Committee Secretariat
Social Services and Community Committee
Parliament Buildings
Wellington

11 June 2026

Submission on the Disability Support Services Bill

Multiple Sclerosis New Zealand strongly opposes the Disability Support Services Bill as presented urging the Select Committee recommend that it does not proceed to Second Reading.

The Bill presented is a mechanism to protect the Crown, limiting its liability as a response to the Supreme Court Ruling on the cases of Fleming v Attorney-General and Humphreys v Attorney-General ([2025] NZSC 188). The irony is that this case arose due to poor legislation introduced and passed under urgency in 2016. We urge the Select Committee not to repeat the errors of the past.

The timeframe, under urgency, is devoid of effective consultation, and the lack of detail exposes the Disability community to significant risk. There is an unnecessary heavy reliance of future ministerial powers and denying disabled people and their whānau from the protection of the legal process.

We call on the Select Committee to:

- Reject the Bill as presented.
- Mandate genuine co-design with disabled people, family carers, and representative organisations.
- Request the return of a Bill consistent with the Enabling Good Lives (EGL) principles and the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

We support a legislative framework for disability support which strengthens and stabilises the system, protecting disabled people, family carers and whānau provided those most affected have a chance to co-design the framework.

We request to appear before the Select Committee to speak to our submission.

The Community We Represent

Multiple Sclerosis New Zealand (MSNZ) is the national organisation representing 18 member societies delivering community-based services across Aotearoa. Collectively, we represent and support over 5,000 people currently diagnosed with Multiple Sclerosis (MS), alongside their families, whānau, carers and supporters.

Many of our member organisations also support people with allied neurological and long-term health conditions, including Neuromyelitis Optica Spectrum Disorder (NMOSD), Myelin Oligodendrocyte Glycoprotein Antibody-Associated Disease (MOGAD), Parkinson's, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Huntington's.

In making this submission we have consulted with members of our community and provided their comments as an appendix to this submission. We urge you to **read** all of their comments**. Please listen** to what the people are telling you and **reject** the Bill.

Current DSS Access for the MS Community

MS is the leading non-traumatic disabling condition in young people globally. It is diagnosed on average at age 38, affects women at three times the rate of men, and its impacts extend across 40–50 years of a person's life.

MS, along with many other neurological conditions are chronic, complex, and unpredictable. For all, progression is underlying, and for many, symptoms may fluctuate with periods of relapse and remission. In the same way, support and care needs are not always consistent but are changeable. Neither the current DSS system, nor the proposed Bill sufficiently account for those with complex and changeable conditions like MS.

Research from the University of Auckland, using the Integrated Data Infrastructure (IDI), shows the MS population has grown nearly 70% since 2006. **Yet only 19.9% of people with MS currently receive disability funding,** a figure far below what the clinical reality of the condition demands. Postcode healthcare, means-testing, and unrecognised symptoms for funding like cognitive impairment (50%) and fatigue (90%) lock people out of the disability support system entirely.

We hear strongly from our community access challenges due to lack of clarity around the Disability Support Services (DSS system), including eligibility, along with frustrations of geographic variation in packages.

As a progressive condition, many people with MS will require increasing support from family and whānau carers, government funding as well as health, disability and community services.

Insufficient Data

The timely report, *Window on Disability*[1] released by the Health Quality and Safety Commission, Te Tāhū Hauora, reveals data from the IDI, disability-led research and disability community engagement, that the quality of healthcare for disabled people has not been measured properly before.

Recent reports from the Government, and proudly published on the DSS website[2], advise that at the most DSS is supporting with funding 181,000 disabled people, made up of:

- 55,0000 adults receiving DSS support
- 26,000 children
- 100,0000 receiving equipment or home modifications

[1] A Window on Disability | Health Quality & Safety Commission Te Tāhū Hauora (May 2026)
[2] www.disabilitysupport.govt.nz

It is possible that the total number is inflated by disabled people appearing in more than one category.

Window on Disability reports, that in fact the truer number is closer to one-sixth of the population, or more than 850,000 people. It also highlights that health data sources poorly collect disability status information impacting the quality of data and previous measurements.

If, as *Window on Disability* reports, the disability population in Aotearoa is 850,000, shockingly, this means 669,000 (850,000 – 181,000 = 669,000) are living unsupported by Disability Support Services.

We highlight these numbers, as the Bill presented impacts a much larger number of people than is simply being covered currently by Disability Support Services.

