

Aide-mémoire

Date: 2 July 2026

To: Hon Louise Upston, Minister for Disability Issues

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Security level: In confidence

Meetings with key stakeholders on Friday 3 July

Meeting/visit details

Time and date:	Friday 3 July 2026, 9am (NZDSN and others) and 5pm (Carers NZ)
Location:	EW5.1

Accompanying DSS officials:

Anne Shaw, Deputy Chief Executive

Justine Cornwall, General Manager DSS Policy

Purpose

To provide you with information and talking points to support your meetings with key stakeholders on Friday 3 July 2026 to discuss reform of the disability support services system and your approach to further legislation.

Background

You have agreed to meet with the following stakeholders at 9am on Friday 3 July. They have indicated that they would welcome the opportunity to share key themes emerging from their members, discuss the practical implications of the Bill for providers, and explore how they can work constructively with you as the reform programme progresses.

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s 9(2)(a) to share the same information and key messages at 5pm on Friday 3 July 2026.

Information to support your meetings with key stakeholders

All the stakeholder organisations you are meeting with made both written and oral submission on the DSS Bill. These are summarised in the table below.

Table: Summary of stakeholder organisation submissions

Stakeholder	Position on the Bill	Their Recommendations
Carers NZ		
A national charitable trust that supports family carers. Serves approximately 80,000 family carers, whānau, and supporters. It also provides secretariat services for the Carers Alliance, a network of around 60 national not-for-profit organisations that work together to advocate for the interests of family, whānau, and āiga carers. States that there are approximately 1 million family carers, two thirds of whom are women.	Supports a legislative framework for DSS to guide disability policy, services, and supports. States that a well-designed statutory framework is overdue. Framing legislation for DSS will help to establish a more accountable, equitable, transparent, well-planned and rights-based disability support system. Disabled people must choose who supports them. May not always be families. Does not support the Bill in its current form.	• More time for disabled people and family carers to give input; the Bill does not need to be rushed. • Ensure the Bill explicitly recognises the rights of disabled people and families under the UNCRPD. • Modify or remove language framing disability support as a contribution to care. • Enhance detail in the Bill about DSS eligibility, assessment, funding, and safeguards. • Ensure the Bill gives family carers explicit options about how they can receive payment. • Ensure Ministerial Programmes cannot be created or changed without consultation with disabled people, family carers, Māori, service providers, and sector organisations, and that new Programmes align with the UNCRPD and other relevant government Strategies and legislation (including the Carers' Strategy). • Ensure Ministerial Programmes have independent monitoring and oversight and are transparent and accountable to the sector and to the public. • Require the Government to assess the cumulative impact of DSS reforms on disabled people and families to ensure reforms do not result in deterioration in living standards, the wellbeing of disabled people and family carers, and their ability to participate in society, study, and employment. Require publication of impact assessments. • Require regular reporting to Parliament on DSS Programme operations, outcomes, and planning, with clear reviews and accountability mechanisms where Programmes are inequitable or not working well.

Stakeholder	Position on the Bill	Their Recommendations
CCS Disability Action		
A community-based organisation that advocates for the inclusion of disabled people. Provides direct support to around 5,000 children, young people, and adults through a network of 18 branches across New Zealand, with a focus on reducing barriers to participation. Administers the Mobility Parking Permit scheme, which supports more than 180,000 people. CCS subsidiaries, Lifemark and Barrier Free, work to improve accessibility in housing and the built environment through advocacy and universal design consultancy services.	Agrees there is a need for a proper legislative foundation for DSS. However, states that the current Bill is "ill thought out with no consultation from those who it will directly impact". Does not support the Bill in its current form.	• Rewrite the Bill so that it is informed by the lived experience of the disability community and UNCRPD rights. • Extend the consultation time to ensure that disabled people are given adequate time to submit on the Bill. • The definitions of who is expected to provide family care be reduced, and immediate family are included. The list in the Bill is too broad and unreasonable. • Families and whānau should not be expected to provide lifelong care for their disabled family member as a substitute for Government support. • Include provisions that would require Government to meet its obligations under the UNCRPD Article 19 to ensure that disabled people have the right and means to live independently in the community. • Add a requirement that any assessment of family resources must include an in-depth documented assessment of carer wellbeing, capacity, and sustainability. • Include clear legislative guidance on the limits of family responsibility, including that family and whānau support has a reasonable limit for what they are expected to provide and for how long, after which time, the disabled person is eligible for publicly funded supports. • Use this opportunity to address fragmentation and inequity in disability support and ensure an adequate standard of living for disabled people and their whānau (as it is obligated to do under Article 28 of the UNCRPD). • Remove Clauses 11(3) (f and g) and ensure that means testing is not implemented to access disability support services OR; • Require that any asset or income testing criteria to be approved by Parliamentary vote, and not simply at ministerial discretion. • Any secondary legislation must uphold the rights of disabled people and take the wellbeing of their family and whānau into account. • Meaningful consultation with the disability community must be undertaken before any programmes are established or changed to meet our obligations under the UNCRPD.

