



11 September 2025

Tēnā koe

Official Information Act request

Thank you for your email of 6 December 2025 requesting the following correspondence between Whaikaha - the Ministry of Disabled People and the Office of Hon Louise Upston, Minister for Disability Issues. Your request was transferred to the Ministry of Social Development (the Ministry) as Disability Support Services (DSS) functions now sit with the Ministry. You requested the following information:

- *All email correspondence between Whaikaha and the Minister's office that may relate to funding for families of young people and children with disabilities.*
- *All advice prepared, including emails, briefings, aide memoires, on carer support since February 2024.*

I would like to apologise for the significant delay in responding to your request for information.

Several of the topics you have requested information about relate to the announcement the Minister for Disability Issues, Hon Louise Upston, made in the past week regarding changes to DSS needs assessment, allocation, and flexible funding arrangements, including respite and support for carers.

The changes announced by the Minister respond to the Independent Review of DSS which was commissioned in April 2024 to provide advice on what actions should be taken to manage increasing cost pressures and ensure the future sustainability of DSS.

The Independent Review identified seven recommendations that included taking immediate steps to stabilise DSS, including financial monitoring and accountability mechanisms, and implementation of future settings to strengthen the system into one that is transparent, fair, and consistent. Details about the Independent Review and the resulting recommendations are available on DSS's website here: www.disabilitysupport.govt.nz/about-us/taskforce/independent-review.

With the changes referred to in the Minister's announcement, people will have more choice and control in their use of flexible funding, and nationally consistent processes for assessing and allocating services and supports for disabled people will be introduced. The changes will create a fairer, more consistent, transparent, and sustainable disability support system, and will support the Government to make the best use of resources.

These changes will come into effect from February 2026.

You can read the Minister's announcement and further information about the upcoming changes at the following links:

- www.beehive.govt.nz/release/improved-support-disabled-new-zealanders and
- www.disabilitysupport.govt.nz/about-us/news/changes-to-assessments-and-allocations-and-flexible-funding

I have considered your request under the Official Information Act 1982 (the Act).

Please find my response to each section of your request set out separately below.

- *All email correspondence between Whaikaha and the Minister's office that may relate to funding for families of young people and children with disabilities.*

Your request for all email correspondence is refused under section 18(f) of the Act as substantial manual collation would be required to locate and prepare all documentation in scope. The greater public interest is in the effective and efficient administration of the public service.

I have considered whether the Ministry would be able to respond to your request given extra time, or the ability to charge for the information requested. I have concluded that, in either case, the Ministry's ability to undertake its work would still be prejudiced.

- *All advice prepared, including emails, briefings, aide memoires, on carer support since February 2024.*

I have interpreted your request to be for advice provided to the Minister for Disability Issues for the period 1 February 2024 up till the date of your request (6 December 2024).

The following documents are released to you in full:

- *Flexible Funding – COVID-19, 2024 – Changes and Respite*
- *REP/WHK/24/4/042 – Briefing - Clarification to Flexible Funding Purchasing Rules and guidance, dated 18 April 2024*
- *REP/24/10/992 – Draft Report - Independent Review response: Draft Cabinet paper and discussion document, dated 31 October 2024*

The following document is released to you as excerpts in accordance with section 16(1)(e) of the Act, as a large volume of the information is out of scope of your request:

- REP/WHK/24/8/128 – Report - *Further Comparisons between Mana Whaikaha and other DSS regions*, dated 9 August 2024.

The following report has been proactively released in part on Whaikaha's website:

- REP/WHK/24/2/018 - Briefing – *Changes to Equipment and Modification Services and flexible funding to manage Whaikaha expenditure*, dated 22 February 2024.

You can access this document at the following link: www.whaikaha.govt.nz/assets/OIAs/9.-REP-WHK-24-1-018.pdf.

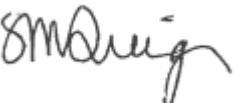
As you will see, some parts of the report have been redacted. The Ministry has not reconsidered these redactions as part of this response to you. However, if you would like us to do so, please let us know and we can log this as a new request.

I will be publishing this decision letter, with your personal details deleted, on the Ministry's website in due course.

If you wish to discuss this response with us, please feel free to contact OIA Requests@msd.govt.nz.

If you are not satisfied with my decision on your request, you have the right to seek an investigation and review by the Ombudsman. Information about how to make a complaint is available at www.ombudsman.parliament.nz or 0800 802 602.

Ngā mihi nui

pp. 

Anna Graham
General Manager
Ministerial and Executive Services

REP/WHK/24/8/128 – Briefing for Hon Louise Upston, Minister for Disability Issues - Further Comparisons between Mana Whaikaha and other DSS regions, 9 August 2024

Differences in the supports available in different locations

7.2 Disabled people are predominantly allocated support that offers them greater authority and flexibility over how the support is used (with 74% using flexible supports such as IF and Carer Support) than more traditional disability support services (e.g., only 27% of people using HCSS).

Table One: Examples of Differences in the Regional Use of Supports and Services

Support type	Availability	Comment on Regional Variations (% figures are of total people who receive funded support)
Carer Support	All regions	The proportion of people using Carer Support varies between 40% and 70% - although only 8% of people use Carer Support in Mana Whaikaha

8.3 There also appears preference for the use of Personal Budgets over other flexible funding arrangements (e.g., Individualised Funding (IF) and Carer Support), when Personal Budgets are available. For example:

- In Mana Whaikaha, 70% of people use Personal Budgets, while only 8% use Carer Support and 2% use IF.
- In contrast, across the country, 57% of people use Carer Support, with 31% of people using IF.

NB: Personal Budgets bring together funding from several different service lines, with funding able to be used flexibly to support the person to build the life they are seeking to build and has options such as one-off funding in response to significant issues or early investments to improve outcomes or reduce later costs. Personal Budgets are only offered where support is available from Connectors. In contrast, IF and Carer Support are allocated for a narrower range of specific purposes.



Flexible Funding – COVID19, 2024 Changes and Respite

Purpose of this note

- 1 This note provides a summary of the changes made to Disability Support Services flexible funding products during the Covid19 pandemic, in March and April 2024, and the impact of these changes on access to respite for families.

Carer Support Subsidy

- 2 The Carer Support Subsidy contributes to the cost of care and supports lower-cost informal alternatives to formal respite arrangements. This service is now difficult to use as the payments were designed to be low cost koha type payments and the funding rules introduced in 2024 ban in-kind payments.

