrutiny.
11. Require the Government to assess the cumulative impact of DSS reforms on disabled people and their families and ensure reforms do not result in a deterioration in living standards, participation, or wellbeing.

2. About IHC

IHC New Zealand Incorporated (‘IHC”) advocates for the rights, inclusion, and welfare of all people with intellectual disabilities and supports them to live satisfying lives in the community. This submission includes feedback received from IHC members on the Bill.

IHC was founded in 1949 by a group of parents who wanted equal treatment from the education, health, and social service systems for their children with intellectual disability. Today IHC is still striving for these same outcomes and is committed to advocating for the rights, welfare, and inclusion of all people with an intellectual disability throughout their lives.

We believe that people with an intellectual disability have the right to be to be part of a family, to be treated with respect and dignity, to have a say in their own lives, to live, learn, work and enjoy life as part of the community, and to have support that meets their goals and aspirations.

IHC is New Zealand's leading provider of services for people with intellectual disability and their families. Beyond service delivery, IHC advocates for the rights of all New Zealanders with an intellectual disability, an estimated 47,000 people, promoting their inclusion, wellbeing, and full participation in society.

IDEA Services, IHC's service provider subsidiary, is making a separate submission on the Bill.

3. Introduction

IHC supports the objective of establishing a legislative framework for DSS. New Zealand has operated a disability support system for decades without a dedicated statutory framework, resulting in a system that is often confusing, inconsistent, and difficult for disabled people and their families to navigate.

The introduction of legislation presents an important opportunity to create a transparent, accountable, and rights-based disability support system. However, in its current form, the Bill raises significant concerns regarding accountability, transparency, human rights protections, and alignment with New Zealand's obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The Bill is being introduced primarily to establish a legislative framework for DSS and to respond to the Supreme Court decision released in December 2025. While legislative certainty is desirable, the response should not come at the expense of disabled people's rights, meaningful participation, and access to support.

3.1 The Bill should not be rushed

Three weeks is not long enough for disabled people and their families and whanau to submit on a Bill that the Minister has described as foundational to disability support services.

The stated justification for urgency, that the Bill should pass before the general election, is not convincing given the significance of the legislation. Nor does the litigation context justify haste. The litigation bar began when the Bill was introduced on 19 May 2026, so there is no pressing need to rush the legislation to avoid further family carer litigation costs.

A Bill of this significance would ordinarily take at least a year to progress through Parliament so it can be properly scrutinised and consulted on. IHC submits that the Bill should proceed through the usual process and that adequate time should be taken to establish this important framework.

The departmental disclosure statement acknowledges both “limited consultation with persons with disabilities and their representative organisations” during development and that “there has been no consultation on the Bill”. To IHC’s knowledge, there has been no direct engagement with affected stakeholders beyond government agencies. That falls short of both Parliament’s expectations and New Zealand’s obligations under the UNCRPD and should be remedied through adequate time for genuine and effective consultation.

Although the Minister and the disclosure statement refer to earlier sector engagement, that engagement was not about this Bill or its proposed framework. It appears to have related instead to the 2024 Independent Review of Disability Support Services, which led to the transfer of overall DSS responsibility from Whaikaha to MSD. That process cannot reasonably be treated as consultation on this Bill.

The Ministry for Regulation has not reviewed the Bill or the regulatory impact statements because the Bill was assessed as not meeting the threshold for review. IHC disagrees as the Bill confers significant regulatory power and enables substantial secondary legislation that may directly affect individual rights.

IHC submits that the Bill should proceed under ordinary parliamentary timeframes and processes so that proper scrutiny and engagement can occur. Additional time should also be provided to ensure disabled people can participate fully in the process.

3.2 Purpose of Disability Support Services

IHC supports the inclusion of a statutory purpose for Disability Support Services.

The provision stating that DSS-funded disability support services are focused on enabling disabled people to live their everyday lives is particularly welcome. This aligns with the principles contained within the UNCRPD, including:

- Article 19 (Living independently and being included in the community);
- Article 3 (General principles);
- Article 26 (Habilitation and rehabilitation).

The reference to supporting disabled people according to their "needs and circumstances" is also positive because it recognises the importance of individualised supports.

However, the purpose clause also contains language that raises significant concerns.

