INDEPENDENT REVIEW OF DISABILITY SUPPORT SERVICES

Phase One Report

A Report to provide advice on the actions that should be taken immediately in the 2024/25 financial year to better manage the increasing cost pressures faced by Whaikaha – Ministry of Disabled People

28 June 2024

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Foreword

1. The Ministry of Disabled People – Whaikaha came into being as a Ministry on 1 July 2022. Prior to then, Disability Support Services had been administered by a directorate within the Ministry of Health. On the same date, the former District Health Boards were reconstituted into a new national health services delivery entity, Health New Zealand – Te Whatu Ora, and a smaller Ministry of Health, focussed on health policy. The much smaller disability entity was created as a departmental agency, hosted by the Ministry of Social Development.

2. The new Ministry is responsible for:

   2.1. Ensuring continuation of Disability Support Services

   2.2. Driving improved outcomes for disabled people across government, through an expanded mandate and new disability-related responsibilities and functions including a strategic policy function, and

   2.3. The national implementation of the Enabling Good Lives approach to disability matters.

3. The decision to establish an agency dedicated to serving the needs and interests of disabled New Zealanders was welcomed by the disability community, and expectations of improved services and levels of support, and new ways of doing things, were evident.

4. In practice, the combination and scale of the new responsibilities has proved very challenging for a small agency with accountability for $2.6 billion of taxpayer funding in the 2024/25 financial year. Numerous risks identified in the planning process for the Ministry have eventuated in practice, including in particular, ongoing budget over-runs.

5. Recent events have revealed that the Ministry was ill-prepared for its important role. Its establishment, in the late stages of the Covid-19 pandemic, was rushed, and challenges soon emerged in dealings with partner agencies that had been charged with providing shared services and other support. The timeframes for implementing the three phases of organisational set-up – establishment, consolidation and transformation – have proved over-ambitious and are not reflected in the current state of the Ministry's operations.

6. The Ministry, as it has been established, lacks many of the public sector disciplines and operational practices seen in other government agencies. Financial controls are poor. It is difficult to gain a clear understanding of how well disabled people are being supported through providers the Ministry has contracted. Monitoring of contracts and reporting of performance is inadequate, and risk identification and management, need to be strengthened. There are also different levels of service being provided across the country – this is similar to describing health services delivery as a 'post-code lottery'.

7. This report sets out recommendations for actions that can be taken in Phase One of the Review of Disability Support Services. They are only first steps, but we believe are essential, if progress towards stability, predictability, and consistency of support is to be achieved.

8. Much more remains to be done to lift the performance, not just of the Ministry, but also the numerous other mainstream government agencies that have a role in supporting those with disabilities. Bigger efforts and improved results for this community must be a priority. And the community voice must continue to be heard as current arrangements are reshaped to make them sustainable and effective.

Sir Maarten Wevers
Lead Reviewer

Leanne Spice
Advisor

Rev Murray Edridge
Advisor

Executive summary

9. In 2021, the Ministry of Disabled People – Whaikaha (the Ministry) was given a dual mandate by Cabinet to deliver Disability Support Services (DSS), including national implementation of the Enabling Good Lives approach (EGL), and a strategic policy function across government. The Ministry has inherited from the former Ministry of Health significant financial pressures, which are longstanding, and already anticipates costs greater than Budget 2024 funding for the coming financial year.

10. This Report provides our findings and recommendations from Phase One of the Independent Review into the Sustainability of Disability Support Services administered by the Ministry of Disabled People – Whaikaha (**the Review**).

11. Phase One of the Review was asked to address the question:

> *"what actions should be taken immediately in the 2024/25 financial year to better manage the increasing cost pressures"*

12. Phase Two of the Review is designed to address the future sustainability of DSS.

13. We make six findings related to management of increasing cost pressures:

(1)	Delivery of DSS is inconsistent
(2)	The DSS 2024/25 appropriation will be breached if spending is not controlled
(3)	There is inadequate budgetary control and commercial rigour
(4)	The two areas of largest cost growth are flexible funding provisions and residential facilities-based care
(5)	The new departmental agency is not set up in a manner that enables it to manage effectively the nature and scale of its appropriation
(6)	Current policy settings and service design do not allow the Ministry to administer and deliver DSS effectively

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14. We make seven recommendations:

(1)	Reinstate: • Indicative budgets for Needs Assessment and Service Coordination organisations (NASCs) • Fixed budgets for EGL demonstration sites and Equipment and Modification Services (EMS) providers • Monitoring and reporting requirements for NASCs, EMS providers, and EGL demonstration sites
(2)	Freeze current levels of funding for residential facility-based care for 2024/25 pending commissioning and completion of a detailed and urgent review of the contract and pricing models
(3)	Take no action on a price increase for providers in 2024/25
(4)	Establish an effective function within the Ministry to monitor the assessment and allocation performance of NASCs and EGL demonstration sites
(5)	Update the assessment and allocation settings for individuals based on level of need
(6)	Establish criteria for access to flexible funding and review the flexible funding guidelines to improve clarity and consistency
(7)	Strengthen: • The departmental agency arrangement with the Ministry of Social Development, and • The shared services agreements with the Ministry of Social Development, Ministry of Health and Health New Zealand

15. These recommendations represent essential first steps towards better management of the increasing cost pressures. The Ministry is clearly under great pressure, and the state of its expenditure controls, monitoring and reporting mechanisms, commissioning and contracting processes, shared service supports, and organisational alignment are the highest priorities for early attention.

16. In our concluding remarks, we suggest that Phase Two of the Review as originally conceived should not proceed at the current time. We fully recognise that this proposal lies outside our Terms of Reference, but assess that the current state of the Ministry, as we have found it, is such that pursuing the Phase Two work programme is not the highest priority currently.

17. We therefore propose that a taskforce with suitable experience should be brought into the Ministry at the earliest opportunity to work with the Chief Executive to improve and strengthen current operationalisation and stabilisation of DSS. We suggest that this taskforce should be in place for a period of 12 months.

Introduction

18. The Terms of Reference define the purpose of the Review as:

> *"An independent review will provide advice on the immediate and longer-term sustainability of DSS, including what actions should be taken to strengthen the provision and certainty of support for disabled people into the future, and ensure strong fiscal management is in place"*

19. The priority for our work as Reviewers has been to focus on the people that the Ministry has been established to serve – disabled people themselves.

20. In our view, the Ministry must always work to ensure that priority is given to:

    20.1. those members of the community who have the highest needs

    20.2. those who will benefit from effective early interventions and behavioural supports, and

    20.3. ensuring that the systems of support for disabled people are effective, transparent, reliable, coherent and well-managed.

21. We know that the lives of many people — not just those with impairments — are affected by disability, including whānau and friends, and the thousands of people who work in organisations supporting the delivery of disability support services. We recognise especially the critical role that natural supports from family and friends play, often for many years, in the life of a disabled person.

22. During Phase One of the Review, we were struck by how many times we were told that the disability support system is "*complex*", "*difficult to understand*", and "*hard to navigate*". Many of those we spoke to welcomed the Review, acknowledging that improvements are required.

23. The immediate circumstances that led to the Review being established are explained below. In short, there was a history of cost overruns for DSS, and a specific concern that the 2024/25 appropriation would be breached.

24. DSS budgets had previously been supplemented almost annually from within Vote: Health and therefore predate the establishment of Whaikaha in 2022 as a departmental agency within the Ministry of Social Development (MSD).

25. The cost of DSS to the taxpayer has grown substantially in recent years, from $1.2 billion in 2015/16 to $2.6 billion in 2024/25.[1] We have formed the view that the Ministry's systems for, and operation of, financial oversight and decision-making, audit and risk, procurement and provider management and accountability, and performance monitoring and evaluation, are weaker than we would expect in a government agency.

[1] This includes the departmental costs for the Ministry.

Timeline

26. The Department of Prime Minister and Cabinet (DPMC) undertook a stocktake in September 2023 that described a range of significant risks facing the Ministry, including financial risks, and people leadership and management challenges due to staffing capacity and capability gaps.[2]

27. On 7 December 2023, the Ministry advised the former Minister that it anticipated a $70 million deficit in the 2023/24 financial year, s9(2)(g)(i) Further advice from the Ministry led to amendments being made to Equipment and Modification Services (EMS), and flexible funding purchasing guidelines being announced by the Ministry on 18 March 2024.[4]

28. On 25 March 2024, Cabinet authorised Joint Ministers to approve changes to the appropriation to manage immediate cost pressures and fiscal risks.[5] Following a request from the Minister of Finance, the Ministry provided updated cost estimates for 2024/25 which indicated that the cost pressures were even more significant than originally believed.