Individualised funding allows people to purchase their own supports

- 3 Individualized funding (IF) was introduced in the 1990s to allow disabled people across the country to hire their own support workers. This allowed disabled people to have greater control over their existing support arrangements.
- 4 In 2013, a court ruling extended Disability Support Services (DSS) policy settings to enable disabled people to hire family carers as their support workers. As part of a package of support centred on family carers, disabled people were able to use IF funding for things such as vehicles and laptops which would have been provided as part of the care package from a non-family member.

Individualised funding was expanded significantly during Covid19

- 5 Social distancing requirements during Covid19 lockdowns (e.g. household bubbles) cut some disabled people off from their support workers. To address this, changes were made so that:
 - All flexible funding recipients were allowed to hire family members as care givers (this had previously been available only to those assessed as being high or very high needs)
 - The scope of IF was changed to align it with the flexibility offered by Enhanced Individualized Funding (EIF) (which was only available in Bay of Plenty Region).
- 6 These decisions were signed off by the Ministry of Health. They were initially temporary but were later extended, and in 2022 they were made permanent.

- 7 Aligning the scope of IF with EIF meant that DSS clients could purchase a much broader range of supports (such as sensory items like headphones). As IF was available nationally, this effectively meant that the policy settings that were in place for a small number of trial sites were now nationwide
- 8 The trial sites had much stronger controls than the IF policy settings. EIF, for example, had local area coordinators, a review panel and a supported transition period to set clear expectations with clients about how flexibility is and is not intended to be used.
- 9 The then Director-General of Health, made it a condition of the decision to expand the scope of IF that controls to manage increased flexibility be put in place. This work was never implemented.

Expanded flexibility was not paired with effective controls

- 10 From 2019, the volume of clients accessing flexible funding increased by an average of 13 percent per year. As highlighted by the Independent Review, flexible funding is one of two areas of the largest cost growth in DSS.
- 11 Flexibility has helped in some cases when disabled people had needs that were not being met through DSS' non-flexible supports. In particular, autistic people have made use of IF to purchase equipment that was not available through either DSS services or supports.
- 12 But in the absence of appropriate controls on the way flexible funding is used, we understand that some disabled people and their families have used flexible funding to purchase supports that should be provided through other agencies and mainstream services. Some recipients of flexible funding may also use IF for services that might be seen as private costs, rather than disability-related services and products.
- 13 The rapid growth in clients accessing IF, the lack of structure around the service and support for NASCs to implement effective controls, has meant that it has been difficult to understand what is causing the growth in total IF costs, or to manage or contain that growth.

Flexible funding was restricted in March 2024

- 14 In response to the rapid growth in IF and fiscal pressure on DSS, the Ministry of Disabled People, introduced purchasing rules (a mechanisms used to shape and control spending under EIF) to clarify what disabled people can and cannot be spent IF on. These rules stopped the use of IF for:
 - overseas travel, accommodation and other costs generally understood to be sensitive expenditure in most contexts,
 - self-care services such as massages, pedicures and other appearance or therapeutic care that is not for the purpose of improving the functional adaptation of the disabled person,
 - the cost of activities or items that, while they might be beneficial to family carers, do not obviously address the care responsibilities of the disabled family member,

- the purchase of items such as consumer electronics, sporting or recreation goods that may reduce the need for a family carer to take a break but may also be hard to distinguish from privately purchased items,
- items that are available through other funding streams, such as Equipment and Modification Services, and behaviour support,
- the responsibilities of another agency, such as transport, equipment, health funded therapy, and day services.

15 All spending through flexible policy lines now has to:

- be in line with the purpose of a service set out in its service specification,
- be related to a person's disability,
- be reasonable and of good value, and
- not occur when subject to an exclusion, including funding things other agencies are responsible for.

16 This guidance was accompanied by a table with a list of 'inclusions' and 'exclusions' by flexible product to help inform and shape spending. Key exclusions include:

- any items other than tablets, headphones, weighted blankets, and sensory items,
- services for carers which are only of indirect benefit to a disabled person,
- travel and associated costs,
- gifts, koha, and other recognition payments.

17 While these changes tightened up the use of IF, they did not return it to the pre-Covid19 settings. At the same time, the changes also restricted non-IF flexible funding lines to a greater degree than was the case prior to Covid-19.

18 The changes did not reduce any DSS client's allocations for IF, rather they restricted what could be purchased using IF. Many clients do not spend their full allocation in any year, and it is possible that the restrictions did not reduce spending at all for many IF users.

The 2024 changes restricted support for carers, including respite

19 Respite supports provide short-term relief so carers can take a break to sustain or prolong the ability for a disabled person to remain in the community, rather than residential care. Traditionally this was provided through facilities where a disabled person could stay while a carer took a break.

20 IF Respite was introduced in 2014 to allow carers choose between a space in a respite facility or a person to provide in-home respite. During Covid19, IF Respite was expanded so that carers could purchase a broader range of items to meet their need to take a break, including equipment or in-kind payments to recognise those who support the disabled person.

21 The restriction on the use of funding for travel and accommodation has probably reduced access to respite care for some families. Facility-based respite is not available

in all regions. It had been common practice for a carer to stay in a motel for a night while someone else cared for a disabled person overnight. With the ban on travel and accommodation, respite funding can no longer be used in this way.

Next steps

- 22 We will pick this issue up in the work we are doing to respond to recommendation six of the Independent Review – establish criteria for access to flexible funding and review and the flexible funding guidelines to improve clarity and consistency.

RELEASED UNDER THE
OFFICIAL INFORMATION ACT

Briefing

Date: 18 April 2024

For: Hon Penny Simmonds, Minister for Disability Issues

File reference: REP/WHK/24/4/042

Security level: In confidence

Clarification to Flexible Funding Purchasing Rules and guidance

Purpose

This paper informs you that we intend to provide further guidance to assist with the implementation of the revised purchasing rules for flexible funding. We do not consider that these clarifications meet the criteria for requiring Cabinet approval. We are concerned that any further delay in us being able to provide such guidance may result in decisions being made that aren't in the best interests of the disabled person.

Summary

On 18 March 2024 Whaikaha announced changes to some aspects of the purchasing rules for the use of flexible funding (REP/WHK/24/2/018, Changes to Equipment and Modification Services and Flexible Funding to Manage Whaikaha Expenditure, 22 February 2024).

We have received numerous questions on the impact of these changes from the community, National Assessment and Co-ordination Services (NASCs) and Host Agencies, seeking clarification to ensure the Guidelines are implemented as intended. Ministers have also received a lot of questions about the changes and have indicated in their answers to those questions that some flexibility to meet the needs of disabled people is reasonable. We therefore intend to issue some clarifications to the guidance to confirm what is intended by the purchasing rules.