This Bill Was Designed to Limit Crown Liability, Not to Support Disabled People

The Supreme Court ruled on the cases of Fleming v Attorney-General and Humphreys v Attorney-General ([2025] NZSC 188) that some family carers are legally employees of the Crown. Rather than honour that finding, the Government introduced this Bill, under urgency, without consultation, to legislate away those rights and responsibilities.

The Regulatory Impact Statement (paragraph 44) **openly acknowledges** this process "may be seen as inconsistent" with New Zealand's obligations under the Convention on the Rights of Persons with Disabilities (UNCRPD) to actively involve disabled people in decisions that affect them. **That acknowledgement alone is grounds for rejection.**

This Bill sets a dangerous precedent and will cause real harm. It is rushed legislation that overrides a Supreme Court ruling, strips employment rights from unpaid carers, and hands extraordinary and unnecessary powers to Ministers without meaningful Parliamentary oversight or community input. It seeks to correct a situation which itself arose from rushed legislation passed under urgency in 2016. **Allowing this bill to proceed risks repeating the same mistakes.**

At a time when so much trust was lost between the government and the disability community, following funding restrictions implemented in March 2024, and the enormity of work undertaken to rectify this, we are astounded that this legislation is being introduced in this way.

The Bill Is Dangerously (and Purposefully) Vague

As primary “umbrella” legislation, it provides unnecessary and extraordinary powers to current and future governments to make changes without effective Parliamentary oversight or community consultation.

The Bill delegates critical decisions regarding eligibility, access, funding levels, complaints processes to future Ministerial regulation. This is not a framework but a dangerous “carte blanche” that risks putting back decades of work to improve lives of disabled people, family carers and whānau.

The Bill must define:

- Clear eligibility and access criteria
- Rights, safeguards, and protections for disabled people and their whānau
- The decision-making process and who holds accountability
- A robust, accessible disputes and complaints mechanism
- Limits on Ministerial powers to change settings without Parliamentary scrutiny
- Proposed legislation must be consulted with and co-designed with disabled people and their whānau first

Without this, disabled people and families are left entirely exposed to whatever a future government decides.

Clause 8 Must Be Rewritten

Clause 8 implies that family must be exhausted as a resource before the Crown steps in. This is unacceptable. It ignores:

- Enabling Good Lives principles that disabled people have the right to make choices.
- Many disabled people have no family.
- Family environments can be unsafe.
- Many carers are already burnt out and struggle to communicate their needs.
- Disabled people and their whānau have in many cases already paid taxes for many years in the expectation that the State would support them in times like this.

The lack of definition and parameters of “family” provides uncertain expectations. This would place undue and unfair pressure on disabled people and extended family, such as grandparents, siblings and non-immediate older and younger generations, to be obligated by the State to provide care.

Clause 8 creates an unlimited, undefined obligation of unpaid care on whānau whilst providing no protections, no boundaries, and no recourse.

For people with MS, diagnosis frequently fractures families. Cognitive changes, personality shifts, financial pressure, grief, and the relentless demands of caregiving dissolve relationships. Forcing "natural supports" onto families already at breaking point is not a care model but an abandonment of responsibility dressed in policy language.

Clause 8 must be rewritten to centre the rights of disabled people to self-determination, and to make explicit that family support compliments, but does not substitute Crown obligations and publicly funded services.

Family Carers Are an Essential Workforce. This Bill Treats Them as a Cost-Saving Mechanism

Family care for people with MS provides a fiscal benefit to Aotearoa, which comes as significant expense to individuals[3]:

- Family carers of people with MS provide an estimated **three million hours per year** nationally.
- The total cost of family care for people with MS was estimated at **$27.5 million in 2021.**
- The total societal cost of MS, including healthcare, lost employment, family care and health quality loss, exceeded $266.3 million.

Across all conditions, the economic value of unpaid family care in Aotearoa **exceeds $17 billion annually.**[4]

However, the result of caring is that:

- Only 21% of carers are in full-time work and 23% in part-time work. Half are forced to give up or reduce paid employment.
- 59% of carers struggle financially to pay bills; 30% cut back on essentials such as food and heating.
- 20% of carers cannot save for retirement at all; 34% have had their retirement plans negatively impacted.
- More than 40% of carers report to have their own health conditions or disabilities[5].

