Submission on the Disability Support Services Bill

By: Disability Connect

May 2026

About Disability Connect

Disability Connect is a parent led disability information service provider supporting disabled people and their parents, whānau and caregivers in Auckland with a reach across New Zealand. The oldest of our almost 5,000 members is a parent in their 90's and we serve Pasifika 14%, Maori 11% and other ethnicities including Chinese, Indian and Other Asian too. We envision a world where disabled people and their families can live the lives they want. We value and respect choice, autonomy and self-determination. Our mission is to lead and influence positive change for disabled people and their families. We can state with assurance that Disability Connect represents the voice of the disabled people and those who support and care for them.

Introduction

Disability Connect opposes the Disability Support Services Bill in its current form. We ask the Select Committee to reject the Bill and require a full redesign that is led alongside and with disabled people, their families, carers, providers, and representative organisations.

Our organisation works every day with disabled people and their families. We hear their stories, their pressures, their hopes, and their fears. This submission reflects those lived realities[1].

Concerns about "natural supports"

The Bill asserts that families whānau, friends, and communities will have a greater responsibility to provide care. This relies heavily on the idea of "natural supports", yet the term has never been clearly defined and in practice it places a burden on unpaid carers.

[1] Our draft submission was shared through our newsletter, website and social media platforms and we have had significant engagement from disabled people and their families who unanimously voiced their opposition to that we received directly is Bill and redesigned through a proper consultative process. A select number of quotes from families are reproduced verbatim.

The direction of this Bill does not reflect the real lives of the families we support. Parents of disabled people do not only care for their disabled children. Many are also caring for grandchildren, for their own children who do not have disabilities but still face challenges, and for elderly parents. Families are supporting multiple generations at once. They are already stretched.

Families have given countless unpaid hours to the government and society over many years. Parents advocate for their children, attend consultations, navigate complex systems, and fill gaps in services. None of this is paid. Caring for a disabled child is not the same as typical parenting. It often requires giving up employment, education, income, and opportunities. The Bill gives the impression that this contribution is not valued. Families feel that they are not recognised as contributing members of society, and that their disabled children are not valued.

Many families are exhausted, financially strained, and ageing. Some provide care around the clock. Increasing reliance on “natural supports” risks pushing families into crisis as evidenced in the recent Carer Wellbeing Report. This Bill drives them away from choices in employment, retirement and education for the betterment of their families.

Disabled people also risk losing independence, choice, and control if the system assumes that family members will fill gaps in formal services. Not every disabled person has family who are able, willing, safe, or available to provide support. Some families live far away. Some relationships are strained. Many carers have their own health or disability needs.

The proposed Bill fails to recognise the circumstances of many migrant families supporting a disabled person, who often have little or no access to the natural supports assumed by the legislation. For these families, care is frequently provided solely by immediate family members, with grandparents, extended whānau, relatives, and culturally familiar carers either unavailable or living overseas. As a result, the wider support networks that play a significant role in disability care for many New Zealand families are often limited or absent for migrant families.

There is a real risk that “natural supports” will be used to justify reducing funded supports or limiting access to services. This creates fear and uncertainty for disabled people and their families

Concerns about the Needs Assessment Tool

We are concerned about the proposal to use the Needs Assessment Tool to measure family wellbeing. This was not the purpose of the OBIR tool when they were developed. It does not measure family wellbeing in a meaningful way and will not ensure appropriate Carer Support and wellness. We are equally concerned that the BAT tool doesn’t take into account the wellbeing of parents and family who will still provide care as a backup to residential placements. Using the tools in this way risks underestimating the real pressures families face.

Concerns about NASC decision making

The Bill assumes that NASC's will play a major role in interpreting concepts such as "natural supports". Families already experience inconsistency, lack of transparency, and stress when dealing with NASC's. Expanding the use of subjective concepts without clear safeguards will increase inequity and uncertainty.

Support from family and community should be respected, but it should never be assumed or required. It must not replace properly funded disability support services. Disabled people have the right to live independently and participate fully in their communities. Families should not be expected to carry responsibilities that belong to the State. The role related tasks of parents and family caring for disabled people differ markedly from those of their peers. These tasks include changing adult nappies, therapies, feeding, bathing, dressing and driving adults.

Concerns about the rights of disabled people

Once disabled people have reached adulthood, they should be able to have the choice to have supported independent lives from their parents. The default should not be family and wider community support unless that is the choice of the disabled person. The bill in its current form does not support the dignity of disabled people to have choices for a good life and how they wish to be supported.

The Bill also does not support disabled people to have the dignity of choice for community participation. Family and community carers often have different participation interests that can conflict with the desire of the disabled person. The disabled person should have a choice of who provides support for them and how they wish to live their lives, from daily routines to interests and community participation.

Concerns about secondary legislation and future policy

The Bill states that current supports will not change immediately, but it leaves the door open for major changes through secondary legislation or Ministerial directives. These include the possibility of means testing, asset testing, and changes to eligibility for Residential Care or the Residential Care Subsidy. This undermines certainty for disabled people and families.

We feel strongly the Bill in its current form has insufficient safeguards for the wellbeing of disabled people and their families from potential changes that have not been consulted on.