Issuing these clarifications as soon as possible is important to enable management of information requests and to provide clarification to disabled people and their families.

On Monday 25 March 2024, Cabinet directed Whaikaha to submit to Cabinet proposals for any future changes to disability support services that are *significant or that will materially impact the services people receive, prior to any changes taking place*.

The clarifications to purchasing rules and related guidance proposed in this paper do not constitute significant changes to disability support services and will not materially

impact the services people receive [CAB-24-MIN-0102 refers]. The estimated cost of these changes is small, between \$1m and \$4m per annum and can be met from Whaikaha baselines.

We propose to announce these clarifications following your sign-off of this report. We have separately provided plans relating to communicating these clarifications to your office.

Recommendations

It is recommended that you:

- 1) **Note** that we will make the following clarifications to the flexible funding purchasing guidelines:
 - i) Ride and driver services can be used to support a disabled person to access services or engage with the community, where this is a reasonable and cost-effective option.
 - ii) The following items can be purchased for a disabled person to assist self-management, on a one-off basis within a flexible funding allocation period:
 - a. Electronic tablet devices
 - b. Noise cancelling headphones
 - c. Sensory toys, fidget spinners etc
 - d. Weighted blankets
 - iii) Household support arrangements in place through Choice in Community Living or a personal budget can continue, where these arrangements are an alternative to residential care that enables people to live in the community.
 - iv) Existing support arrangements can continue where:
 - a. the disabled person has committed to employment, a course of study, therapy, or a timebound programme; and
 - b. they have relied on the availability of flexibility under the previous Purchase Rules to support them to participate in those commitments; and
 - c. that commitment was made before 18 March 2024.

Noted

- 2) **Note** that we estimate the impact of these clarifications will be between \$1M and \$4M per annum, or between \$250,000 and \$1M for the remaining quarter of

the financial year. Whaikaha can meet these additional costs from our existing appropriation.

Noted

3) Note that we will inform staff, providers and disability community groups of the clarifications above once you have signed this report.

Noted

Hon Penny Simmonds
Minister for Disability Issues
Date



Paula Tesoriero MNZM
Chief Executive
16 April 2024

Actions for private secretaries:

Clarification to Purchasing Rules and Related Guidance

Background

1. As a part of making changes to equipment and modification services and flexible funding purchasing rules, Whaikaha sought to strengthen the prioritisation of its disability support expenditure on the essential needs of disabled people and tāngata whaikaha Māori. Following the changes, we have received a significant amount of feedback about situations in which the flexible funding purchasing rules now prevent the purchasing of essential items that cannot be accessed without flexible funding being available.
2. Ministers have also received a lot of questions about the changes and have indicated in their answers to those questions that some flexibility to meet the needs of disabled people is reasonable.
3. As a result of this feedback on the changes, we have identified situations where clarifications to the flexible funding purchasing rules would enable people to purchase items that would directly support important needs arising from their impairment. This paper therefore sets out clarifications to purchasing rules to enable purchasing of those items that are consistent with the broad intent of the changes.
4. We have been working with your office following the March 18 changes to the Guidelines on whether the clarifications in this paper meet the threshold for Cabinet approval. Further assessment of the proposed clarifications has strengthened our advice that these are outside the scope of matters covered by CAB-24-MIN-0102.

Clarifying purchasing rules

5. We propose to make it clear that:
 - 5.1 Ride and driver services can be used where it makes sense for the disabled person to do so. Sometimes ride and driver services, like Driving Miss Daisy, are the only practical option where no other transport is available.
 - 5.2 Where a person has household support arrangements through Choice in Community Living or a personal budget, and these arrangements are an alternative to residential care that enables people to live in the community, those arrangements can continue. This ensures that we aren't asking people to change their supported living arrangements, such as to move house, due to the changes.
6. A key area needing clarification is the reference in the new rules to the inclusion of "expenses that are a necessary part of supporting the disabled person while the full-time carer takes a break". While the purchase of general consumer

"items" is excluded, we plan to make it clear that the following items can be purchased for a disabled person to assist self-management, on a one-off basis within a flexible funding allocation period:

- 6.1 Electronic tablet devices
- 6.2 Noise cancelling headphones
- 6.3 Weighted blankets.

7. These items are not general consumer items when purchased to meet the needs of a disabled person. For example, sensory toys are purchased to meet a specific need, rather than as a general toy. Clarifying this will therefore better achieve the intent of the rules issued on 18 March 2024.

8. Sensory toys help children with autism to relax, focus and calm. There is evidence on the effectiveness of access to sensory toys for autistic children. Research on the perspectives of parents shows that parents of autistic children perceived fidget toys and fidget spinners to be more beneficial overall than parents of neurotypical children, especially in relation to reducing anxiety.¹

Transition arrangements

9. We are proposing that existing support arrangements can continue where:

- 9.1 the disabled person has committed to employment, a course of study, therapy, or a timebound programme; and
- 9.2 they have relied on the availability of flexibility under the previous Purchase Rules to support them to participate in those commitments; and
- 9.3 that commitment has been made before 18 March 2024.

10. These kinds of transition arrangements are good administrative practice, because we would otherwise be asking people to drop out of employment, programmes of study, courses of counselling or other timebound commitments they have entered into. For example, some disabled people have told us that they rely on flexible funding to enable a support worker to travel with them outside their region for work commitments, and we propose that these arrangements should continue. Providing this support worker flexibility to support employment of a disabled person is consistent with the purpose of disability supports.

11. Making these clarifications quickly will reduce concern and confusion and avoid disabled people needing to exit existing commitments made prior to 18 March 2024. For example, some of the queries we are receiving are people asking if they need to stop behaviour therapy programs, because NASCs and EGL Sites

¹ Roche, M.A., Back, E. & Van Herwegen, J. Parental perspectives on the use of fidget toys and sensory-seeking profiles in autistic and neurotypical children. *Curr Psychol* (2023). <https://doi.org/10.1007/s12144-023-05483-3>

are unable to clarify. We are concerned that, in the absence of guidance, decisions are being made that aren't in the best interests of the disabled person.