29. The Review established by Cabinet on 29 April 2024 posed two questions:[6]

> *what actions should be taken immediately in the 2024/2025 financial year to better manage the increasing cost pressures;* (Phase One)
>
> *what should be done to ensure the future sustainability of DSS;* (Phase Two)

30. The current Minister appointed three independent Reviewers who began work on 14 May 2024. The Terms of Reference are attached at Appendix 2. The Minister emphasised to the Reviewers that she expected:

    30.1. A focus on stabilisation, certainty, and consistency of service delivery

    30.2. Prioritisation of those with the greatest level of need.

31. In reaching our conclusions, we have drawn on the experience and knowledge within the Ministry, MSD, other agencies, and a selection of participating non-government entities. We also had a valuable opportunity to talk to Ray Griggs, Secretary of the Department of Social Services, Canberra, about the Australian National Disability Insurance Scheme and its rollout. A complete list of interviewees is attached at Appendix 3.

32. We have commissioned and received a significant number of documents from a range of parties. We acknowledge, in particular, the cooperation and support provided by the Ministry.

33. Time constraints, combined with the narrow focus of Phase One, meant that engagement with the disability community was not possible during this phase of the Review.

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[2] DPMC-2023/24-405
[3] REP/WHK/23/12/012
[4] REP/WHK/24/2/018
[5] CAB-24-MIN-0102. Cabinet also invited the then-Minister to return to Cabinet with options for a review, and directed the Ministry to "*submit to Cabinet proposals for any future changes to disability support services that are significant or will materially impact the services people receive, prior to any changes taking place*"
[6] CAB-24-MIN-0141

About the Ministry

34. In 2021, in deciding to establish the Ministry, Cabinet:[7]

> *agreed that relevant Disability Support Services functions, including responsibility for the national implementation of the Enabling Good Lives approach, would transfer from the Ministry of Health to the new Ministry*
>
> [and]
>
> *agreed that the new Ministry will be responsible for driving improved outcomes for disabled people across government, which requires an expanded mandate and new disability-related responsibilities and functions, including a strategic policy function*

35. The new and separate entity became a Departmental Agency hosted by MSD. MSD is the appropriation administrator and provides shared services. The new Ministry's Executive Leadership Team (ELT) comprises a Chief Executive, four Deputy Chief Executives and a Kaihautu (Chief Advisor Māori). The Ministry has approximately 270 employees.

36. The assessment of needs and allocation of disability support services is undertaken through 15 NASCs and three EGL demonstration sites. The Ministry contracts out delivery of disability support services, under more than 800 contracts, to approximately 475 service providers.

DSS clients

37. DSS eligibility criteria were originally established through a 1994 Cabinet decision.[8] The criteria have not been substantively reviewed since.

38. The Ministry funds services for approximately 50,000 DSS clients. This number has increased from approximately 35,000 clients in 2019. This represents 43% growth in five years.

39. Not all disabled people are eligible to receive DSS, but all DSS clients are disabled people. People are eligible for disability support funded by the Ministry generally if they have a long-term intellectual, physical or sensory disability, including autism, that arises before they turn 65, which lasts longer than six months and requires ongoing support to live independently.

40. All DSS clients have a recorded 'principal disability'. Often, a disabled person will have multiple impairments (or will develop additional impairments) over their lifetime. The nature of principal impairments is changing over time.

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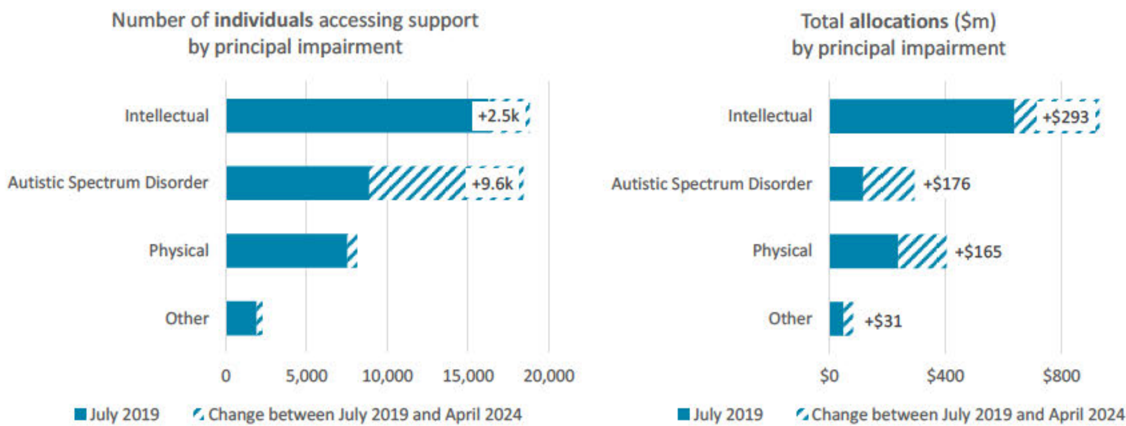
[7] SWC-21-MIN-0146

[8] CAB (94) M 3/5(1a). Later Cabinet decisions excluded people with psychiatric disabilities (2001) and people with age-related disabilities (2003)

Chart 1: Number of individuals and total allocations by principal impairment

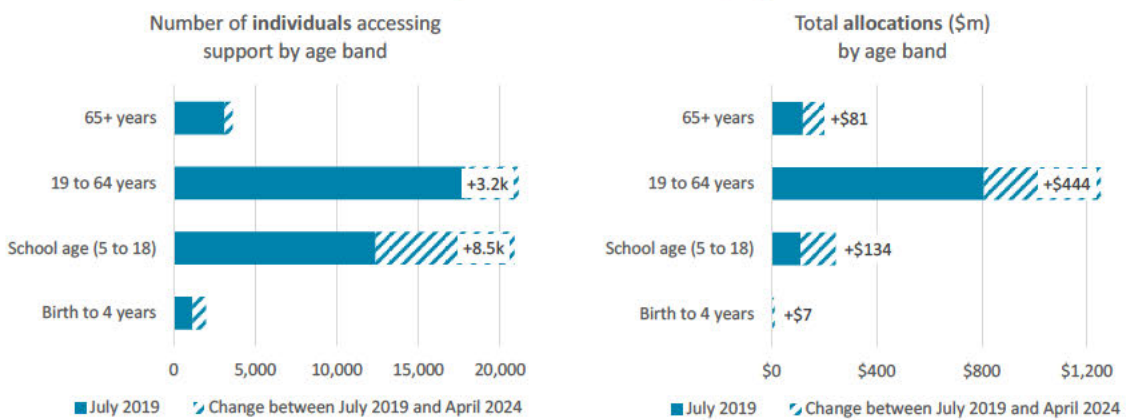


This chart shows that the greatest growth in client numbers is in clients with autism as their principal impairment. The greatest growth in allocation of support is for clients with intellectual impairments.

Note: *Allocation is not the same as actual expenditure. Allocation data is sourced from a workflow tool used by the NASCs. This captures service allocations and links this to demographic information about clients. Not all expenditure lines are included. For example, pay equity advanced interim payments (a significant portion of the cost of residential care) are not captured.*

41. We can also see trends in the age of DSS clients.

Chart 2: Number of individuals and change in total allocations by age band (2019 – 2024)



This chart shows that there has been a significant increase in the number of school age children receiving support (volume) however the biggest allocation growth (spend) is for clients aged 19 to 64 years old.

Note: *People must be under 65 years old to be eligible for DSS. If a person is receiving DSS, support will continue after they turn 65. Te Whatu Ora | Health NZ provides supports for people over 65 who were not assessed as eligible for DSS prior to turning 65.*

42. The Ministry also funds 100,000 equipment and modification support clients annually. A person may receive DSS and EMS services. EMS is also available to people who may not be eligible for DSS.

43. DSS service lines include provision of equipment, support for daily activities (e.g., personal care, household management), residential support, and support for family caregivers (payment for care and respite). Services are provided in communities, private homes, and residential facilities.

