

Aide-mémoire

Date: 15 May 2026

To: Hon Louise Upston, Minister for Disability Issues

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Security level: In confidence

Stakeholder Engagements on Introduction of the Disability Support Services Bill

Meeting/visit details

Time and date: 18 May 2026 (**Appendix One** sets out the Run Sheet)

Location: Teams Link to be provided by your office.

Primary contact/s for this visit

Accompanying DSS official – Anne Shaw

Purpose

To provide key talking points on the Disability Support Services Bill (the Bill) to inform a briefing with select stakeholders on Monday 18 May 2026, after the Bill has been introduced in the House.

Key Messages

- The Bill builds on what disabled people, families, whānau, and carers have told us, and the actions already taken to strengthen and stabilise Disability Support Services (DSS). DSS is fragmented, and difficult to navigate. This Bill will improve that.
- The Bill does three things:
 - Creates a clear legal foundation for DSS.
 - Sets out what it means when a disabled person employs a family member to provide care.
 - Responds to the Supreme Court's decision last December regarding paid family care.

- The Bill provides a more transparent and consistent framework for policies and funding and reduces the risk of disruption and unexpected cost increases that could impact available support.
- Court cases have highlighted issues with DSS. The Bill makes it clear that the Crown is not and was never intended to be the employer of family carers.
- The Bill provides short-term arrangements to allow time to move to better, more suitable, systems for families who provide care and for supporting disabled people who may not be able to make their own decisions.
- Family and whānau play a significant and important role in caring for disabled people. An employment model is not appropriate for family carers, as it can impact the health and wellbeing of both the disabled person and their family member. DSS officials are working on a new carer support package that better recognises and supports their contribution. They will work with key stakeholders, including consulting with family and whānau to develop this.
- The Bill is the first step in building a foundational legal framework for DSS. More changes will come later, including safeguarding and complaints processes. These will be shaped by what disabled people and the community tell us.
- There are no immediate changes to DSS services, funding or eligibility. People should continue to access their supports and funding as they do now. Existing assessment and allocations processes continue.

Appendices:

1. Runsheet including speaking notes for meeting with stakeholders
2. Talking points for meeting with the Labour Spokesperson for Disability Issue
3. Details of the Bill
4. Decisions and litigations on PFCs since 2010

Next steps

DSS officials will continue to support you with further engagement on the Bill as required.

End

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Appendix 1: Runsheet

Meeting details:

Teams meeting currently scheduled from 4pm to 4.30pm on Monday, 18 May 2026.

Stakeholders:

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RUN SHEET 18 MAY – Minister’s pre-engagement timeline and script

Time	Action	Who
3.25pm	Arrival at the Beehive	Officials
3.30-4pm	Prep time	Officials and Minister’s Office
4-4.30pm	Pre-engagement with stakeholders <i>There will be an interpreter for the DPO coalition</i>	Officials and Minister’s Office
4.00pm	Minister opens with acknowledgement and purpose for the engagement • Tēnā koutou katoa, and thank you for joining me today. • I’m here today with DSS officials and Donna [name of the interpreter] – does anybody require an NZSL interpreter? • Wanted to take this opportunity to talk about setting the foundations for a clearer, more consistent and sustainable disability support system • As such, today I will be introducing the DSS Bill, to provide a clear framework for how DSS operates. • I will make some opening remarks and there will be time for questions at the end • But before I talk about the Bill • I would like to take a moment to reflect on this past year.	Minister Upston
4.02pm	Minister provides background/context • The Government has committed an additional \$1 billion investment over four years to DSS. • This year, DSS has implemented a more consistent assessment and allocation process. Flexible funding users also now have more choice and control. • Work has been underway to build on these stabilising actions to DSS and address other issues. This included work to give DSS a proper legal foundation.	Minister Upston