3.3 Operating in a constrained funding environment

The Bill explicitly states that disability support services operate in a constrained funding environment.

While Article 4(2) of the UNCRPD recognises that economic and social rights may be progressively realised within available resources, the Convention does not permit governments to define disability support primarily through fiscal limitations.

The UN Committee on the Rights of Persons with Disabilities has repeatedly expressed concern about disability support systems that are driven by austerity measures, restrictive eligibility criteria, and inadequate funding. In its review of the United Kingdom, the Committee criticised reductions in disability support and recommended that support systems be based on the human rights model of disability rather than budget-driven restrictions (Committee on the Rights of Persons with Disabilities, 2017).

The Committee emphasised that disability support should promote inclusion, participation, autonomy, and an adequate standard of living. It further recommended that reforms be assessed for their cumulative impact on disabled people's lives and should not result in a deterioration in living standards (Committee on the Rights of Persons with Disabilities, 2017).

A statutory purpose that explicitly centres a "constrained funding environment" risks positioning fiscal considerations ahead of the rights and wellbeing of disabled people.

3.4 Disability support as a contribution to care with reliance on natural supports

The Bill also describes DSS-funded supports as a "contribution to care".

This wording suggests a welfare or charity-based model in which the Government contributes towards support that families are otherwise expected to provide.

This sits uneasily alongside the rights-based approach reflected in the UNCRPD, which views disability supports as mechanisms that enable disabled people to exercise their rights and participate equally in society.

The Bill appears to assume that families will continue to carry substantial caring responsibilities and that natural supports will remain the primary source of assistance. There is little indication that the legislation seeks to reduce the burden currently carried by families or address longstanding unmet need.

Historically, families have carried the majority of responsibility for supporting people with intellectual disability in New Zealand. The evidence suggests that this reliance on unpaid family care has come at a considerable social and economic cost. Rather than reducing disadvantage, the current approach has contributed to people with intellectual disability and their families becoming one of the poorest groups in New Zealand.

Recent IHC research demonstrates that people with intellectual disability experience significantly higher levels of hardship throughout their lives than the rest of the population. They are twice as likely to experience hardship in early adulthood and almost three times as likely to experience hardship in middle age (Beltran-Castillon, McLeod, & Stone 2025). Rates of severe hardship are double those experienced by other New Zealanders in young adulthood and triple those experienced by the general population during middle age (Beltran-Castillon, McLeod, & Stone 2025).

The depth of this disadvantage is reflected across almost every measure of material wellbeing. Nearly half of people with intellectual disability would be unable to pay an unexpected bill within a month without borrowing money, compared with fewer than one in five other New Zealanders (Beltran-Castillon, McLeod, & Stone 2025). They are more than four times as likely to be unable to afford regular meals containing meat or a vegetarian equivalent, almost three times more likely to cut back on fresh fruit and vegetables because of cost, and more than twice as likely to put up with being cold because they cannot afford heating (Beltran-Castillon, McLeod, & Stone 2025).

The impact of poverty is particularly concerning for children with intellectual disability. On every hardship indicator examined, children with intellectual disability were more likely to miss out on essentials due to cost (Beltran-Castillon, McLeod, & Stone 2025). They were almost twice as likely to lack adequate shoes, warm winter clothing, or waterproof coats. Nearly one-third were unable to have friends over for a meal because of financial constraints, compared with fewer than one in ten other children. They were more likely to miss out on fresh food, school activities, internet access for homework, sporting participation, and other opportunities that most New

Zealand families would consider fundamental aspects of childhood (Beltran-Castillon, McLeod, & Stone 2025).

Housing outcomes tell a similar story. People with intellectual disability are significantly more likely to live in rental accommodation throughout their lives and are more than seven times more likely to live in social housing (Beltran-Castillon, McLeod, & Stone 2025). They are more likely to experience crowded housing, damp housing conditions, and difficulty affording adequate heating (Beltran-Castillon, McLeod, & Stone 2025). Throughout their lives they are consistently overrepresented in the most deprived communities in New Zealand and are substantially more likely to require hardship assistance such as Special Needs Grants (Beltran-Castillon, McLeod, & Stone 2025).