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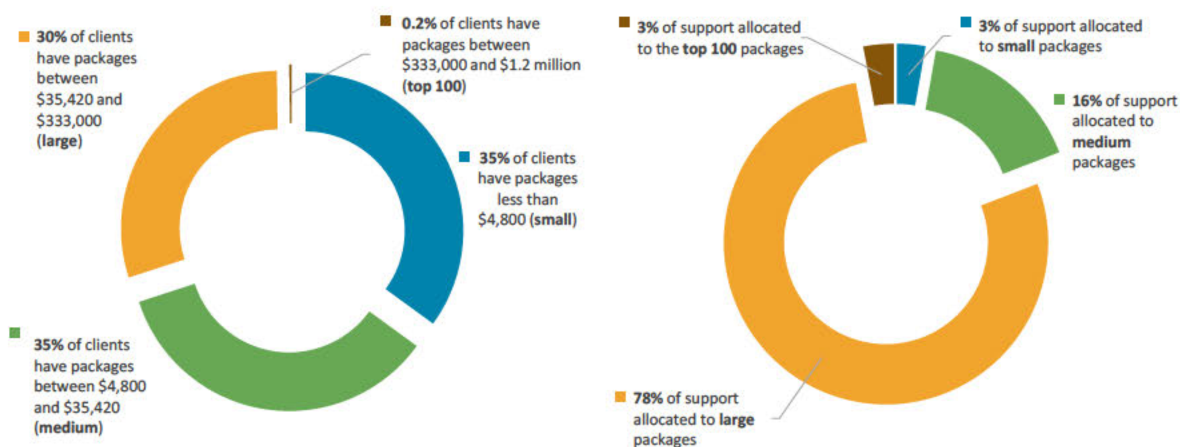
DSS expenditure

44. DSS currently provides over 100 service lines (categories of support which include facility-based residential care, household management, personal care, respite, behavioural support). There are five forms of self-directed funding available that offer a disabled person flexibility and choice to purchase disability supports from a preferred supplier, and how and when they are used (flexible funding).

Chart 3: Distribution of clients receiving DSS by support package size and share of support allocated[9], as at April 2024



The pie charts above show that 30% of clients receive 78% of allocated supports (large). A further 35% of clients are allocated support packages below $4.8k (small).

Data and information

45. The Ministry does not have ready access to mature and historical data. In part, this is due to the use of multiple systems across different service lines which are still operated by Ministry of Health (MOH) and Te Whatu Ora | Health New Zealand (HNZ). The main source of data provided to us originates in a workflow tool which we are advised is no longer fit for purpose[10].

46. A recent gap analysis completed by EY records that there are gaps in available information which is affecting the Ministry's ability to obtain the desired level of understanding about expenditure.[11] As a result, the Ministry does not have sufficient data and insights to support informed decision-making on DSS.

47. We also note that the Ministry does not have data on disability services and support provided by other government entities to support its role in strategic leadership of disability issues.

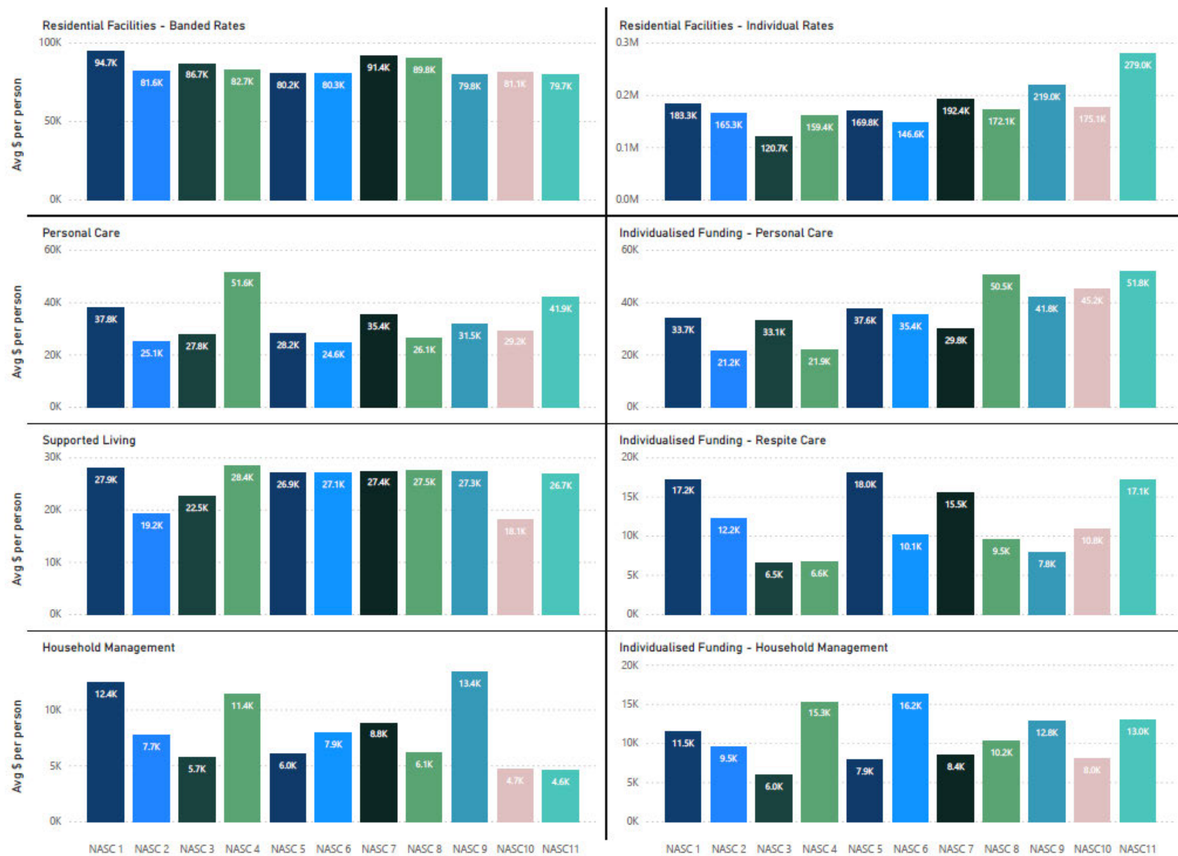
[9] Allocation, while represented in $, does not equate to actual expenditure. Actual expenditure is generally lower than the allocated support package.
[10] As a result of the data challenges the allocation data used for a number of our charts is considered indicative rather than authoritative.
[11] *Gap Analysis: Forecasting & Understanding Non-Departmental Expenditure*, EY, 17 May 2024

Our findings

Finding 1: Delivery of DSS is inconsistent

48. There are inconsistencies in the assessments and allocation of disability supports, and value of support packages, across New Zealand. This variability has been acknowledged by the people we have spoken to within the Ministry and the sector, who recognised this variation is longstanding and inequitable. This can be interpreted as another example of the 'post-code lottery' used to describe health service provision across New Zealand.

Chart 4: Average allocation ($) per person assessed as Very High or High needs for the top eight service lines (by number of people) across different NASCs



These charts show the extent of variation between NASCs in the assessed allocation of eight service lines (for example Individualised Funding-Respite Care average allocations range from $6.5k up to $18k even though people have been assessed as high or very high needs).

This chart also shows that the use of commercial mechanisms like banded rates for residential care controls the cost of services based on needs. Banded versus individual rates are discussed later in this report.

***Note**: These service lines are those with the greatest number of clients. The number in the bar is the average allocation within that service line per person ($). Clients can be allocated funding across multiple service lines.*

49. There is currently no evaluation to support assumptions on the reasons for this variation. Monitoring of variation in assessments was in place up until March 2022 and the monitoring was used to

investigate and address variation in assessment and allocation practices. This monitoring is currently not in place.

50. In addition to our finding above, where you live impacts the choices you have. The EGL demonstration sites in Manawatu, Waikato and Canterbury provide additional, and different, types and levels of support – sometimes significantly so – from disability support services available elsewhere in the country. In addition, Choice in Community Living, another pilot, is available only in Auckland, Waikato, the Hutt Valley, Otago and Southland. We consider that this is inequitable and unfair.

Finding 2: The DSS appropriation will be breached for 2024/25 if spending is not controlled

51. Over the previous 10 years, DSS expenditure has not remained within the funding allocated at Budget and has required additional funding (see Table 1). There has also been accelerating growth in the cost of service provision.