	• The recent Supreme Court decision on paid family carers has highlighted vulnerabilities in the system and also created a risk of unmanageable costs that may impact service provision. • It highlights that an employment model is a poor fit for family carers and has created uncertainty for disabled people and their families, whānau and carers. • Work on a DSS Bill has been accelerated to address this, and give disabled people, families, whānau and carers certainty by setting a clear legal foundation.	
4.05pm	Minister provides information on what the Bill intends to do • The Bill intends to: ○ Provide a more transparent and consistent framework for policies and funding and reduces the risk of disruption and unexpected cost increases that could impact available support. ○ Respond to the Supreme Court judgment while maintaining continuity of care for disabled people. ○ Mitigate crown fiscal and litigation risks to avoid impacting funding for services and supports for disabled people. • The Bill does not change eligibility or funding for anyone accessing DSS. • Now I will hand it over to [DSS Officials].	Minister Upston
4.06pm	[DSS Officials] cover the key features of the Bill • The Bill will: ○ Create a legal framework for how DSS works, including the purpose for DSS. ○ Clarify the respective contribution of the state and family to care. • Ministerial programmes will be established for all DSS programmes and funding to improve transparency, including how funding is targeted. • The Bill clarifies employment relationships in response to the supreme court decision, making it clear that the Crown is not an employer of family carers. • Decision-making authority is restored to parliament to mitigate fiscal and legal risk to the Crown - e.g. the Bill applies	[DSS Officials]

	retrospectively, saves successful claims, extinguishes waiting claims and puts in place a litigation bar. • The Bill ensures continuity of care by validating key arrangements for people who may lack decision-making capacity for a period of three years while people are supported into more suitable arrangements. • It includes a provision for the Minister to introduce further support for carers.	
4.09pm	Minister goes over what the Bill says about the role of families and whānau • The Bill clarifies that: - DSS sits alongside other supports available to disabled people – both from families and whānau, and other public services, and, - responsibility for the wellbeing of disabled people rests in the first instance with their family and whānau as natural supports, where this is appropriate. • This is how the system works now. The Bill does not introduce new obligations for families and whānau.	Minister Upston
4.10pm	Minister goes over what the Bill means for disabled people • For disabled people, the Bill will: ○ Give greater certainty to disabled people, and improve the consistency, fairness, transparency, and long-term sustainability of the DSS system. ○ Avoid unnecessary disruption to the arrangements that are in place for disabled people while further work continues to improve DSS. • Now I will hand it back over to [DSS Officials].	Minister Upston
4.11pm	[DSS Officials] will cover how DSS will support people who may lack decision-making capacity. • Thank you, Minister Upston. • We would like to go over how DSS will support people who may lack decision-making capacity. • The Supreme Court judgment has highlighted the need to change how DSS supports people who may not be able to make decisions for themselves.	[DSS Officials]

	• This is a sensitive area, but we need to ensure these arrangements are safe, enable the right support, and are on a legal basis. • We also need to make sure that where possible we support people to make their own decisions, and ensure their will and preferences are reflected in the support they receive. • To ensure continuity of care and take the time needed to work through this issue carefully, the Bill validates current arrangements. This also means that those currently representing and providing care to these disabled people will continue to be able to do so. • Now we will hand it back to Minister Upston who will explain future support for carers.	
4.13pm	Minister covers future support for carers. • Thank you, [DSS Officials]. • The Bill enables us to establish a new carers support package for family carers. • DSS recently introduced a new assessment process for disabled people, that also considers the needs of family carers and the contribution they make. • The nature of an employment model has never been a comfortable fit with care in the context of a familial or social relationship. • MSD officials are working on a new carer support package that better recognises and supports this contribution, outside of an employment model. • The support package will be informed through consultation with the community and carers groups, and developed over the course of this year.	Minister Upston
4.15pm	Minister goes over what the Bill means for people who have current claims against the Crown. • The Bill treats people with current claims differently depending on their situation. • If a person's claim has already been decided, including the two people who took their claim to the Supreme Court, it will stay in place. That means that the Supreme Court claimants will remain MSD employees and their legal processes will continue as if the Bill has not happened. • If the Bill passes as it is now, other unresolved claims will come to an end.	Minister Upston

	• The Bill will also limit new claims about past events before the law was introduced. • I know this is a complex and sensitive issue. It is not one that I have taken lightly. My intentions are to make sure that this Bill draws a line under the past and creates a more stable DSS system for the future.	
4.17pm	Minister goes over how people can have their say on the Bill. • The Bill will be referred to the Social Services and Community Select Committee on 21 May 2026. • It is likely that the Select Committee will call for public submissions. • I will hand it back over to [DSS Officials] now.	Minister Upston
4.18pm	[DSS Officials] cover the community consultation. • Thank you, Minister Upston. • In parallel with the Bill, DSS will be doing some in-person and online consultations on further operational improvements to the service that DSS currently provides • In areas the community have told us matter most to them, so they are responsive to the needs of disabled people, their whanau and carers. • We will be making announcements on the community consultation soon.	[DSS Officials]
4.20pm	Minister welcomes questions for the stakeholders • DSS officials will continue to support you with further engagement on the Bill as required. • And I'm happy to take questions now	Minister Upston and [DSS Officials]
4.30pm	Minister closes the meeting • Thank you again for your time today • And appreciate your support in keeping this information confidential until it is publicly announced	Minister Upston
4.35-5pm	Engagement with the Labour Spokesperson for Disability Issues	Minister Upston
4.45pm	Bill introduction	