Estimated financial impact

12. Estimating the costs of these clarifications is difficult due to us having limited data about expenditure patterns at a granular level. We have therefore identified a range for potential costs.
13. For the majority of spending items considered in this report, Whaikaha has data from a flexible funding host organisation that covers 61% of flexible funding users (apart from carer support). From that dataset we are able to construct a match of the items listed in this report to a Host organisation spending categorisation, and extrapolate that to an annual spend estimate for those items of between \$1M and \$4M. For the remaining quarter of this financial year that equates to an expected cost of between \$250,000 and \$1M.
14. Data on carer support is captured by another system, but we estimate it to fit within the bounds of the range above. The impact of the clarifications on the financial position of Whaikaha of between \$1m and \$4m per annum is not material within the overall flexible funding budget of around \$525m.
15. In addition, these costs offset savings that would otherwise be achieved through the tightened purchasing rules. In other words, they allow a small range of additional expenditure that will reduce the total savings that would otherwise occur from the tightened flexible funding rules. As a result, Whaikaha does not require additional funding to implement these clarifications.

Next steps

16. While we do not consider that the clarifications to purchasing guidance need to be approved by Cabinet, we recommend that you note our intention to provide this guidance material.
17. Following sign off from you, we will brief staff, providers, and disability community groups to inform them of these clarifications ahead of the public announcements being made.

End

Author: Ben O'Meara, DCE Policy, Strategy and Partnerships



Report

Date: 31 October 2024
To: Hon Louise Upston, Minister for Disability Issues
File reference: REP/24/10/992
Security level: In confidence

Independent Review response: Draft Cabinet paper and discussion document

Purpose

This report seeks your direction on immediate actions in response to the Independent Review into Disability Support Services (DSS). These actions aim to stabilise, restore fiscal controls, and reduce complexity in the funding of support for disabled people and their families, as set out in:

- an initial draft Cabinet paper, which seeks decisions on the range of immediate actions
- a draft outline of a discussion document to support public consultation in early 2025
- a proposed pathway out of the freeze on DSS funding for residential care services
- options to make changes to respite care.

Executive summary

Your feedback and decisions are sought on our approach to restoring government control over funding for DSS, so that the system is sustainable and delivers fair, consistent and transparent services for disabled people and their families into the future.

Following recent discussions with you, a package of advice has been prepared to support your report back to Cabinet in December 2024. This advice describes next steps for action in the short-term in response to recommendations 2 (review of residential care pricing and contracting), 5 (update assessment and allocation settings), and 6 (improve consistency and clarity in flexible funding) from the Independent Review into DSS. These actions focus on stabilising DSS and establishing a forward momentum of reform.

Cabinet agreement is proposed to release a discussion document for use in public consultation on policy options in early 2025. Close and careful work is needed with the disability community and sector to ensure that the impact of changes are well tested and understood. This consultation will build on the initial engagement now underway with more specific detail on recommendations 5 and 6.

A pathway to remove the freeze on funding for residential care (recommendation 2) is proposed that prioritises restoring fiscal control and forecasting through the design of a single pricing model. We have described in some detail our initial understanding of the underlying problems with residential care, which requires fundamental change. However, we also have considered the need for immediate action. Therefore, our proposal establishes an inclusive price for residential care that applies to providers and reduces complexity in current practice. This action will establish the foundation for any future changes to residential care. Your feedback on trade-offs is sought and will set the parameters for the design of the single pricing model. This will inform the Cabinet decisions sought in December 2024.

Options are provided for your decision on changes to the availability of respite care for families. Your feedback is sought on whether to commission further advice, hold off until a review of flexible funding is completed in 2025, or advance limited changes this year.

Given the short timeframe to undertake the policy work and reflect current consultation, we ask that you provide direction to officials at our meeting on 6 November so that progress can be maintained. We will continue to develop both the Cabinet paper and the discussion document, in light of feedback from the consultation process underway. We will also incorporate feedback from consultation with Ministers and officials. Final advice will be provided to you in late November 2024.

Recommended actions

It is recommended that you:

- 1 **provide feedback to officials on the draft Cabinet paper and draft outline discussion document by 6 November 2024**

AGREE / DISAGREE

Pathway to remove the funding freeze for residential care

2 **provide feedback** on the initial policy trade-offs identified for Cabinet decisions in December 2024 that could form the parameters for the design of a single pricing model for residential care (subject to further policy work and consultation feedback),

AGREE / DISAGREE

Options to make changes to respite care

3 **note** that there has been significant community feedback highlighting a lack of access to respite as a result of the March 2024 decisions.

4 **note** that the level of expenditure and volume of people in Individualised Funding: Respite Care has returned to around the same level as before the March 2024 decisions.

5 **agree** the next step on work to address respite care and maintain fiscal controls:

5.1 undertake further work to understand the data and, in light of this, the options to open up travel and accommodation while managing fiscal control to support decision making in early 2025 (official's recommended option)

5.2 no changes now and instead respond following the full review of recommendation six (Cabinet decision in May 2025)

5.3 include in the December 2024 Cabinet paper a proposal to change access to respite care by making:

5.3.1 changes to the purchase guidelines to clarify what constitutes 'reasonable' for:

5.3.1A travel and accommodation-related expenses in the respite context and remove the exclusion [Officials' recommendation]

AGREE / DISAGREE

AND/OR

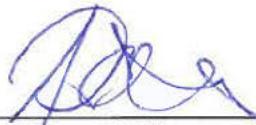
5.3.1B gratuity expenses in the context of carer support and flexible respite and remove the exclusion

AGREE / DISAGREE

6 **note** that if you agree to recommendation 5.3 above, MSD will progress work with urgency to ensure appropriate budget management and communication approaches are in place to support a December 2024 announcement.

Budget 2025 and approach to system funding

7 **note** we continue to work with the Treasury on establishing a credible funding path, including the conditions for maintaining fiscal control.



Alastair Hill
Programme Director, DSS Taskforce

31-10-24

Date

Hon Louise Upston
Minister for Disability Issues

Date

Background

1. You directed officials to prepare a Cabinet paper for consideration in early December 2024 [REP/24/9/909 refers] to seek approval for public consultation on options to implement the Independent Review's:
 - 1.1. recommendation five (updating the assessment and allocation settings for individuals based on level of need), and
 - 1.2. recommendation six (establish criteria for access to flexible funding and review the flexible funding guidelines to improve clarity and consistency).
2. In addition, you have asked for urgent advice on:
 - 2.1. progress with recommendation two (a detailed and urgent review of contract and pricing models for residential facility-based care) and the pathway to remove the funding freeze for residential care
 - 2.2. changes to the availability of respite care following March 2024 restrictions on use of flexible funding.