52. There are no controls in place to contain this trajectory. Accordingly, we have no reason to believe that the anticipated cost growth will be constrained in 2024/25, even within the 6% growth in funding that has already been provided in Budget 24.[12]

Table 1: Overview of funding over time $m.

Financial year	Funding approved at beginning of the year (BEFU)	Funding approved at the end of the year (Supps)	Actual expenditure	% change since previous year	Difference BEFU and Supps	Difference between BEFU and actuals
2015/16	$1,158	$1,167	$1,167	-	$9	$9
2016/17	$1,166	$1,183	$1,188	1.8%	$17	$22
2017/18	$1,208	$1,238	$1,256	5.7%	$30	$48
2018/19	$1,269	$1,352	$1,358	8.2%	$83	$89
2019/20	$1,345	$1,599	$1,599	17.7%	$254	$254
2020/21	$1,707	$1,659	$1,659	3.7%	-$48	-$48
2021/22	$1,830	$1,859	$1,870	12.7%	$29	$40
2022/23*	$2,008	$2,074	$2,059	10.1%	$66	$51
2023/24*	$2,245	$2,361	-	14.7%	$116	-
2024/25*	$2,594	-	-	-	-	-

**Vote Health 2015/16 to 2021/22, Vote Social Development from 2022/23*

53. This finding regarding the lack of expenditure control is consistent with the Ministry's own internal risk rating. s9(2)(f)(iv)/9(2)(g)(i)
s9(2)(f)(iv)/9(2)(g)(i)

54. We were concerned that the seriousness of a possible breach of appropriation seemed not to be widely appreciated by the Ministry's executives. Operating within the appropriation that has been

12 s9(2)(f)(iv)/9(2)(g)(i)
13

approved by Parliament is a matter of law for all Government agencies and, in our view, must be treated as a top priority. The past practice of addressing funding shortfalls through a transfer within Votes is no longer appropriate.[14] Far better financial management is essential.

Finding 3: There is inadequate budgetary control and commercial rigour

55. The Ministry has not been established in a manner that enables appropriate financial control over non-departmental expenditure. This is a significant finding to make of any government agency. The impact of this finding is particularly concerning given Finding 2.

56. The Ministry is not able to forecast costs accurately. This is a fundamental aspect of budgetary control.[15] In addition, there is a lack of real-time cost data.

57. Cost control levers are not being utilised. There are no budgetary controls and monitoring of expenditure through NASC or EGL assessments and the management of provider contracts is not effective for controlling cost or quality. For example, operational guidance for NASCs, including the 2016 Support Package Allocation tool (SPA tool) which prescribes pricing by need-level, is not fit for purpose.

58. Our finding is consistent with a recent independent review (commissioned by the Ministry following the DPMC stocktake) which assessed the Ministry's commercial practices as "*failing*". It also found that practices are deteriorating[16] and that some provider contracts have not been reviewed or updated in many years and are no longer fit for purpose. For others the contract term has expired without steps being taken to agree an extension, and for some, extensions occur well after the expiry date.

59. In addition, the Ministry lacks data and evaluation on provider performance. There is no evidence of priority being given to performance reviews and quality and safety audits of providers.

60. We observe a lack of commercial rigour over expenditure including through:

    60.1. Repeated references to "demand driven" expenditure and a widespread belief that cost growth cannot be constrained by budgetary controls.

    60.2. An ongoing expectation that additional funding will be made available every year.

    60.3. A lack of recognition and use of the levers that are available to control use of public funds.

    60.4. An assumption that the Ministry will always need to match prices offered by other government agencies and cannot influence or control the pricing of the services they commission and fund.[17]

    60.5. Absence of reference to the obligations of the Public Finance Act 1989 and Public Service Act 2020.

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[14] In Vote Health, cost pressures were managed within the Vote until 2019, when cost pressures bids were sought each year to manage pressure

[15] A project has been initiated to provide more accurate forecast modelling

[16] *Rapid Assurance Review: Commercial Management*, Link Consulting, May 2024

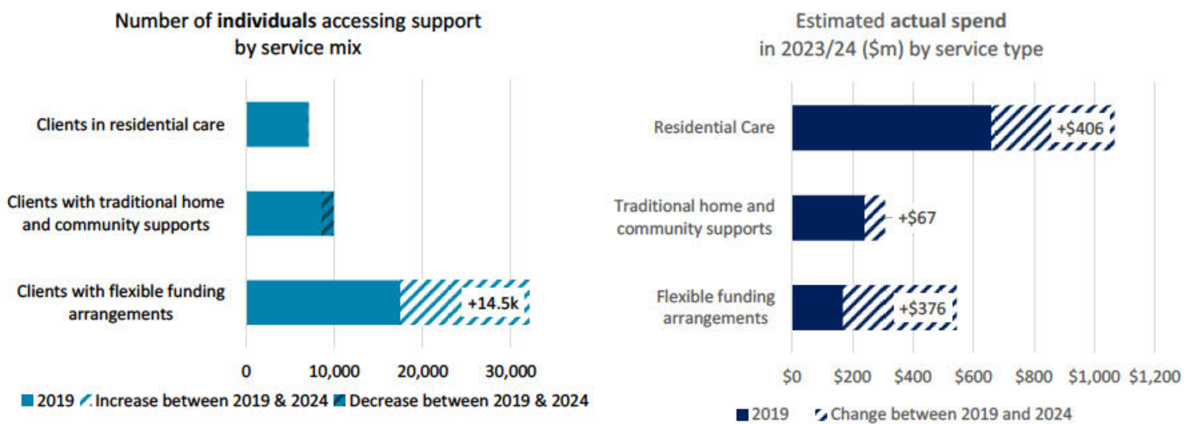
[17] *Rapid Assurance Review: Commercial Management*, Link Consulting, May 2024

61. In our view, the plans that are in place to address the commercial and contract management risks are insufficient and lack the urgency required to control the risks that have been identified in the independent review.[18]

Finding 4: The two areas of largest cost growth are flexible funding provisions and residential facilities-based care

62. The two largest areas of growth in the cost of DSS since 2019 are residential care, and flexible funding arrangements. Flexible funding has also been the largest source of new clients, with 14,500 more people receiving these packages now than in 2019.

Chart 5: Change in number of individuals accessing supports and actual spend, by service mix



These charts show the growth in the number of individuals and overall expenditure (rather than allocations) between 2019 and 2024, grouped by the mix of services they receive. The number of people accessing facilities-based care has reduced slightly yet represents the largest cost increase. The number of people accessing flexible funding arrangements has increased rapidly and so have the associated costs.

63. The increase in cost of residential facilities-based care and flexible funding support packages makes up over 80% of the cost growth since 2018/19.

64. The combination of growth in facilities-based care costs and the pass through of litigation-related costs to address workforce compensation issues, equates to an average increase of 11% per year over the last 5 years[19] and accounts for 43% of the cost growth since 2018/19. Expenditure on flexible funding support packages that are available across the country has increased on average by 24% per year over the last 5 years[20] and accounts for 41% of the cost growth since 2018/19.