Appendix 2 – Talking Points for Meeting with the Spokesperson for Disability Issues

1. Today I will introduce the Disability Support Services Bill into the House. The Bill:

- Creates an authorising framework and establishes a legislative hierarchy for DSS.
- Introduces certainty regarding employment relationships for paid family care. On a temporary basis, it also validates existing employment and representation arrangements for disabled people who may lack decision-making capacity.
- Responds to the December Supreme Court decision regarding paid family care – *Fleming v Attorney-General* and *Humphreys v Attorney General* [2025] NZSC 188. It mitigates Crown fiscal and litigation risks to avoid impacting funding for services and supports for disabled people.
- Importantly, the Bill does **not** change eligibility or funding for anyone accessing DSS.

2. This builds on work to stabilise and strengthen DSS:

- This year, DSS has implemented a more consistent assessment and allocation process. Flexible funding users also now have more choice and control.
- Work has been underway to build on these stabilising actions to DSS and address other issues. This included work on to give DSS a proper legal foundation.
- The recent Supreme Court decision on paid family carers has highlighted vulnerabilities in the system and also created a risk of unmanageable costs that may impact service provision.
- It highlights that an employment model is a poor fit for family carers and has created uncertainty for disabled people and their families, whānau and carers.
- Work on a DSS Bill has been accelerated to address this, and give disabled people, families, whānau and carers certainty by setting a clear legal foundation.
- The Bill is the first step in building a foundational legal framework for DSS. More changes will come later, including safeguarding and complaints processes. These will be shaped by further community consultation.

3. For the first time, the Bill will create a legislative framework for DSS

- The Bill clarifies that:
 - DSS sits alongside other supports available to disabled people – both from families and whānau, and other public services, and,
 - responsibility for the wellbeing of disabled people rests in the first instance with their family and whānau as natural supports, where this is appropriate.

- This is how the system works now. The Bill does not introduce new obligations for families and whānau.
- The establishment of Ministerial programmes will make it easier for disabled people to understand what support is available and how decisions are made. Like welfare programmes, these are secondary legislation and will be disallowable instruments.
- This will make DSS more fair, consistent and transparent.

4. The Bill clarifies employment relationships for paid family carers

- The Crown and its providers do not employ family members as carers, unless there is a written employment agreement.
- The Bill also makes it clear that the employment relationship sits between the disabled person and their family carer.
- Where people have used flexible funding for a paid family carer, the employment relationship is between the disabled person and their family member.
- For three-years after the Bill takes effect, care provided by a family carer beyond Crown-funded hours under a DSS policy or ministerial programme will not be treated as “work” for the purposes of the Minimum Wage Act 1983.
- The Bill keeps current arrangements in place for three years for people who are not able to make their own decisions. This allows time to move to better long-term arrangements.

5. Ultimately, employment is not the right mechanism for family care

- Treating family members as government employees is not the best way to do recognise family care. It can create complexity and uncertainty, and does not always work well for the people involved.
- Care arrangements need to work well in real life, not just on paper. Turning family care into an employment relationship can change those relationships in ways that do not always work well.
- The Bill enables us to establish a new carers support package for family carers. This will better recognise and support family contribution, and will not be an employment relationship.
- DSS recently introduced a new assessment process for disabled people, that also considers the needs of family carers and the contribution they make.
- The new carer support package will be informed through consultation with the community and carers groups, and developed over the course of this year.

6. The Bill will also help DSS provide support for people who may lack decision-making capacity

- The Supreme Court judgment has highlighted the need to change how DSS supports people who may not be able to make decisions for themselves.

- This is a sensitive area, but we need to ensure these arrangements are safe, enable the right support, and are on a legal basis.
- We also need to make sure that where possible we support people to make their own decisions, and ensure their will and preferences are reflected in the support they receive.
- To ensure continuity of care and take the time needed to work through this issue carefully, the Bill validates current arrangements. This also means that those currently representing and providing care to these disabled people will continue to be able to do so.