A draft Cabinet paper and draft outline discussion paper for consultation are attached

3. Your feedback is sought on an initial draft Cabinet paper and a draft discussion paper that will be used in public consultation in early 2025.
4. The draft outline discussion document sets out the suggested scope and content for the consultation. We seek your early direction on any changes in focus that you would like to see. We will continue to draft the discussion document, building in the feedback we are gathering from the issues consultation currently underway with the disability community and sector.
5. The draft Cabinet paper has placeholder text in areas where the analysis is still underway. We have set out further advice in this report to you on:
 - 5.1. Rapid review of residential pricing
 - 5.2. Possible changes to respite care
 - 5.3. Approach to system funding and Budget 2025.
6. There is a very tight timeframe for the paper to be submitted for consideration by the Cabinet Social Outcomes Committee on 4 December 2024. We ask for your feedback by 6 November 2024, so that we can provide a revised paper to you for approval to engage in Ministerial consultation.
7. We have formed a Policy Deputy Chief Executives Group to provide advice and across government coordination on implementing the Independent Review's recommendations. This group will be used for departmental consultation on the draft Cabinet paper and draft options paper.

8. We are working to the following timeframe:

Timeframe	Deliverable
Week beginning 18 Nov 24	Ministerial consultation on Cabinet paper
28 Nov 24	Lodgement of Cabinet paper
4 Dec 24	SOU consider Cabinet paper
9 Dec 24	Cabinet decisions
Dec 24	Communicate proposed residential pricing changes to providers
Dec 24 – Feb 25	Prepare accessible materials for consultation with disability community and sector
Feb 25	Rec 2 Cabinet paper and final decisions
Late Feb 25	Consultation begins on recs 5 and 6 and scope of longer-term policy work
May 25	Cabinet paper and decisions on recs 5 and 6 and scope and approach of longer-term work
PLACEHOLDER BUDGET May 25	

Rapid review of residential pricing

9. On 16 October 2024, you directed that the DSS Taskforce accelerate progress on the Independent Review's recommendation two, so that Cabinet can make decisions on a pathway to remove the residential care funding freeze in December 2024. Our plan provides for final decisions from Cabinet in February 2025 [REP/24/10/972 refers].

The Independent Review called for a review of pricing and contracting for residential care to understand the increasing costs

10. The Government's decision to freeze funding for residential care at 2023/24 levels was recommended by the Independent Review because it was concerned that the cost for residential care has been increasing greater than inflation over recent years while the number of people accessing residential care has been more-or-less static [CAB-24-MIN-0301 refers].

11. For 2023/24, the total expenditure on residential care funded by DSS was around \$1.1B across 267 unique providers. This is split out along the following service lines (note: there are some providers engaged in multiple service types):

Table 1: Expenditure by four residential care service lines and number of providers for 2023/24

Service type	Number of providers	Total expenditure (GST exclusive) in 2023/24
Community Residential Care in Group Homes	106	\$895,010,786
High and Complex and Compulsory Care	9	\$76,875,792
Community Residential Care in an Aged Residential Care Setting	176	\$75,976,018
Community Residential Care for Children and Young People (which are individualised packages commissioned by Oranga Tamariki and funded by DSS)	1	\$8,888,368
Total expenditure:		\$1,056,750,964

12. Figure 1 below shows the increasing expenditure across residential care is contributed to predominantly by Group Homes and then to a much lesser extent aged care. The residential care expenditure for children and young people is not included due to the relatively low amount.

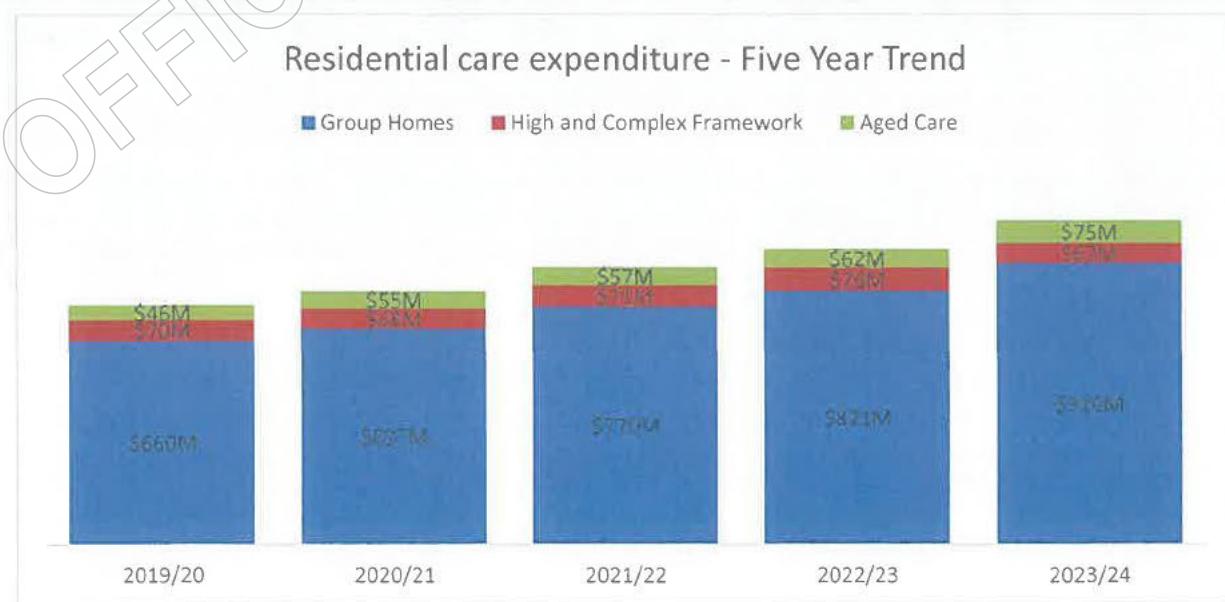


Figure 1: Residential care expenditure showing five year trend

13. Figure 2 below shows that while the overall number of people accessing residential care has remained more-or-less static in recent years, there has been a growth in disabled people in aged care and a reduction in disabled people in group homes. Not shown in the graph below, the number of children and young people in residential care from Oranga Tamariki has also been increasing from 89 in 2020/21 to 117 in 2023/24.