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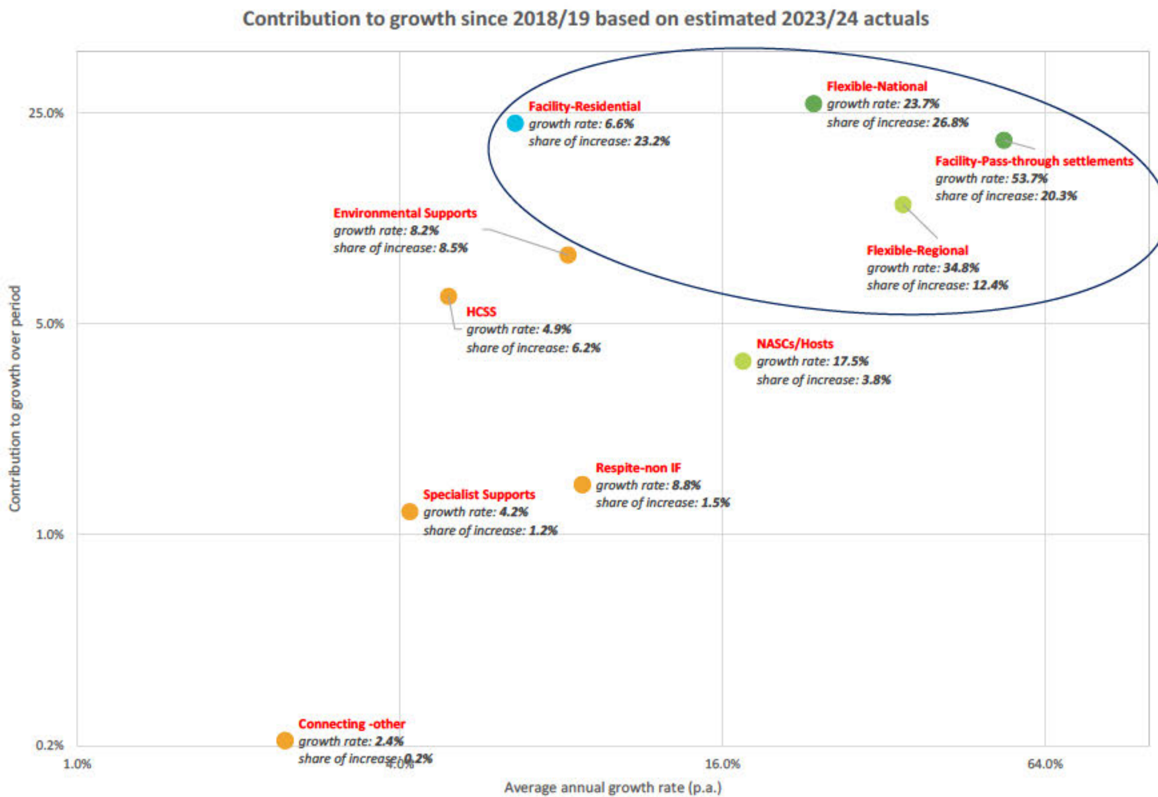
[18] *Rapid Assurance Review: Commercial Management*, Link Consulting, May 2024

[19] Based on estimated full year 2023/24 costs using April 2024 year to date actual costs

[20] Based on estimated full year 2023/24 costs using April 2024 year to date actual costs

Chart 6: Areas of growth since 2018/19 based on estimated costs in 2023/24



This chart demonstrates that facility-based supports and flexible funding account for over 80% of the growth between 2018/19 and 2023/24 (estimated).

Flexible funding

65. The flexible funding service lines available nationally are: Individualised Funding (Personal Care, Household Management, and Respite) and Carer Support. Additional service lines only available in certain regions are: Enhanced Individualised Funding,[21] Personal Budgets,[22] and Choice in Community Living.[23]

66. We found that, in recent years, increasing numbers of clients have been accessing flexible funding (volume has increased by an average of 13% per year over the last 5 years). In 2022/23 $424 million was spent on flexible funding supports compared to $169 million in 2018/19 (cost has increased by an average of 24% per year over the last 5 years). The rapid growth in this area has been occurring since 2015/16 and is therefore unrelated to Covid-19. This may reflect unmet need, but we were unable to verify this.

67. We fully recognise that – in line with EGL principles – there are benefits in providing flexibility to clients. Flexibility offers choice in selection of providers of goods and services and the best mix of

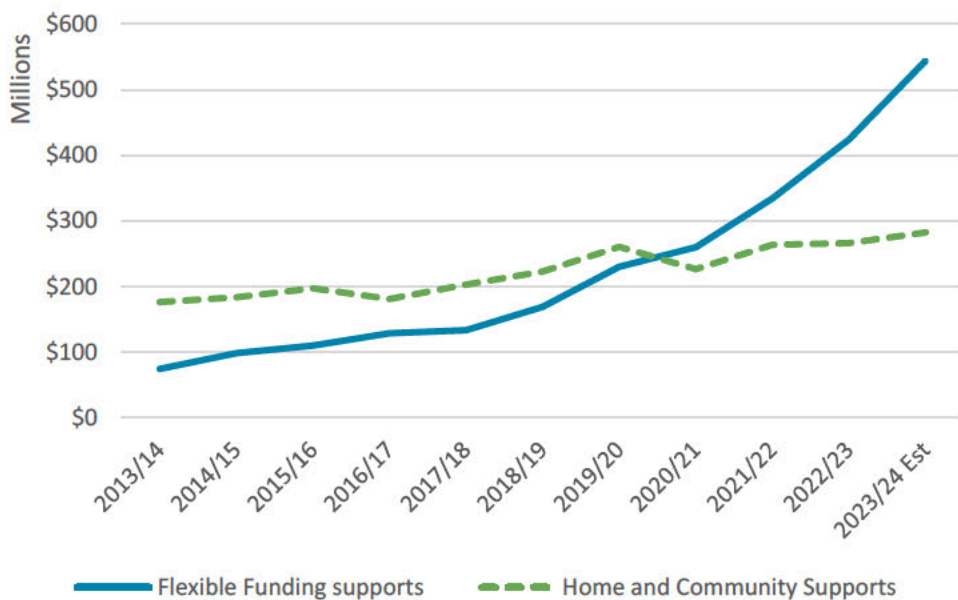
[21] Available in the Bay of Plenty
[22] Available at EGL demonstration sites in Waikato, Mid-Central and Canterbury
[23] Available in Auckland, Waikato, the Hutt Valley, Otago and Southland

services that help with disability support needs. But we did not find established criteria to support to whom, and in what circumstances, such flexibility should be offered.

68. The apparent lack of established criteria, and the flexible use of funding, is potentially blurring the distinction between income support (the responsibility of MSD) and the provision of DSS.

69. In addition to the growth in volume, NASCs and EGL demonstration sites are allocating increasingly larger packages of flexible funding to clients (spend). Comparing the top third of clients by package size (between $35k and $333k) – the average allocation for those with a flexible package was over $72k per annum, compared with just under $60k for those primarily allocated standardised home and community supports.

Chart 7: Total spend on flexible funding supports vs standardised home and community supports –



This chart demonstrates that much higher growth is seen in flexible funding supports (actual spend). This trend began in 2013/14 and has escalated in the years since.

70. Flexible funding purchasing guidelines were relaxed during Covid-19, to assist in the provision of alternative supports due to the restrictions in place during lockdowns. This relaxation appears to have lifted expectations of ongoing flexibility in the use of allocated funding. It is unclear whether the March 2024 changes have restored all pre-Covid settings.

Residential facilities-based care

71. In 2022/23 $990 million was spent on residential facilities-based care compared to $706 million in 2015/16. The number of people receiving this support has decreased slightly while costs have increased faster than inflation over time. We were unable to fully analyse the reasons for the cost increases.

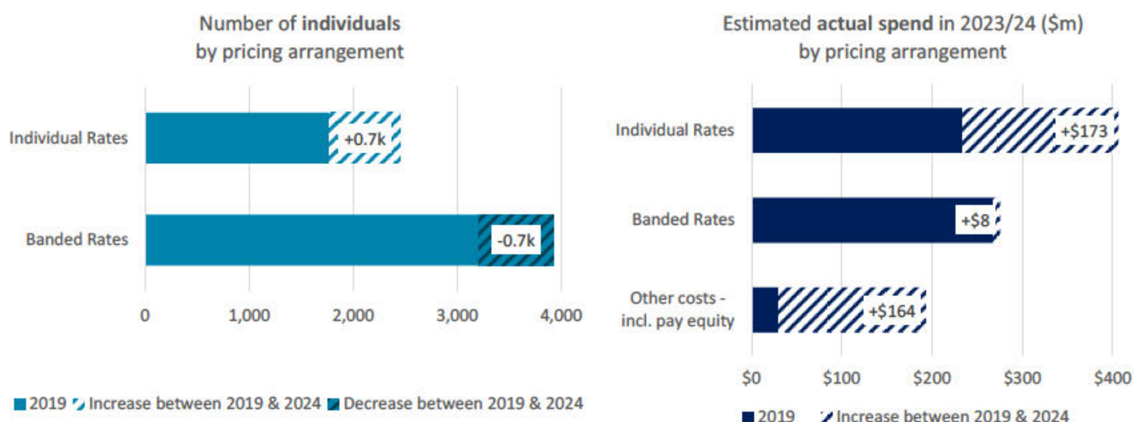
72. There are two categories of residential facilities-based care funding: banded rates and individual rates. We understand banded rates are contractual rates agreed between the Ministry and the

provider. Individual rates are negotiated between the NASC/EGL demonstration site and the provider.

73. At present, the median banded rate is $222 per day, while the median individual rate is $371 per day. In addition, there are variations in the gap between banded and individual rates across the NASCs. NASCs range from having 92% of clients on banded rates, to around 19%. It is, however, unclear whether this can be explained by different needs or operating costs in different locations.