OIA data from the Ministry of Social Development, provided to MSNZ (2025) indicates only 171 people with MS are currently accessing Carer Support, with package values well below the national average. This is evidence that a **significant proportion of MS carers are receiving limited or no funding or respite support at all.** We hear from our community the frustrations with navigating the DSS system are a significant barrier to access and that packages nationally are inequitably and illogically provided.

Family care is not informal support, **but is skilled, complex, intensive labour,** providing; medication management, behavioural support, crisis response, 24/7 supervision. **The only thing informal about it is that the Crown doesn't pay for it.**

If a family member provides 40 or more hours of care per week, they *must* be entitled to fair wages, leave entitlements, and KiwiSaver contributions. Instead of being considered as a cost, it should be considered as an investment in New Zealanders and their futures. That must be legislated rather than deferred to future Ministerial discretion. The Carers Alliance has over 10,000 signatures on a petition supporting legislative protections for the financial, physical and mental health of carers to this effect.

The Bill strips carers of the rights the Supreme Court found they were entitled to such as minimum wage, sick leave, KiwiSaver, ACC cover, health and safety protections, and access to

[3] New Zealand Institute of Economic Research, Economic Burden of MS (2021)
[4] Synergia, The State Of Caring In Aotearoa (2022)
[5] Synergia, The State Of Caring In Aotearoa (2022)

personal grievance processes, and replaces them with nothing concrete. Clauses 12–15 explicitly bar carers from pursuing employment claims through the courts.

These were rights created by legislation, passed by governments of various political persuasions over many years.

This sets a dangerous legal precedent to change Supreme Court decisions with retrospective legislation and a rights violation.

The Inequality Between ACC and Disability Support Is Indefensible

A person who acquires a disability through accident receives funded rehabilitation, equipment, home modifications, and earnings compensation through ACC. No questions about family capacity to support are asked.

A person who acquires a disability through illness, like MS, must fight for every support, prove eligibility, and is now to be told their family must step in first.

This two-tiered system is unjust and will be further entrenched by this Bill. People with disabilities, regardless of cause, deserve equivalent rights, support, and access.

This Bill Is Inconsistent with Te Tiriti o Waitangi

Māori and Pacific whānau frequently rely on family-centred models of care as a culturally grounded expression of values. The Bill risks weaponising those values to justify withholding State support, increasing carer burnout, and removing employment rights disproportionately from these communities.

A Bill consistent with Te Tiriti must be developed alongside Māori, must reflect Mana Motuhake and whānau-centred models of care, and must not use cultural values as cover for cost-cutting.

Conclusion

Support from families and communities is invaluable to New Zealand. Across all conditions, the economic value of unpaid family care in Aotearoa exceeds $17 billion annually.[6] Families must choose to provide care. It must not be imposed or taken for granted. It must not be used by the State as a substitute for its own responsibilities.

- The Government's own Regulatory Impact Statement admits this process undermined New Zealand's international obligations.
- The community it affects was given no meaningful opportunity to participate or co-design.
- The Bill overrides a Supreme Court ruling to remove rights from some of New Zealand's most vulnerable people and those who care for them.

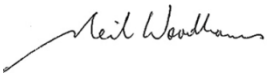
[6] Synergia, The State Of Caring In Aotearoa (2022)

We ask the Select Committee to reject this Bill and require the Government to return with legislation that is:

- Co-designed with disabled people, family carers, and representative organisations
- Consistent with the Enabling Good Lives principles and the UNCRPD
- Specific, rights-based, and free of unchecked Ministerial discretion
- Be fair to family carers and recognise their labour, protect their rights, and ensure their well-being, physically, mentally and financially.

We thank the Governance and Administration Committee for considering our submission and look forward to presenting our submission in person.

Ngā mihi nui,



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Appendixes

In preparing this submission we sought feedback from our community. The below comments highlight the anger, frustration, confusion and distrust that this Bill has brought to our community. They highlight:

We urge you to **read** all of their comments**. Listen** to what the people are telling you. **Reject** the Bill as presented. **Demand** legislation which is co-designed with disabled people, family carers, and representative organisations

- *"Please do not make life any harder for those who suffer from disability through no fault of their own. A considerable number of families are stretched to the max trying to hold a fulltime job and also care for loved ones. If more pressure is applied through lack of funding, the only ones really hurting are the disabled. Please think very clearly before proceeding with this Bill."*