What we support in the Bill

There are some positive elements. Disability Support Service needs a clear legal foundation and there is an obvious need to introduce legislation to replace what the Ministry of Health has repealed. There is great value in clarifying who the employer is for family carers of a disabled person with limited decision-making capacity. A three-year transition period is realistic. Schedule 1 was useful in giving clarity for disabled people their parents or carers, and the organisations and services who support them.

What needs clarifying

Parts of the Bill are unclear and create confusion.

- It is not clear how employment of family carers will work.
- There is a conflict between welfare guardianship and employment that has not been resolved.
- The definition of “family member” is individualistic and close relationship is open to interpretation. It seems to imply that disabled people must rely on all family members and acquaintances before seeking DSS support, but this is not clearly stated.
- Clause 8 implies a “family first” expectation, suggesting that all family members are responsible for providing care.
- The Bill is vague about the Minister’s power to create new programmes. This creates instability.
- The Bill destabilises family care relationships and provides no certainty about employment conditions or wages.
- It is unclear when family support ends or reduces. The Bill implies that disabled people will require a family carer for life.

What is missing

Our key contention is that the Bill undermines disabled people’s rights to choose who provides their care. This is underscored by the absence of any reference to the UN Convention on the Rights of Persons with Disabilities, Enabling Good Lives, or rights-based approaches. Framing disability support as a “contribution” to an “everyday life”, rather than a right to a good life which is included in the New Zealand Disability Strategy, is simply missing.

Of equal importance is the lack of recognition of health and safety needs of disabled people through the supports who assist with daily activities and community participation. Existing legislation, such as the Oranga Tamariki Act (1989) gives clear purpose and responsibility that the health and safety of the person is of paramount importance. This includes appropriate carers, with capability and capacity and safeguards to be put in place. It is the State’s responsibility to ensure the protection of its most vulnerable people alongside the family unit through its legislation and policy development.

No meaningful consultation with disabled people and families has resulted in a Bill in which disabled people who are carers themselves are not recognised.

What needs to change

- Remove the means testing clauses in Clause 11(3).
- Remove or rewrite Clause 8 to remove any expectation of unpaid care and to clarify what is meant by “family first”.

- Remove the reliance on secondary legislation, which leaves disabled people vulnerable to political change.
- Rewrite Clauses 12 to 15, which prevent complaints about breaches of employment law.
- Guarantee that family carers can be paid equitably to non-family carers with proper employment conditions when this level of care is required.
- Restore disabled people's right to choose who provides their care. This must be central to the Bill.

Sample Feedback Received

"I'm a single mum to a 19 yo with Down syndrome. I have sacrificed career progression because of her ongoing support needs. I work part time as full time would be extremely difficult, so our financial situation is not secure. I have no family support in my area. My daughter's dad has her every second weekend. My daughter's "natural supports" that the government wants her to rely on is one person - me. I am constantly stressed, exhausted and anxious. I've sacrificed so much over the last 20 years and I need some light at the end of the tunnel that she will move into supported living and I will have more space in my life to focus on my wellbeing. This bill takes much of that hope away.

I want my daughter to live a full, satisfying and independent life separate from me. She wants that too. She has a human right to that as set down in the UNCRPD. She wants to go flatting and live with friends. To do that she will need a lot of support, financial support I am unable to give, and day to day practical support for which I little energy left.

I worry that this Bill will decrease the options for independent living. I worry that she will need to live with me ongoing - that is a concern both for her and me. The government seems to assume that disabled people have family support. Yes she does, but to expect one person to do the bulk of her care at significant financial disadvantage for the rest of her or my life is unfair on both of us. I love her and will always be there for her but I can't do what I've done for the last 20 years for the rest of her life. I'm too tired.

This Bill would affect women and single parents far more than other groups. Women are the majority of family carers and single mothers are already struggling with raising disabled children on their own, financially, emotionally, spiritually. This Bill also increases the already massive divide between disabled people receiving ACC funding and disabled people received non-ACC support. There is a hierarchy of disability in NZ where people funded under ACC are eligible for more support and it

appears to be easier to get this. It's an incredibly unfair and inequitable system that discriminates against my daughter simply because she was born with a congenital condition.

I am absolutely opposed to this Bill."

" I am a migrant. There is only three of us in our family. Auckland has been home for me and my boys for over 25 years. I have cared for my two sons who are both autistic and have intellectual disability, and some physical disability by myself all these years. I do not have natural supports such as grandparents, siblings, uncles, or aunts who I can rely on."

Conclusion

Strong disability supports strengthen families and communities so everyone has an opportunity to thrive with employment, education, housing and the hope of retirement. Weak supports push disabled people and families into crisis and poverty of choices.

This Bill does not provide clarity, certainty, or rights protections for disabled people or their families. It relies on unpaid labour, expands subjective decision making, and leaves too much to future Ministers to make changes that are aligned with a charity framework of disability that developed nations have moved on from.

Disability Connect asks the Select Committee to reject the Bill and require a full redesign that is led with disabled people, their families, carers, providers, and representative organisations. The process must honour the UN Convention on the Rights of Persons with Disabilities, embrace a social disability framework, be consistent with the NZ Disability Strategy and Enabling Good Lives. The wellbeing of disabled people and their families including their health and safety must be prioritised in legislation governing disability support services and reflect the lived realities of the people most affected.

We would welcome the opportunity to present an oral submission.

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