74. The number of clients being allocated residential facilities-based services by NASCs and EGL demonstration sites is relatively unchanged.[24] But the composition of the funding is changing significantly as NASCs and EGL demonstration sites are allocating individual rates at an increasing frequency (volume) and at increasing support package size (spend). In 2019, approximately 30% of clients in residential facilities were on individual rates. Currently this proportion is around 45%.

Chart 8: Number of individuals in facilities-based care and total allocations by individual or banded rates



The chart shows more people are now on individual rates and the rates per person are significantly higher.

***Note**: Other costs include pay equity advanced interim payments and the cost of the sleepover settlements. Not all provider contracts have been updated to include sleepovers.*

75. When comparing trends over time, we note that pay equity, in-between travel and sleepover payment litigation has led to imposed cost increases for residential care. We have been unable to quantify the actual impact of these cost increases.

Finding 5: The new departmental agency is not set up in a manner that enables it to manage effectively the nature and scale of its appropriation

Establishment

76. The establishment of the Ministry was rushed, and the Ministry inherited significant and known risks when DSS was separated from the former MOH. The "lift and shift" approach did not address those risks adequately.[25]

[24] This appears to be constrained (in part) by supply as there are waiting lists, however we have been unable to verify this.

[25] This finding is consistent with the DPMC stocktake conducted in September 2023

77. We find that the "dual mandate" is in fact three separate mandates: delivery, transformation and stewardship. The first aspect of the Cabinet mandate, namely the delivery of DSS and the transformation toward national implementation of the EGL approach, conflates two very different purposes. This has led to a failure to prioritise effort towards sustainable delivery of existing services.

78. The Departmental Agency Agreement with MSD was established in a way that presents challenges for both parties. We are of the view that the Departmental Agency arrangement should be reassessed for this Ministry, with its limited capability and large and growing budget.

79. In addition, shared services arrangements with HNZ and MOH are not supporting the Ministry as effectively as they should.

80. Shared services provided by MSD, MOH and HNZ are not optimal given the scale of the appropriation and services, and the Ministry's need to prioritise cost reduction:

    80.1. MSD provides HR, Carbon Neutral Government Programme, workplace services, fleet services, Chief Financial Officer and financial operations, IT, information management and Chief Information Security Officer, emergency management and business continuity services.

    80.2. MOH provides financial services and information management services.

    80.3. HNZ provides sector operations, audit and compliance, contract support services, IT and financial services.

81. A recent independent review (commissioned by the Ministry after the DPMC stocktake) of the shared service arrangements with MOH and HNZ found that the default service setting appeared to be reactive management by exception, and there was a failure to hold constructive meetings regarding the shared services.[26] In addition, that review found that aspects of shared services are not fit for purpose.

82. The performance of shared services arrangements directly contributes to problems with expenditure control in the Ministry.

Current set up

83. We find that organisational processes, leadership and governance mechanisms are not fit for purpose. This was evident in our interviews with executives, as well as our interviews with officials in other agencies and various plans and minutes of meetings.

84. Two examples demonstrate the consequences of this finding and the level of support required:

    84.1. There is a lack of reporting line from the Ministry's finance team to its Chief Financial Officer (the Chief Financial Officer of MSD). Furthermore the arrangements for the Chief Financial Officer for providing advice to the Chief Executive are informal.

[26] *Independent Review of Service Agreements Te Whatu Ora & Manatū Hauora to Whaikaha*, Ascent Business Consulting, April 2024

84.2. The current work programme is aspirational, too large and fails to prioritise actions to address the risks of breaching the appropriation and internal control failure.

Finding 6: Current policy settings and service design do not allow the Ministry to administer and deliver DSS effectively

Policy settings

85. There is, as yet, no specific legislation providing for the administration and delivery of DSS. The Ministry's mandate is drawn from (often dated) Cabinet or Ministerial decisions that do not provide adequate direction on:

85.1. The role of Government in providing services to improve outcomes for disabled people

85.2. The purpose of DSS

85.3. The policy intent of the different services

85.4. The Ministry's functions and duties

85.5. What Government will and will not fund through DSS

85.6. The relationship between DSS and other disability supports provided across government, including income supports

85.7. The primacy of natural supports.

86. The overarching purpose of the DSS appropriation demonstrates this lack of clarity: "to support tāngata whaikaha Māori and disabled people and their families to create good lives for themselves".

87. There is also a blurring of the line between DSS and income support that is provided through MSD. This is evident in relation to flexible funding and the uncertainty regarding what people can buy with disability funding.

Ad-hoc decision making

88. Cabinet and Ministerial decisions have been made on an issue-by-issue basis over decades. Three examples demonstrate the result:

88.1. The environment is peppered with pilots that have never ended and have resulted in a fragmented system with regional inconsistencies.

88.2. In establishing the Ministry, Cabinet agreed to "implement the Enabling Good Lives approach to Disability Support Services nationally, subject to Budget 2022 decisions".27 This has led to expectations of national rollout in the same form as the demonstration sites. Evaluations of the pilots to date are qualitative and lack the financial analysis required to support decision-making relating to commitment of further public funds.

[27] SWC-21-MIN-0146

88.3. The 2014 "clarification" that clients with autism as their sole impairment are eligible for DSS was made by a previous Minister of Health, not Cabinet.28 The decision was based on advice that additional costs would be managed within the existing appropriation. At the time the decision was made, 2,834 DSS clients had autism spectrum disorder recorded as their 'primary disability'; the equivalent number today is 17,419. S

Service model

89. The DSS service delivery model lacks rigour and coherence.

90. Incremental operational changes have occurred without consideration of overall system coherence and financial sustainability. This is most clearly illustrated in the duplication of service lines, poor operational guidance, and uncontrolled growth of demand for flexible funding.

91. We find that operational guidance is frequently outdated to the point where we question its relevance. The following table shows the outdated nature of NASC operational guidance as an example.[29]

Date	Document	Stated purpose
1994	Standards for Needs Assessments for People with Disabilities	Minimum national standards for assessment services for people with disabilities[30]
2002	Support Needs Assessment and Service Co-ordination: Policy, Procedure and Information Reporting Guidelines	Identify policy and procedures that apply at each point of the disabled person's contact with the NASC system, and information that needs to be collected and disseminated at each point of the disabled person's pathway[31]
2005	Operational Manual for Needs Assessment and Service Co-ordination Managers Volume 1 and 2	For all NASCs to be led and managed competently and confidently to provide facilitation of support needs assessment, service planning, co-ordination and resource allocation and budget management in a manner consistent with agreed policies and protocols[32]
2016	Support Package Allocation (SPA) Guide	To assist in the determination of a person's disability related need level, equitable service allocation within and across NASC[33]

[28] REP 20131421

[29] These are the documents that have been provided in response to our request for "Form(s) used by NASCs to determine eligibility"

[30] *Standards for Needs Assessments for People with Disabilities* (1994), p4

[31] *Support Needs Assessment and Service Co-ordination: Policy, Procedure and Information Reporting Guidelines* (2002), p4

[32] *Operational Manual for Needs Assessment and Service Co-ordination Managers Volume 1 and 2* (2005), p1

[33] *Support Package Allocation (SPA) Guide* (2016), p2

92. These documents have been superseded by later operational changes such as the creation and subsequent disestablishment of allocation review processes. This includes review processes to oversee consistency of assessment practice:

    92.1. A High-Cost Review Panel (pre-2012), which reviewed allocations that were above $85,000 a year (which, at that time, was about the average cost of a residential care package).

    92.2. An Autism Spectrum Disorder Exceptions Panel (2016 to 2022), which had the purpose of reviewing and making decisions on access to residential services for all adults with a disability diagnosis of autism spectrum disorder only.

    92.3. Between 2012 and 2020, decisions on high-cost claims were made by the National NASC Reviewer (decisions above $85,000) and Independent Review Panel (above $150,000).

93. We have not been able to determine what the current review mechanisms are and the operational policies guiding those reviews.

94. The Operational Manual was not updated to include these review processes, all of which have now been disestablished. We question the relevance of an Operational Manual that does not refer to such a vital part of the allocation process and leaves room for inequity in support allocation and outcomes for disabled people. This is one example; we suggest there will be many more.