These findings raise important questions about the assumption that families can continue to absorb caring responsibilities with limited additional support. The evidence suggests that families are already carrying a significant burden and that this burden has contributed to persistent and intergenerational poverty.

Against this backdrop, describing DSS as merely a "contribution to care" risks reinforcing a model that has already produced poor outcomes for disabled people and their families. Rather than assuming that families will continue to fill gaps in support, the legislation should recognise that disability support services are a critical component of social participation, wellbeing, and equal citizenship. A rights-based system should seek to reduce the financial and caring burden experienced by families, not entrench it.

The Bill should therefore provide stronger recognition that disabled people are entitled to support that enables participation, inclusion, and an adequate standard of living, consistent with New Zealand's obligations under the UN Convention on the Rights of Persons with Disabilities.

As drafted, the Bill risks enshrining a model in which families have primary responsibility for supporting disabled family members and Government support remains supplementary. This approach does not adequately recognise disabled people as rights holders entitled to support that enables participation, autonomy, and inclusion.

3.5 Lack of a Disability Rights Framework

A significant concern is that the Bill lacks an explicit disability rights framework.

There is no clear statement that DSS exists to give effect to the rights of disabled people under the UNCRPD. There is no reference to autonomy, self-determination, participation, inclusion, dignity, or equal citizenship.

Instead, much of the Bill focuses on means testing, natural supports, government discretion, and funding constraints.

The result is legislation that appears to reinforce many of the structural features of the current system rather than addressing the dysfunction that disabled people and their families regularly experience.

3.6 Ministerial Programmes and Accountability Concerns

The Bill proposes that key aspects of the future DSS system will be established through new Ministerial Programmes. This represents a significant shift in decision-making power from Parliament to the Executive, particularly given the centrality of these Programmes to how disability supports will be defined, accessed, and delivered.

At present, the Bill provides limited detail about how these Programmes will be developed in practice. It is unclear which agencies will take primary responsibility, what decision-making criteria will be applied, how consultation will be structured, or what safeguards will ensure consistency, fairness, and alignment with the Bill’s stated purpose. There is also limited clarity on how oversight will operate where Programmes have significant impacts on disabled people’s daily lives.

This lack of specificity makes it difficult for disabled people, families, providers, and advocates to understand how the system will function in practice or to meaningfully assess its likely impacts at this stage.

An example of detail missing in the Bill currently is the lack of any reference to the NZ Disability Strategy, or the Ministry of Disabled People and their role in relation to the new DSS framework.

3.7 Transparency and accessibility of decision-making

The proposed new use of Ministerial Programmes raises concerns about transparency and stability. Unlike primary legislation, these instruments may be more frequently amended and may be less visible to the public, particularly if changes are published online without sustained parliamentary scrutiny. This creates a risk of policy settings shifting over time in ways that are difficult for disabled people and their families to track or anticipate, undermining clarity about rights and entitlements.

3.8 Consultation and participation

The Bill does not clearly require structured or mandatory consultation with disabled people, whānau, Māori, disability representative organisations, or service providers in the development or amendment of Ministerial Programmes. Without explicit consultation requirements, there is a risk that future policy settings may not adequately reflect lived experience or sector expertise and may be perceived as lacking procedural fairness.

3.9 Oversight and quality assurance

Compared with regulatory instruments, Ministerial Programmes may not be subject to equivalent requirements for Cabinet approval, Regulatory Impact Statements, public submissions, or independent review. This reduces formal opportunities for scrutiny and external quality assurance at the point where significant policy decisions are made.

3.10 Implications for disabled people and families

Taken together, these design features place substantial discretion in the hands of the Minister while offering limited detail about how accountability will be ensured in practice. Key questions remain unresolved, including what supports will be available over time, how eligibility will be determined, whether current levels of support will be maintained, and how unmet need will be addressed in a consistent way across regions.

For many disabled people and their families, DSS is not simply an administrative system. It is central to financial security, wellbeing, and the ability to sustain daily life and caring responsibilities. The absence of clarity about future arrangements therefore creates understandable uncertainty within the disability community.

3.11 Equity, Te Tiriti, and human rights considerations

The breadth of Ministerial discretion also raises broader concerns about equity and rights. In the absence of clear safeguards, there is a risk of variation in access between regions, unequal outcomes for people with high support needs, and disproportionate impacts on Māori, Pacific peoples, and people with complex disabilities.