Stakeholder	Position on the Bill	Their Recommendations
IHC		
Advocates for an estimated 47,000 people with intellectual disabilities, promoting their inclusion, wellbeing, and full participation in society. IDEA Services, IHC's service provider subsidiary, made a separate submission on the Bill.	Supports the objective of establishing a legislative framework for DSS. Notes that the lack of legislation for DSS has resulted in a system that is often confusing, inconsistent, and difficult for disabled people and their families to navigate. Asks for transparency on significant policy shifts. Inclusion is missing – in the process of developing the Bill, and the way that the Bill operates and its impact on disabled people. Recommends the Bill is strengthened to ensure that DSS is grounded in rights, not merely administered within fiscal constraints.	• Allow more time for disabled people to have their say. • Explicitly recognise the rights of disabled people under the UNCRPD in the Bill. • Strengthen the purpose clause by including autonomy, participation, inclusion, dignity, and self-determination. • Remove or amend language that positions disability support primarily as a contribution to care. • Require mandatory consultation with disabled people, Māori, whānau, representative organisations, and service providers before Ministerial Programmes are established or amended. • Require publication of impact assessments, including UNCRPD, equity, and Te Tiriti analyses. • Establish independent oversight arrangements for Ministerial Programmes. • Require regular reporting to Parliament on DSS Programme operation and outcomes. • Provide clear review and accountability mechanisms where Programmes are ineffective, inequitable, or inconsistent with the purpose of the Act. • Ensure future Programme development is transparent and subject to appropriate public scrutiny. • 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.

Stakeholder	Position on the Bill	Their Recommendations
Manawanui		
Manawanui has operated as a provider of Individualised Funding (IF) host services for disabled people and their whanau since 2004 and currently supports more than 10,000 disabled people and their whanau to self-direct their disability supports. They enable people with disabilities to access safe, high-quality support that meets their unique needs, and select and pay for that support themselves.	Supports a legislative framework for disability support services to improve transparency, consistency, and legal certainty. Questions whether provisions that extinguish existing claims and limit future accountability are a proportionate response to the Supreme Court decision. Notes that fiscal pressures are already being managed, with a projected \$170 million DSS underspend, making some provisions, particularly clause 11, potentially unnecessary. Raises concerns that aspects of the Bill could disadvantage disabled people, especially those who rely on paid family carers and self-directed, flexible supports.	• Amend clause 8 to clarify that the families-first principle cannot be used to reduce a person's funding on the basis that family members could provide care informally and without payment. • Include a guarantee that no validated employment agreement will expire until an alternative payment model is in place and available to that person. • Require co-design of the alternative payment model with disabled people, their whanau, and IF host organisations. • Add a reporting requirement for MSD to report annually on funded-to-actual hours ratios for paid family carers. • Reconsider the scope of the litigation bar, and at minimum confirm that prospective human rights complaints arising after the Bill's commencement will remain available. • Amend the purpose clause (clause 7) to better reflect a rights-based approach consistent with the UNCRPD. • Remove or substantially narrow clause 11, particularly 11(2)(b) and 11(3); if clause 11 is retained, include a statutory right for eligible people to choose self-directed and flexible funding. • Remove the explicit authorisation of income and asset testing from clause 11(3)(f) and (g) or require separate primary legislation before means testing can be introduced.

Stakeholder	Position on the Bill	Their Recommendations
New Zealand Disability Support Network (NZDSN)		
NZDSN is the national peak body representing around 170 disability support providers. Its members deliver a wide range of disability services, including residential support, supported living, home and community support, employment and vocational services, respite, behaviour support, early intervention, and kaupapa Māori services. NZDSN submits on the DSS Bill from the perspective of: - frontline disability support providers; - organisations responsible for quality, safety, and sustainability; - disabled people and whānau who rely on continuity of support; and - a sector that has worked closely with successive governments on disability reform. NZDSN members support tens of thousands of disabled people and whānau and employ a	Supports disability system reform and the goal of a legislative framework for disability support services but believes the Bill should not proceed in its current form. Notes the Bill was developed without sufficient consultation or co-design and leaves too many important decisions to future Ministerial programmes, operational policy, and secondary legislation. Is concerned the Bill lacks adequate safeguards, review and appeal rights, accountability mechanisms, and protections for disabled people's autonomy and access to support. Particularly opposes provisions that could increase reliance on unpaid family care ("natural supports") and believes the Bill should be substantially redeveloped with stronger rights protections, Parliamentary oversight, and implementation planning.	<i>Overarching recommendation</i> - Return the Bill to DSS for substantial redevelopment through a co-design process involving disabled people, whānau, carers, providers, and representative organisations before progressing further. <i>If the Bill proceeds</i> - Separate family caregiving and "natural supports" provisions from the broader Bill and only progress these provisions to the extent necessary for immediate clarity and safeguards. The remainder should be redeveloped. - Introduce stronger legislative guardrails, including: - stronger rights protections; - limits on discretionary powers; - protections against arbitrary reductions in support; - independent review and appeal rights; - transparency and accountability requirements. - Extend the Select Committee process, including a longer submission period, nationwide hearings, and accessible participation methods. - Provide accessible consultation processes, including Easy Read formats, NZSL, translated materials, and culturally appropriate engagement. - Require statutory consultation obligations for all future secondary legislation, operational policy, Ministerial programmes, funding mechanisms, and implementation plans. - Increase Parliamentary oversight of Ministerial programmes through public reporting, consultation requirements, and limits on changes made solely through administrative direction. - Include greater operational detail in primary legislation, particularly around eligibility, assessments, funding, complaints, review rights, and accountability mechanisms. - Strengthen alignment with UNCRPD and Enabling Good Lives, including explicit protections for autonomy, independent living, community inclusion, participation, and choice and control.