95. Incremental changes to operational settings and guidance alongside the implementation of demonstration sites has resulted in a very complex system that is inequitable and difficult to navigate, particularly when trying to access both income support and services funded by a range of government agencies.

96. In summary, we observed significant opportunities to improve and simplify the disability support system.

Our recommended actions to better manage the 2024/25 financial year

97. The recommendations set out below have not, in the time available, been able to be properly evaluated for their financial impact. Nevertheless, we believe that early movement on a series of steps like these – many of which are intended to introduce or strengthen core disciplines and control mechanisms for the use of public money – are an essential part of stabilising the performance of the Ministry.

98. Our judgement is that these recommendations will contribute to the purpose of the Review, namely "to strengthen the provision and certainty of support for disabled people into the future, and ensure strong fiscal management is in place". We suggest that recommendations 1-4 be considered and implemented as a package as soon as possible. Recommendations 5-7 are intended to initiate processes for change to be delivered at a later stage.

99. The Ministry has provided an estimate of the potential impact of these recommendations on the cost pressures. These are provided at Appendix 5.

100. To successfully implement these recommendations, we propose that a taskforce of suitably experienced people be brought into the Ministry at the earliest opportunity to work with the Chief Executive. We suggest that the taskforce should be in place for a period of 12 months.

Recommendation 1: Reinstate indicative budgets for NASCs, fixed budgets for EGL demonstration sites and EMS providers, and monitoring and reporting requirements for NASCs, EMS providers and EGL demonstration sites

101. Implementing budgets and monitoring requirements will reintroduce a critical control and establish prioritisation mechanisms for allocation of support. These steps alone will not control the price of services, and complementary steps will be required to achieve stabilisation of the system and expenditure (see recommendations 2-4).

102. NASCs and EGL demonstration sites are not currently allocated fixed or indicative annual budgets. This is a fundamental control that we would expect to see for a publicly funded service. We were advised by a NASC, and the Ministry has confirmed, that indicative budgets for NASCs were in place prior to the establishment of the Ministry, as was monthly reporting against budgets. We were advised that budgets have been introduced for the two EMS providers and we recommend these budgets continue in 2024/25 and outyears.

103. Budget controls will contribute to constraining growth in expenditure in 2024/25 to no more than 6% in accordance with the DSS appropriation. It will also contribute to stabilisation of the services in future years. Effective application of budget controls will drive the requirement for prioritisation of funded support based on need.

104. If implemented well, we consider this control will direct resources to those with highest needs. The Ministry described this as a good option.

Recommendation 2: Freeze current levels of funding for residential facility-based care for 2024/25 pending commissioning and completion of a detailed and urgent review of the contract and pricing models

105. We have not seen growth in the number of people in residential care despite population growth. However, costs have been increasing year-on-year at a rate faster than inflation and it is unclear how the provider costs are being monitored and controlled.

106. Freezing current levels of funding will provide the opportunity to better understand the requirements for supply of, and demand for, these services. We propose maintaining funding for facility-based care contracts at the 2023/24 actual expenditure levels. The review of existing contracts and pricing models is a priority and must be concluded by early 2025.

107. The review will stabilise the financial underpinnings of services to a group of clients with some of the highest needs. Providers will in due course have more certainty about levels of funding and be encouraged to use their capacity more fully.

108. Effectiveness will be enhanced by implementing this in parallel with recommendations 1, 3 and 4.

109. The following risks will need to be managed:

    109.1. In the interim, some smaller providers may express concern about business viability and there may be reduced availability of facility-based care until the review is completed.

    109.2. Pressure on NASCs to move clients to individualised rates may increase. This needs to be implemented alongside clear guidelines for NASCs moving people from banded rates to individual rates.

110. The Ministry is concerned about the risks of this proposal and advised us of ongoing price pressures for residential support providers.

Recommendation 3: Take no action on a price increase for providers in 2024/25

111. Budget 2024/25 contains provision for a 6.0% increase in DSS funding. In addition, $92 million was allocated for a further provider price increase of 3.6%. We understand this funding was time-limited for only one year.

112. If the provider price increase is passed through, the Ministry will face even greater cost pressures in the outyears. We consider that this is avoidable. A more detailed analysis of cost structures, contracts, pricing and the impact on DSS clients is required to determine better use of the DSS budget (Recommendation 2).

113. Providers will be most impacted by this recommendation. However, this can be mitigated where necessary by targeting use of the 6% increase in funding for 2024/25 to meet increased demand (not for price).

114. The Ministry advises that providers are expecting price increases in 2024/25. This issue needs to be addressed through the recommended pricing and contracting review (Recommendation 2) and is linked to the need to urgently address procurement and contract management inadequacies.

115. The Ministry agrees this is a good option for some of the price increase. The Ministry considers they are a 'price taker' for some contracts because of higher funding levels provided by other government agencies. This response is consistent with Finding 3, particularly the assumption that the Ministry will always need to match prices offered by other government agencies.

Recommendation 4: Establish an effective function within the Ministry to monitor the assessment and allocation performance of NASCs and EGL demonstration sites

116. s9(2)(f)(iv) & 9(2)(g)(i)

Recommendation 5: Update the assessment and allocation settings for individuals based on level of need

124. We consider that the SPA tool used for the assessment of client need provides the required steps to appropriately assess a person's needs. Despite requests for information, it remains unclear how the

current tool's need levels and pricing, set in 2016 dollars, translate into the funded package of supports that a client receives and the cost of each package at the present time.

125. The intent of this Recommendation is to contribute to improved consistency of allocations and associated costs across the country in both 2024/25 and beyond. A key outcome of this will be improved standardisation of levels of support against needs, thereby removing current inequities in the system.

126. Effectiveness will be enhanced by implementing this Recommendation in parallel with recommendations 1-4. The monitoring of variation in assessment practice and consequential corrective actions will be critical.

127. The following risks will need to be managed:

    127.1. Some support packages may have to be adjusted through the annual reassessment processes.

    127.2. Because the prices are currently based on 2016 figures the SPA prices will increase. While it is unclear how the costs of a support package are currently set, updating prices may increase the total package size but can be mitigated by improved budget control and prioritisation according to need (Recommendation 1).

128. The Ministry considers this to be a good option but raises concerns that implementation will increase pricing allocations and therefore mean fewer people can be supported within the fixed appropriation. We consider that this concern is consistent with the risk of any controls that are in place for use of public funds and requires effective commercial arrangements and monitoring to ensure funding is being allocated based on priority of need.

Recommendation 6: Establish criteria for access to flexible funding and review the flexible funding guidelines to improve clarity and consistency

129. The option to choose flexible funding is aligned to the EGL principles. We have not seen any evaluation of the effectiveness of flexible funding in terms of both outcomes and cost.

130. Flexible funding, particularly Individualised Funding (IF), is one of the fastest growing areas of DSS expenditure. In 2022/23 flexible funding costs were $424m (42% of the non-residential supports costs). At the end of April 2024, these costs were on track to be 30% higher than 2022/23.

131. Establishing criteria for access to flexible funding is critical to achieving the appropriate balance between assessed needs and expenditure, now and in the future.

132. The introduction of stable, consistent, and transparent criteria to access flexible funding and guidelines for use of flexible funding could help to contain increasing costs, whilst ensuring those who need and would benefit most from flexible funding can continue to access it.

133. Well-designed and implemented criteria and guidelines will support achievement of the EGL principles in a sustainable way.

134. This is an important piece of work well-suited to consultation with the community. Effective implementation will rely on recommendations 1-4 being in place.

135. There is a risk that the community may consider establishing access criteria and guidelines for use of flexible funding will limit their choices. Consultation can help to mitigate this and embed flexibility.

136. The Ministry supports this option and considers the Recommendation aligns with its current work on family carers.

Recommendation 7: Strengthen the departmental agency arrangement with the Ministry of Social Development and the shared services arrangements with the Ministry of Social Development, Ministry of Health and Health New Zealand

137. This Recommendation is independent of, but related to, our concluding remarks below.

138. Together, strengthened departmental agency arrangements and better performance of shared services will improve the organisational capability of the Ministry.

Departmental agency agreement

139. The nature of the departmental agency relationship has proved challenging for all involved. Of particular concern is the lack of conventional mechanisms within the Ministry for financial oversight and control, procurement, contract management, and monitoring and performance review and audit.