The Bill would benefit from stronger and explicit requirements that future Programmes are developed consistently with Te Tiriti o Waitangi, the UN Convention on the Rights of Persons with Disabilities, the New Zealand Bill of Rights Act, and the Human Rights Act. Embedding these frameworks with mandatory requirements to include them as considerations in the development of new Ministerial Programmes would provide clearer guidance for decision-making and strengthen accountability for outcomes affecting disabled people.

3.12 Comment from IHC members

IHC received 79 responses to its call for feedback between 3 and 9 June. Given the short consultation period, this represents a significant level of engagement from the disability community. The majority of responses were from parents and family members of people with intellectual disability. Respondents were overwhelmingly opposed to the Bill, with 99 per cent expressing opposition to its passage in its current form.

A consistent theme across submissions was concern about the limited time available for consultation on legislation that will have substantial and long-lasting implications for disabled people and their families. Many respondents felt that the process did not allow sufficient opportunity for meaningful engagement with the disability community. Respondents also expressed strong opposition to the provisions preventing further litigation relating to paid family care arrangements. Many viewed these provisions as limiting accountability and restricting avenues for disabled people and families to seek redress where they believe they have experienced discrimination.

Another recurring concern was the breadth of ministerial discretion provided by the Bill. Many respondents considered that the proposed framework lacks adequate safeguards, transparency, and independent oversight, resulting in significant decision-making power being concentrated in the hands of the Minister.

Human rights concerns featured prominently throughout the feedback received. Respondents raised concerns that aspects of the Bill may be inconsistent with New Zealand's obligations under the UN Convention on the Rights of Persons with Disabilities and could weaken protections for disabled people and their families. Overall, the feedback received by IHC reflects a high level of concern within the disability community regarding both the content of the Bill and the process through which it has been developed.

On the Rushed Timeline

> *"The short time frame just prior to the election indicates that the current government wishes to prevent parents of disabled people and others in this sector from coming together to present an evidence-based and coherent opposition to the Bill."*

On Removal of Court Access

> *"The removal of a person's right to use the courts to fight for employment entitlements is a deeply troubling erosion of natural justice, one that undermines the dignity of workers."*

On Ministerial Power Without Consultation

> *"Too much power in the hands of one politician and no checks and balances to redress any breaches of human rights. Appalling principle."*

Personal Impact Statements

> *"I get physically assaulted at least once a week, not something most people have in their day-to-day job... Currently I'm working below minimum wage in an abusive environment. I am sad that my hard fought for career is not something I can have any more."*
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> *"At 68 I thought I might relax a little, but now I am worried that this might be taken from us. I have been caring for them for the last 15 years on my own, 38 years in total. I should be retiring."*
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> *"I am shocked and feel afraid for myself and my son's future... It terrifies me and makes me feel uncared for by my government."*

On Human Rights

> *"NZ signed up to the UNCRPD in 2007 and this was ratified in 2008... It is time to start honouring the UNCRPD. Disabled people must be consulted and their rights acknowledged."*
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> *"Disabled people should not be classed as 'forever children' but given recognition as people in their own right, and as such deserving of full participation in society."*

4. Conclusion

The introduction of a statutory framework for Disability Support Services is a significant opportunity to create a more transparent, consistent, and accountable system. However, the Bill currently places substantial power in the hands of a Minister while providing limited safeguards, limited accountability, and insufficient recognition of disability rights.

Disabled people and their families need confidence that future reforms will promote inclusion, autonomy, dignity, and wellbeing. The Bill should be strengthened to ensure that Disability Support Services are grounded in rights, not merely administered within fiscal constraints.

5. References

Beltran-Castillon, L., McLeod, K., & Stone, G. (2025). *The Cost of Exclusion: Hardship and People with Intellectual Disability in New Zealand*. IHC New Zealand. https://doi.org/10.6084/m9.figshare.29387705.v1.

Committee on the Rights of Persons with Disabilities. (2017). *General comment No. 5 (2017) on living independently and being included in the community* (CRPD/C/GC/5). United Nations. https://digitallibrary.un.org/record/1311739