Stakeholder	Position on the Bill	Their Recommendations
substantial national workforce across urban, rural, and remote communities.		• Strengthen protections around "natural supports", including: ○ limits on use in funding decisions; ○ protections against coercive family caregiving; ○ recognition that family support must be voluntary and sustainable; ○ safeguards against shifting responsibility to unpaid carers. • Strengthen complaints, review and appeal mechanisms, including independent complaints pathways, procedural fairness protections, and accessible review processes. • Strengthen Te Tiriti and Māori partnership obligations, including Māori co-design, equity commitments, kaupapa Māori protections, and engagement requirements. • Strengthen Pacific engagement and cultural responsiveness, including Pacific participation in policy development and culturally responsive implementation. • Develop a national disability workforce strategy to address recruitment, retention, sustainability, capability development, and workforce shortages. • Undertake comprehensive implementation and transition planning before major reforms proceed. • Assess provider sustainability and financial viability risks, including pricing adequacy, workforce affordability, and risk of provider failure or withdrawal. • Recognise the link between disability supports, housing and community inclusion, supporting independent living and avoidance of institutionalisation. • Ensure future reform is co-designed, rights-based, transparent, implementable, adequately resourced, and developed in genuine partnership with disabled people, whānau, carers, providers and communities.

Please note: the following page (page 8), has been withheld under S 9(2)(f)(iv)

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Talking points

Key messages for you to convey at the meetings are included at Appendix 1.

Appendix 2 provides an overview of what phase 2 legislation will focus on.

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Appendix 1 – Talking points

- Submissions have come from a range of people and organisations and capture different views on support for disabled people, public services and family and whānau.
- The main concerns we have heard is that the Bill:
 - may directly reduce allocations or trigger reassessments
 - may enable future decisions that could reduce support
 - could further shift responsibility to families and remove choice for disabled people
 - does not include any processes to involve disabled people, the disabled community or carers in processes determining policy or funding settings or secondary legislation
 - should be rights-based.
- The Bill is currently going through Select Committee so there's only so much we can say at this stage in the process. I am listening to what is being raised through the submissions.
- Based on the feedback, I am considering amendments to clarify that:
 - Families are generally expected to contribute care support, where this support is available and appropriate, alongside the contribution DSS makes and that DSS should continue take this support into account when allocating supports.
 - The Bill does not mean a disabled person has to use every other type of support before they can get help from DSS. The Bill reflects the current practice.
 - To clarify that DSS considers the disabled person's choice, their safety and dignity, and the durability of care arrangements.
 - Consultation to occur with representatives of disabled persons when making secondary legislation (support programmes) as appropriate.
- I have heard the calls for consultation – this Bill is about clarifying the current system and putting in place more checks and balances than what exists now. I need your support to make this point clear.
- I have heard consistently from the disability community that the system is unclear and subject to change without any legislative safeguards. This lack of a legislative framework has also left DSS exposed to litigation, with the Supreme Court decision being one example of this.
- I am not prepared to accept for any longer a system based on ad-hoc funding and policy design decisions. This Bill fixes that.
- Establishing support programmes will make DSS more transparent than it currently is by introducing more checks and balances. The first support programmes are expected to primarily lift and shift current DSS services into secondary legislation – to provide a transparent basis for the system and to make current practice clearer.

- I acknowledge the need to fill in more gaps – that will come in phase 2 legislation. I expect this phase will look to simplify the system, increase efficiency and measure effectiveness and clarify other aspects of the system like complaints, reviews and safeguarding.
- This will also take into account relevant insight from the current consultation, which includes a focus on complaints processes.
- If I'm Minister, there will be a discussion document to support the next stage of legislative work, expected mid-next year. I expect it to fill in a lot of the detail I hear people want.
- We are also looking at better ways to support family carers than formal employment arrangements through a carer's support package.
- DSS will work with key stakeholders as this work progresses. The work will happen at pace and could include a carer payment, improved respite options, and other practical support.

Appendix 2 – Phase 2 Legislation

A second legislative phase will focus on further strengthening and future sustainability

- A second legislative phase is envisioned that will build on the foundation established by this DSS Bill, by providing authorising for such things as
 - Safeguarding
 - Information gathering
 - Strengthened appeals and complaints processes
 - Initial scoping of this phase is intended to be explored mid-2026.
1. This work will also explore standardising eligibility settings so that a coherent and principled structure can be integrated into the new legislative framework.