- *"I feel there has not been enough engagement with those who are directly connected with supporting people with disabilities. Just casting the net wide for families with a very broad definition does not take into account those who do not have family or communities nearby. The Bill lacks a lot of detail and does not seem to take into account the varying conditions for people with disabilities"*

- *"I am extremely concerned that the new bill will remove funding from people I know who absolutely rely on it. Pushing full time unpaid care on to families is just not realistic, side from which* ***it is callous and harmful****. If a society cannot support its most vulnerable people, which includes disabled people, it is really failing quite horribly. I don't know anyone who takes more than they need, if anything there is little enough help already.*

- *"We want fairness for those who have medical concerns that are not supported as accidents are covered by acc. My wife has had MS for over 24 years."*

- *"Strengthen protections for disabled people within the Bill itself.*
  Ensure disabled people remain at the centre of decision-making about their own support.
  Clarify that families are not expected to replace publicly funded support services.
  Include stronger rights of appeal and independent review.
  Continue meaningful consultation with disabled people, whānau, and disability organisations.
  Thank you for considering my submission."

- *"I have Multiple Sclerosis and cancer. I cannot work, therefore I am on the supported living benefit.*
  I am estranged from my blood relatives for many reasons, but mainly because they are abusive to me.
  I can't drive anymore. I suffer from motion sickness from having MS and require a driving service that understands how to drive carefully when I need to go places. I cannot walk very far, my mobility is severely impacted also.
  I cannot afford the therapy I need to keep myself strong enough to not become a burden on my children or the healthcare system.
  I rely heavily on the services that are available to someone in my situation.

I am a solo parent. My life is difficult and isolating. I wish the people making the rules would talk to people with the lived experience of the struggle that is our everyday life."

- *"The lack of clarity and adequate consultation with disabled and their requirements and needs indicates that this bill is disadvantageous to the disabled community."*

- *"Without proper consultation with any support network caring for people with disabilities the bill will never provide adequate care where needed as anyone without a family member with a disability can never understand the everyday needs to function as normally as possible."*

- *"This Bill is yet another step in the direction of further budget cuts which the disability sector can ill afford. The fact that it was proposed at all and then read, for the first time after hours speaks to the idea that there was awareness of the fact that it was wrong. I, for example, employ a support worker who cares for her severely disabled father during the day and then cares for me during the night. This means that she essentially works a twenty-four-hour day, just to make ends meet. She is therefore both a taxpayer and employed which is 2 positive behaviours, which, in turn, should be rewarded, not discouraged. The vague wording of the Bill also suggests a lack of understanding and consultation as well as an opportunity for loose interpretation."*

- *"I find the bill insulting in the extreme. I have rights just as others do in New Zealand to participate in society and be a human being."*

- *"Make it more accessible to get help and not be moved from one door to the next door, family and partners should be given support financially to be able to take care of their family member or partner that needs support and help."*

- *"I don't get support for my disability now. I don't trust the government that will change."*

- *"I'm very concerned that my care is going to cost my siblings. They are all of retirement age and cannot afford to pay for my care. I have had MS for almost 30 years. But have been reliant on govt support since 2018. I am in a full-time residential care facility and have been unable to work since 2005. Without govt support I would be not only homeless, but unable to get out of my wheelchair. This legislation will be another step towards isolating and shaming the disabled."*

- *"The Bill minimises the role of family carers as workers. The amount of detail lacking in the Bill which will be left to future legislation. The lack of consultation with disabled people and support agencies in the creation of this framework."*

- *"This bill will only make it harder for people like me who currently present as not physically disabled to access help when or if I need it in future."*

- *"The Bill fails to stress that MS and other neurological conditions are complex, progressive and often fluctuating, meaning people's needs cannot be met through rigid rules, narrow eligibility criteria, or assumptions about informal care. Reforms must be supported by clearer legislation, stronger safeguards, proper consultation with Disability Representative Organisations as well as comprehensive staff training to ensure decisions are fair, consistent and informed by actual lived experience.*

An aside: to suggest that "The Bill then defines "family member" to include a person's spouse, civil union or de facto partner, child, tamaiti whāngai, stepchild, grandchild, sibling, half-sibling or step-sibling, parent or step-parent, a person who acts as a parent, grandparent, uncle, aunt, nephew, niece, and first cousin. It also includes any other member of the person's family, whānau or culturally recognised family group who is in a close relationship with them.