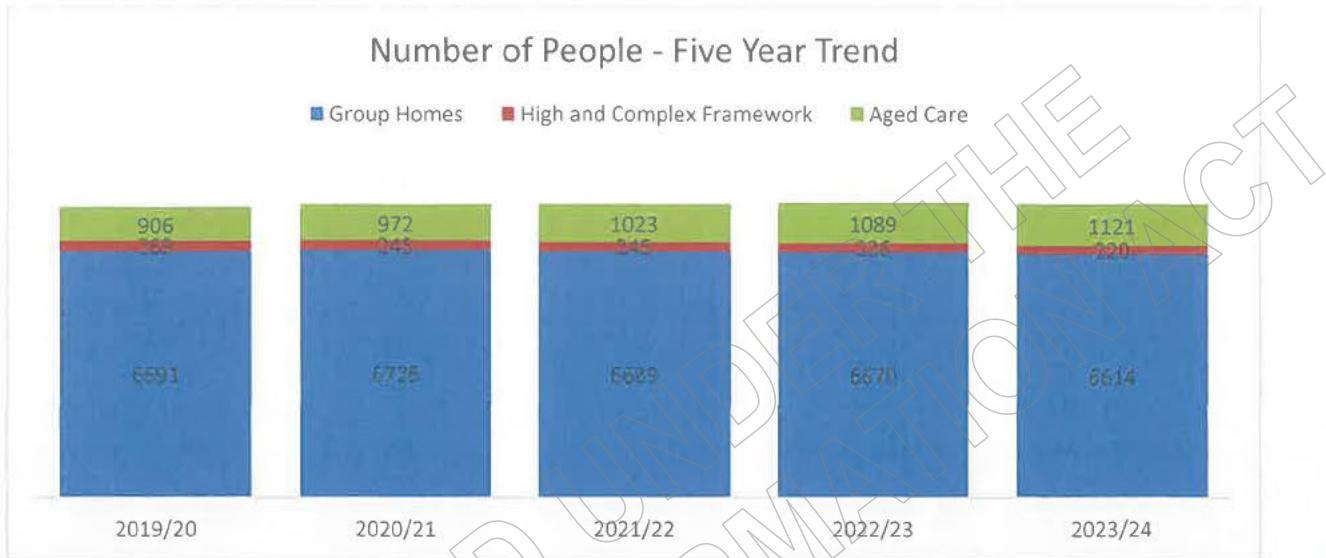


Figure 2: Number of people accessing residential care showing five-year trend

There are several drivers contributing to the increasing cost

Incremental growth of funding arrangements, with decreasing fiscal controls

14. There have been several court decisions brought by providers and unions that has required extra funding for:

- 14.1. Pay equity advance interim payments, which follow the agreement to increase the funding for support work wages.
- 14.2. Sleepover top-ups, where staff are required to be present in a facility over night
- 14.3. Day activity contributions, for people over 65 who do not attend an external day activity service and instead remain at the residential care facility during the day.

15. These decisions were not implemented by variation to existing core funding contractual arrangements. Instead, additional funding streams were created that operate separately and differently to each other. Funding of DSS residential care has become very complicated, lacks transparency and consistency, involves high levels of transactions, and different treatment for different providers. Critically, there is no longer a clear picture of the price of residential care.

16. Alongside these funding changes, there have been several pricing tools developed and used across DSS. There is no mandated consistent practice which has contributed to inconsistencies across providers and around the country.
17. The contracted rates have not been updated in recent years and no longer reflect a current understanding of the cost of providing support and accommodation. Providers have responded to this by routinely using the exceptional provision in their contracts with DSS to request NASC consideration of an individual rate.
18. The wide ranging use of individual rates make it difficult to accurately forecast expenditure for residential care. These rates reflect a negotiation at a point in time and are not consistently or transparently linked to level of need or support required.
19. As an example, Table 2 below shows that in June 2024, there were 6,226 people in Group Home services under 2,849 different rates.

Table 2: Funding arrangements for people in Group Home residential care in June 2024

Type of funding rate	Number of rates	Number of people covered in rate type	Percent of total people covered
Contract banded rates	112	3,452	55%
Individualised rates	2,737	2,812	45%
Total	2,849	6,226	100%

Possible limiting factors on supply

20. There may be other factors influencing drivers of cost, however these need further investigation to better understand the evidence. Anecdotal information suggests that there are issues affecting supply of residential care, including:
 - 20.1. limited bed capacity, where priority is given to people with the highest support needs and therefore higher cost
 - 20.2. constraint on provider development, due to uncertainty on the future direction of residential care compared with community-based individual care
 - 20.3. lack of incentives for new providers to enter the market, or innovation from existing providers
 - 20.4. possible challenges with retaining skilled workforce and levels of pay.

It is not clear why the demand for residential care has remained static

21. We do not yet fully understand what is happening to the demand for residential care. It could be assumed that as the population of disabled people increases that there would be a resulting increase in demand for DSS, including for residential care. As noted above, overall demand is relatively static.

22. More work is required to understand the nature of demand, however, anecdotal information suggests:

- 22.1. policies, such as flexible funding, that support access to a wider range of support are keeping people living in the community longer
- 22.2. demographic change as the cohort of people deinstitutionalised in the 1980s and 1990s moves through DSS, and the following cohorts have less need for residential care
- 22.3. changed expectations of disabled people and their families, as well as disabled people having better experiences in growing up with support and mainstream integration
- 22.4. potential constraints on provider supply (as noted above)
- 22.5. an intentional focus in some parts of DSS on community-based support packages rather than residential care (which at the high end of support could cost similar or more than residential care).

We are developing a pathway to remove the funding freeze on residential care

23. We consider that priority should be given to restoring fiscal controls and moving away from the current practice of accepting the price asked by providers. A thorough tidy up and simplification of complex and inefficient financial administration and contracting is necessary to stabilise the system.
24. The starting point is to design a single, inclusive pricing model that collapses the complexity and is more directly tied to the level of support needed. This would:
 - 24.1. remove varying bespoke arrangements for providers and install a common treatment for all funding.
 - 24.2. remove the use of individual rates except in exceptional circumstances.
 - 24.3. allow the system to accommodate very high cost supports with a high bar for individual rates for exceptional situations.
 - 24.4. maintain credibility in the pricing tool through regular review.
25. These changes will create a clear price for residential care and better inform budget forecasting and monitoring when the funding freeze is removed. With this in place, there will be opportunity for other changes to residential care to be explored.
26. Our approach will focus on modelling the Group Homes service line, because it has the largest expenditure and number of people receiving support, and then test a draft model to the other service lines.

We seek your feedback on our provisional advice for Cabinet decisions

27. Our initial thinking has identified three main trade-offs within which the single pricing model would be developed. In advance of further detailed work to come (which will include financial modelling which may change our final advice to you), we are propose that the Cabinet paper seek direction on:

27.1. **Scope of change and timing of implementation:** ensuring enough simplification can be put into place to make a difference, but can be implemented in the short-term (which means operating within the current IT and system setup, and identifying dependencies):

27.1.1. ***limited:*** bundle up the various funding rates into an inclusive price, while retaining the current fee-for-service approach. This will remove the need to update IT systems or other administrative processes and allow implementation for 1 July 2025, with further change in residential care pricing to be considered in future work; or

27.1.2. ***greater:*** explore how to have fewer transactions through alternate funding arrangements for providers (for example, bulk funding providers based on level of funding in the year from 1 July 2024). This would involve system changes and may not be completed by 1 July 2025, and we would need to test that the changes do not end up replicating the complexity in the current approach.