7. The Bill mitigates the fiscal and litigation risk

- The Bill treats litigants differently depending on the status of their claim.
 - It saves the Supreme Court proceedings and the remedies claims that flow from it – that means they get to “keep their victory”.
 - It extinguishes pending claims. That means the claims will end upon commencement, unless they are settled or determined first.
 - It bars new claims about past events.
- I acknowledge that this Bill engages constitutional concepts and human rights.
- I know this is a complex and sensitive issue. It is not one that I have taken lightly. My intentions are to make sure that this Bill draws a line under the past and creates a more stable DSS system for the future.
- The financial risk of the allowing individual Court cases to determine fundamental system funding settings is significant. More importantly, those decisions should be made by the Executive within the parameters set by Parliament.

Appendix 3 – Details of the Bill

The DSS Bill:

- sets out the **purpose** of DSS-funded disability support:
 - DSS operates in a constrained funding environment.
 - It is a contribution to the support needs that enable disabled people to live their everyday life. It exists alongside family, community and other public services.
- establishes a **mechanism for decision-making**, which includes powers for the responsible Minister to establish ministerial programmes and provide ministerial directions.
- clarifies that the Crown or its contracted providers are **not employers** unless there is an intentional written employment agreement, where a disabled person uses their funding allocation to pay a carer, including a paid family member.
- clarifies that the Crown or its contracted providers are **not ‘third-party controlling agents’ or ‘persons in breach’ under the ERA**, in relation to where a carer is employed by a disabled person.
- **validates these employment and temporary representative arrangements** for three years to enable time to transition to more appropriate arrangements.
- **responds to the Crown’s risks** arising from the Supreme Court judgment.
- states that family care, outside of the hours funded by DSS, will not count as paid work for three years to recognise the nature of the family relationship and that the Government sets funding policies not the Courts.

Appendix 4 – Timeline of family carers legal action and Government decisions

Date	Events	Notes
2010 to 2013	Cabinet considers how to respond to the Atkinson v Ministry of Health litigations and conducts public consultation on payments to family carers <u>Cases:</u> Atkinson v Ministry of Health [2010] NZHRRRT 1 Ministry of Health v Atkinson [2012] NZCA 184	- In 2010, the Human Rights Review Tribunal finds that the Ministry of Health's policy of excluding family members from being paid to care for disabled relatives is discriminatory. - In 2012, the Court of Appeal upholds the Tribunal's decision. - Consultation finds that people favour an allowance, but notes that employment offers equity with paid carers.
	Parliament amends the New Zealand Public Health and Disability Act to introduce Part 4A: Family care policies	- The Crown and District Health Boards can only pay family members for support services under a family care policy. "Family member" includes spouses, partners, parents, stepparents, grandparents, children, stepchildren and grandchildren, siblings, aunts, uncles, nephew, nieces, cousins. Unlawful discrimination claims are precluded.
2013	The Minister of Health issues the Funded Family Care Notice 2013 <u>Power to issue notice:</u> New Zealand Public Health and Disability Act 2000 s 88	- Disabled people accept the terms of the Notice when they accept their first payment of funding. - Payment terms are the minimum adult wage plus allowance for "on costs" and maximum of 40 hours per week. - Criteria includes the disabled person must have high or very high needs and would not be able to remain at home if they could not employ a family carer.
2019 to 2020	Cabinet agrees to widen Funded Family Care and agrees to repeal Part 4A entirely without a litigation bar. <u>SWC-22-MIN-0054</u> Part 4A is repealed entirely	- Family carers are treated the same as other employed support workers and there is no longer a requirement for the disabled person to be the employer. - This includes spouses and partners, and disabled people under 18 with high or very

		high needs who receive care from parents or close family members.
2020	The Ministry of Health widens the family care policy to include disabled people of all need levels. Existing flexible funding allocations can be used to pay family carers.	• This is a response to COVID-19. • The Independent Review of DSS identified this change was a driver of increased flexible funding costs. By 2022/23 flexible funding costs were \$424m (42 percent of the non-residential supports costs). At the end of April 2024, these costs were on track to be 30 percent higher than 2022/23.
2022	The Ministry of Health undertakes targeted consultation. Cabinet agrees to a new family care policy <u>SWC-22-MIN-0110</u>	• People supported the proposal to enable people with low to moderate impairments to pay a family carer. • Family members providing care to disabled people of all need-levels and all ages can be paid. • s 9(2)(h)
2024-2025	Court of Appeal and Supreme court Judgments (Fleming v AG and Humphreys v AG)	• Supreme Court overturns Court of Appeal and finds Ms Fleming and Mr Humphreys are employed by MSD as homeworkers.