This definition does not allow for "lived experience" my spouse in their mid-70s already does more than enough for me, as for children we are estranged from 2 of them, 1 is overseas never to return to NZ and the 4th does not have time or finances to assist me as they has their own "disabled" (terrible word) dependent. And since all other suggested forms of family are not in NZ that seems to only leave a long and arduous argument with some untrained person at a desk or on a phone to have to fight for any care or help that could be required in the future. This government has done all it can to ensure there are different levels of society."

- *"What is concerning is the clear lack of consultation with agencies and services directly supporting people living with MS and other life changing conditions. There cannot be a one size fits all approach to support as each and every situation is unique. A clear, transparent and fit for purpose criteria for identifying individual support needs should be developed with sector consultation before any bill can be passed. Demographic, geographical needs should be taken into account also as not everyone has access to support networks in the first instance. For some, family are the only support available."*

- *"We with MS are not defined by the disease. We are human and deserve to be treated as such! We try our best from the functionality we have, which occasionally will make us worse. I have MS, it doesn't have me!"*

- *"Need more support so family can take care during this critical times. Without support it's very difficult to manage."*

- *"Disability needs to recognise cognitive issues not just physical issues. I keep physically quite well, but heat intolerance and cognitive issues hit hard, but not "Governmentally" recognised. My wife looks after me, and we spend a fortune keeping cool in summer."*

- *"We do need a disability framework. This Bill as it stands is not it.*

  We are already stressed and traumatised from the changes that happened in March 2024. Those rules have just been relaxed, however new needs assessments (NASC) have not been done, so we are already unsure what is going to happen in the future. Now with this new bill, once again we are being made to feel as a burden on society. It takes away choice to choose suitable carers, opens up avenues for abuse.

  If it has to have means testing in the bill due to housing modifications, state clearly that it is for this part of disability funding only, otherwise it is left open for any future minister to decide to means test, maybe for equipment, care hours etc.

  If the individual has to buy equipment, companies do not give trials as is specified by MOH. Leads to a lay person trying to work out what is best and talked into something that perhaps is not fit for purpose. Buying power is also diminished, equipment checks

become disabled persons responsibility or the carers. Own responsibility of getting rid of obsolete equipment, keeping not fit for purpose equipment.

If care hours is put in 1st instance for family to provide, expect to see even more carer burnout quicker.

I am a fulltime carer for my disabled husband. For families like ours, care is not an abstract policy question. It is the structure of every day and every night, the organising principle of our work, our finances, our health, and our future.

For us, my husband is close to 24/7 care. Comparable people, with less disability, under ACC receive 24/7 care. He receives 40 hours paid carer hours per week. I am his main carer, and do well over 100 hours every week.

What defines family? Is it the expectation to pull our children into the care arrangement? Which child's life do we upset? The apprentice builder, apprentice electrician or the masters student doing her thesis on childhood trauma and the ideation of suicide? Do we make one or more of them less able to get ahead in their life and perhaps end up as a beneficiary instead of a productive member of society? This in turn has the ability to create resentment from them leading to more likelihood of abuse of the disabled person ... or instead I continue doing huge hours without breaks, so our kids continue to thrive and live their lives. Imagine the awfulness we as parents would feel if we stopped them living for themselves and instead encroached on them. I'm not saying that they don't help, they do, but not with any formal expectation.

Mental Health issues?? Let's cause some more.

Who is family and natural supports? Is it neighbours? Elderly parents? Local volunteers? Aunts Uncles Brothers Sisters Cousins 3x removed? Let's create a disabled community that has to literally beg for someone to come and help. How demeaning is that?

Carer respite ... In our case means hospital level care, 1:1 24/7. The only bookable in advance hospital level care facility of suitable standard is in Dunedin. They were already fully booked for the year in February, and have not responded to queries for next year. This is a 3-hour trip one way. Closer to home are rest homes, however beds there are only available when someone dies, until the next permanent person goes in. I've had our name down at the local one since it opened in 2021 and have yet to have a call, apart from one a couple of years ago, to see if we still wanted to be on the waiting list. But it can't be booked in advance anyway, so I can't plan to go away anywhere.

Does Minimum Wage Act limitation mean in 3 years my husbands individualised funding can't be used to pay family carer?

What happens in 3 years?

This framework gives too much ministerial scope to make sweeping changes, without any certainty in the actual bill itself for disabled people."