27.2. **fiscal impact for Budget 2025:** whether the pricing model is designed to limit increases in funding (except if invited for any cost pressure price uplift), though a more consistent approach. This may result in winners and losers across providers and may affect supply:

27.2.1. ***keep within current funding envelope:*** there may be a negative impact on provider viability and some winners/losers from the proposed standardised funding approach; or

27.2.2. ***allow for increases in the funding envelope:*** the single pricing model may result in the need for increased funding to achieve consistency across providers as well as responding to the drivers of costs.

27.3. **impact on providers:** whether to roll out the single pricing model to apply all at once, or to apply progressively:

27.3.1. ***progressive roll-out:*** to reduce pressure on providers, implementation from 1 July 2025 could apply only to new people entering residential care or where changes are sought to existing residential care support. Existing recipients could be grand-

parented until their supports are next annually reviewed. This approach will require maintaining the current and new pricing mechanisms, with greater complexity and transactions. We would also need to consider the different impacts on providers as well as MSD DSS operations and NASCs if two different approaches are in operation simultaneously; or

27.3.2. **everyone all at once:** keep the momentum of change by transitioning all residential care packages to the new pricing model. This may involve more pressure on providers but will result in increased consistency and transparency sooner, and remove the risk and pressure of maintaining two different approaches.

Next steps on residential care pricing and contracting

28. We have engaged EY to extend our access to specialist financial and policy capability for detailed work on the rapid review. The knowledge and experience that EY has developed through its work developing a forecasting model for DSS and in High and Complex Care will be useful in this work.
29. Next steps will focus on the following:

Milestone	Activity
Mid November 2024	Targeted workshops with a limited range of providers. These will be led by EY, with our participation, and will focus on allowing providers to confirm our problem definition and feedback on issues from their perspective. The timing of the workshops will allow input to the December Cabinet paper advice.
Late November 2024	Advice for the December Cabinet paper, including an indication of the fiscal impact of different pricing model options, so that it can inform Budget 2025 preparations, and choices on parameters for the pricing model.
4 December 2024	Cabinet Social Outcomes Committee, makes decisions on trade-offs and parameters for pricing model design and implementation.
16 December 2024	Cabinet
January 2025 to early February 2025	Design pricing model and test impact on providers. Engage with providers and NASCs.

Late February 2025	Cabinet decisions on final approach to pricing model for residential care and plan for implementation.
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Changes to the availability of respite care

Flexible funding was one of the largest cost drivers

30. Flexible funding was introduced in the 1990s so that disabled people and carers could commission their own support workers. In specific trial sites, its scope was expanded to allow disabled people and their families greater choice in the kinds of supports that they could directly purchase.
31. To ensure that disabled people could access the support they needed while COVID-19 restrictions were in place, flexible funding was expanded to cover all of New Zealand. The Ministry of Health made these changes permanent in 2022. The controls that were put in place to manage flexibility in the trial sites were never implemented for the rest of New Zealand.
32. As highlighted by the Independent Review, flexible funding is now one of two areas of the largest cost growth in DSS. Poor data means it is very difficult for us to understand exactly how flexible funding is used.

Restrictions were placed on use of flexible funding to manage costs

33. In response to the rapid cost growth, the Ministry of Disabled People announced on 18 March 2024 changes that restricted how flexible funding could be used. Key exclusions introduced to carer support and respite funding included:
 - 33.1. travel related costs including accommodation, and food
 - 33.2. gratuity payments, koha or gifts to facilitate informal care
 - 33.3. significantly narrowing the kinds of items that funding could be used for
 - 33.4. limiting spending to 'necessary expenses' (not massages, pedicures etc).
34. The most common ways that carers used carer support and flexible respite prior to these changes were to:
 - 34.1. pay for accommodation away from home to take a break
 - 34.2. use funds to encourage informal care, often paired with gratuity or koha
 - 34.3. purchase services that provided a break (such as enrolling a disabled person in a class)
 - 34.4. purchase services which supported their caring role (such as massages for muscle pain from heavy lifting)
 - 34.5. purchase equipment or items which mitigate household challenges and the need to take a break in the first place.

35. Each of the above practices were either excluded or restricted by the March 2024 changes.

Feedback has highlighted that carers now find it harder to access support to take a break

36. Community feedback on the March 2024 changes included submissions focused on the impact on carers and their households. Key themes were restrictions around travel, accommodation and gratuity, the lack of contracted services in their area and the negative well-being impacts of not having access to respite options for disabled people, carers, and other members of their families.

37. The exclusion of travel and accommodation could mean that some families are without meaningful respite as:

- 37.1. facility based respite is not available in their region
- 37.2. impairment related challenges (such as changes in routine for autistic people) means facility based respite is not a good option
- 37.3. facilities can refuse to take disabled people with high-needs.

38. The exclusion of gratuity payments may mean people have access to less respite as they are now restricted to more expensive formal care options.

But expenditure is now the same as before March 2024 changes

39. Data on both expenditure and volume of people, however, shows that the IF Respite Care has largely returned to the levels it was before the March 2024 decisions.

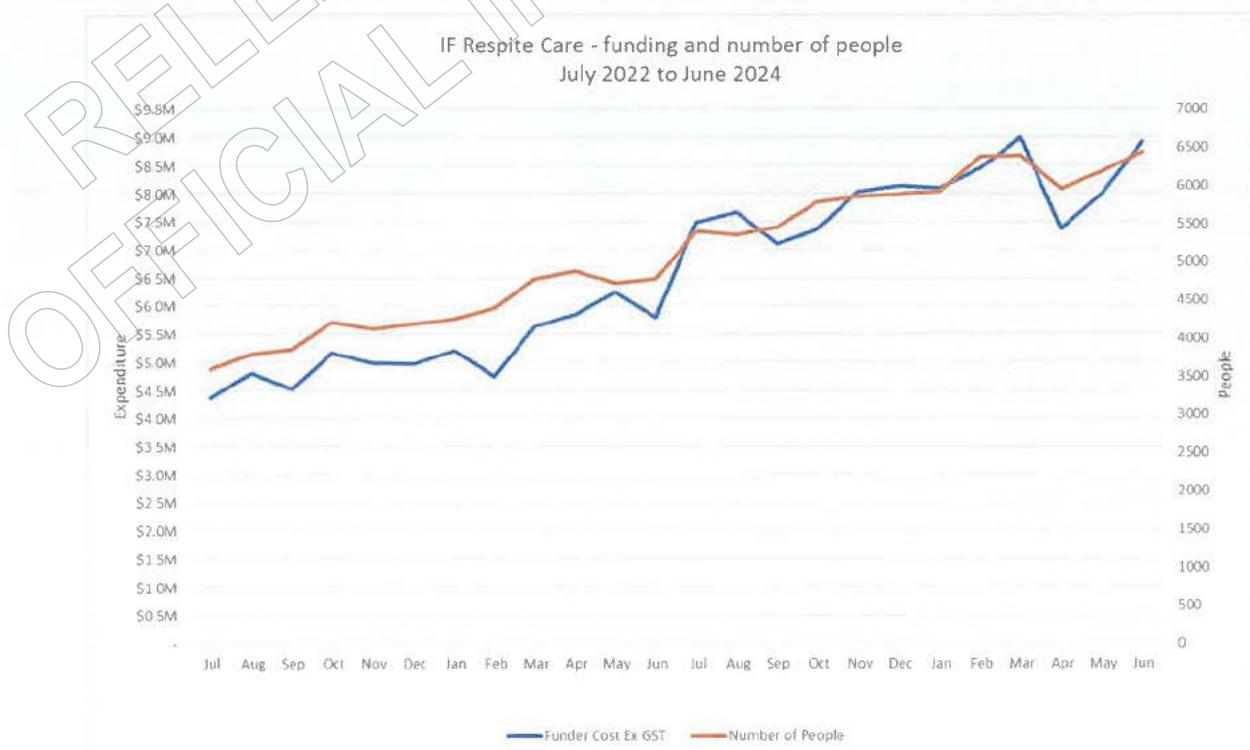


Figure 3: Individualised Funding for Respite Care by expenditure and number of people for the period July 2022 to June 2024

40. We do not know what is driving this, or how to reconcile this return to pre-March support levels with the ongoing feedback about a lack of support for carers. Plausible reasons could include families:

- 40.1. accessing more expensive formal care, as gratuity and koha that they used to support informal care is no longer available
- 40.2. spending their allocations on things that are allowed (i.e. tablet devices, noise cancelling headphones)
- 40.3. finding ways around the rules.

41. It may also be that the number of people affected by the March changes is small compared to the total number of people accessing IF respite.

Changing the rules could improve access to respite care

42. It is unclear from the data available that there has been a real reduction in the support available to carers and families. It is clear, however, that the rules removed the ability of families to do two things that they valued:
 - 42.1. excluding travel and accommodation means that carers are no longer supported for these costs if they choose to access respite care through having a substitute carer come to the family home while they take a break.
 - 42.2. gratuity and koha that enabled them to recognise friends and family providing them support.
43. Changes to the purchasing guidelines to address these issues could include:
 - 43.1. travel and accommodation: clarify what constitutes 'reasonable' travel and accommodation-related expenses in the respite context and remove the exclusion.
 - 43.2. gratuity: clarify what constitutes 'reasonable' gratuity expenses in the context of carer support and flexible respite and remove the exclusion.
44. We do not recommend opening up gratuity payments at this time. Gratuity payments point to a broader policy issue of the balance between formal and informal support, the role of families and volunteers. Gratuity can be hard to define and administer and has potential to create significant loopholes in the rules – e.g. Prezzy cards make it impossible to exclude the purchase of items or expenses that do not align with the intent of the guidelines.
45. Balancing the available evidence, we do think there would be benefit in making changes to allow for travel and accommodation-related expenses in the respite context. It is probable that some families are currently unable to access meaningful respite and we have heard stories that this change in particular has disrupted successful respite care arrangements.

But there are risks in opening up the Individual Funding rules

46. The risks that we would need to manage include:
 - 46.1. poor data
 - 46.2. possibility of increased costs
 - 46.3. lack of community consultation.
47. The data issues we face are a function of the devolved nature of the system. Access to flexible funding is through NASC or EGL sites and the purchasing rules and guidelines are implemented and monitored through Hosts or EGL sites. As set out above, this means we have limited insight into the exact nature of the issue in respite care.
48. The lack of quality and timely data means that we cannot be sure that any opening up of the IF Respite rules would be managed within the current Budget. The operational policy in this area is also poorly defined making it difficult for us to monitor compliance. We would have to work closely with NASCs and EGL sites to ensure that they understood this rule change was about substituting existing IF Respite Care funding, not an increase in the Budget. Given our data issues, we would have very limited ability to respond quickly to any uptick in funding.
49. While we know that an opening up of IF Respite to cover travel and accommodation would be welcomed, there is a risk in making this change without consultation. It is possible that we could be criticised for picking an issue without testing the possible problem with the disability community and sector.

Next steps on respite care

50. Given the risks and the clear priority on building and maintaining fiscal control, we do not recommend making immediate changes to IF: Respite Care at this stage. The choices for next steps include:
 - 50.1. further work with Hosts and EGL sites to understand the data and issues better. We would then report back to you with options to support decision making in early 2025
 - 50.2. respond once we have done the full review of recommendation six (Cabinet decision in May 2025)
 - 50.3. accept the risks set out above, and use the December Cabinet paper to make changes to the purchase guidelines to clarify what constitutes 'reasonable':
 - 50.3.1. travel and accommodation-related expenses in the respite context and remove the exclusion

and/or

50.3.2. gratuity expenses in the context of carer support and flexible respite and remove the exclusion.

Funding and Budget '25

51. There is placeholder text in the Cabinet paper indicating that we are working with the Treasury to reset the overall funding rules for DSS. This has three components, being the development of
 - 51.1. simplified, consistent and credible pricing tools across the system (e.g. residential pricing)
 - 51.2. regular pricing reviews that ensure the pricing tools retain credibility and underpin our forecasting (considering key factors such as cost drivers for providers, demand from disabled people and productivity and affordability objectives for the government)
 - 51.3. a credible funding path for DSS. The current fixed appropriation has not delivered fiscal control.
52. We will update the Cabinet paper as this work progresses, and any fiscal impacts from the residential price review become clear.

Next steps

53. Following your feedback we will revise the Cabinet paper and the discussion document.
54. We will continue to revise both, as our analytical work continues and as we get further input from the consultation process we are currently undertaking.