140. Currently, the Chief Financial Officer of MSD holds the same position in the Ministry; we do not believe that this arrangement serves the Ministry well. The uncertainty around roles in relation to appropriation administration is contentious.

141. As a first step, the Chief Executives of MSD and the Ministry, with the support of the Public Service Commission and the Treasury, should take steps to strengthen the operation of the current departmental agency arrangement.

Shared services arrangements

142. At present, the shared service arrangements between the Ministry, MSD, MOH and HNZ are not effectively supporting the Ministry – see finding 5. Roles and responsibilities should be made clear.

143. We recommend a reassessment of the Ministry's shared services arrangements, including to ensure suitable cross-agency governance mechanisms for effective oversight and appropriate performance.

Critical risks to be mitigated

144. The most pressing risks facing the Ministry are the need to stabilise operations and improve performance. It is for this reason that we are proposing the early deployment of an external taskforce to work in support of the Ministry's Chief Executive.

145. If adopted the recommendations will require a realignment of the Ministry's current priorities and allocation of resource. There is a risk that the implementation of the recommendations will not be effectively prioritised in relation to the current work programme.

146. The expectations of the disability community are high, and the relationship with Government has been eroded in recent times. Clear communication of any changes pursued as a result of the Review, including the rationale behind decisions made, and any potential impacts, will be imperative to mitigate the risk of further erosion of trust and confidence in the Ministry.

147. There is a risk that decisions arising from the Review will raise a variety of concerns among providers. Mitigations include careful communication of changes and responsive stakeholder management alongside improvements to commercial management practices.

148. There is a risk that the quality of care being provided to disabled people may erode during a period of funding constraint. We consider that the monitoring proposed in Recommendation 4 will be an important part of the mitigation of this risk; but we acknowledge that it may take time to establish a responsive monitoring function. In the meantime, internal processes for complaints, concerns and ongoing stakeholder management must recognise this risk and provide transparency to executives on how risks are being managed.

Additional factors

149. We are aware of a range of factors that create additional risks to the Ministry's ability to constrain costs. We have not had the opportunity to fully consider these risks given the timeframe and narrow focus of our Review, however, given the potential for these to have significant financial impact we have included them for future consideration and monitoring. Additional factors include:

 149.1. Decisions taken outside the direct control of the Ministry could have flow-on consequences to the cost or scope of services. These include responding to the Ombudsman's s9(2)(ba)(ii) ; family carer payments, future pay equity claims; and the current review into Aged Residential Care (administered by HNZ).

 149.2. If the number of people eligible for support increases further than expected, so will the fiscal risk. Any expansion of eligibility will impact the DSS costs.

 149.3. As seen in other countries, there is significant growth in demand for DSS for children with autism. The support needs required to improve whole-of-life outcomes for young people as they age remains unclear, as does the potential growth rate in the number of young people with autism.

 149.4. We note that the people receiving Equipment and Modification Services form a much broader group than those eligible for DSS and includes people aged over 65 who receive their other disability supports from HNZ. As the population ages, this growing segment of the population could place additional demand pressures on these services.

Concluding remarks

150. This Review has been conducted under a very tight timeline. Nonetheless, the Reviewers are comfortable that the broad findings we have reached, and the recommendations we have suggested, are sufficiently soundly based to meet the requirement for early advice that we were asked to meet. In the time available, only limited engagement with external parties was possible.

151. The Terms of Reference required us to provide advice to the Minister that answer the question *"what actions should be taken immediately in the 2024/25 financial year to better manage the increasing cost pressures".*

152. The Terms of Reference envisage that Phase Two of the Review will be undertaken immediately after the completion of Phase One and will address issues related to longer term sustainability of Disability Support Services. In considering the future sustainability of DSS, the following matters shall be addressed:

    152.1. Eligibility for DSS, with a focus on entitlement to, and allocation of, funding

    152.2. The purpose of different funding streams within DSS and the appropriate level of flexibility for each

    152.3. The capability and processes that need to be in place in the Ministry to manage DSS, including for risk management, commissioning, and organisational form and structure

    152.4. Interactions between DSS and other systems (including health, welfare and education)

    152.5. The legal framework for DSS

    152.6. Stakeholder relationships.

153. We have compiled a list of issues that we consider deserve further attention as a result of our work in Phase One (see Appendix 4).

154. It is the assessment of the Reviewers that the Ministry is in urgent need of change. Current fiscal controls are inadequate; monitoring and evaluation is poor; there is a worrying lack of clarity about the terms and conditions of existing provider contracts; the roles of the NASCs and hosts are in need of review, and the shared services provided to the Ministry by MSD, MOH and HNZ, and the Departmental Agency Agreement with MSD, need to be reassessed and strengthened.

155. In addition, the Reviewers are uncomfortable about the continued operation of the NASC-based system of needs assessment, allocation, and service provision, alongside three longstanding EGL trials. This needs to be addressed. The continuing coexistence of these two very different forms of DSS is confusing and muddled, and results in inequities in the services and support being provided to clients. The EGL principles are, in our view, worth giving effect to, but a revised approach needs to be developed.

156. During the review we were provided with two external reports critical of agency performance. Together they underline that urgent action is needed to address what are described as "failures" in commissioning and contract performance and management, on the one hand, and shared services support, on the other.

157. These reports and our findings describe an agency that requires strengthened processes and disciplines to ensure that the services that are being provided to DSS clients can be delivered effectively, efficiently and appropriately to those who need them most. There are significant risks and deficiencies in the current situation, not all of which are well understood.

158. It is for this reason that the Reviewers suggest that Phase Two of the Review as originally conceived should not proceed at the current time. It would seem that the more pressing need is for a team of experienced staff to be brought into the Ministry at the earliest opportunity to work with the Chief Executive to strengthen processes and systems, improving monitoring and controls, and reset current procedures and arrangements as necessary, to deliver stability and confidence to the Ministry, and its critical role.

159. We would expect that if a taskforce is established, its role in supporting the Chief Executive to implement any decisions arising from this Review, would also extend to considering the longer term sustainability of DSS as was originally envisaged within the Phase Two deliverables.

Appendices

(1) Glossary
(2) Terms of Reference
(3) List of people spoken to by the Reviewers
(4) Suggested list of Phase Two considerations
(5) Estimated financial impact of recommendations as assessed by the Ministry.

Appendix 1: Glossary

Term	Definition
Appropriation	An appropriation is the basis on which Parliament authorises the executive government to spend money An appropriation specifies the type, amount, scope, and period of spending which are allowed
Appropriation administrator	The department that administers the appropriation on behalf of the appropriation Minister[34] MSD is the appropriation administrator of the DSS appropriation
Appropriation Minister	The Minister responsible for the appropriation The Minister for Disability Issues is the appropriation minister for the DSS appropriation
Banded rates	Relates to residential facilities-based care funding Banded rates are standardised contractual rates for various need levels agreed between the Ministry and the providers. Banded rates are used unless an individual rate is agreed
Clients	Disabled people who are currently receiving DSS In this report, people referred to as clients have been screened as eligible to receive DSS by NASCs or at EGL demonstration sites and have had support packages allocated to them. Eligibility may also be determined by EMS providers
Demonstration site	The phrase used for the Enabling Good Lives (EGL) pilots The three demonstration sites are EGL Christchurch (2013), EGL Waikato (2015) and Mana Whaikaha / EGL MidCentral (2018). EGL Christchurch focusses on young people aged 14 years and older in receipt of Ministry of Education Ongoing Resourcing Scheme funding and support. EGL Waikato allows people to “opt-in” to the programme. Mana Whaikaha in Mid-Central is a prototype of a transformed system[35]
Departmental agency	A departmental agency is an operationally autonomous agency hosted by a Public Service department. It is legally considered part of its host department[36] A departmental agency is headed by its own chief executive who is directly responsible to an appropriate minister for its clearly identified, ring-fenced activities and performance

[34] Public Finance Act 1989, section 2
[35] REP/WHK/23/11/005, page 22
[36] Legally defined in the Public Service Act 2020 as “any of the agencies that are listed in the first column of the table in Part 2 of Schedule 2, and that are each part of the corresponding host department stated in the second column of that table”.

Disabled people *(UNCRPD and New Zealand Disability Strategy definition)*	People who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others[37]
Disabled people eligible for DSS	Not all disabled people are eligible to receive DSS; but all DSS clients are disabled people People are eligible for disability support funded by the Ministry generally if they have a long-term intellectual, physical or sensory disability, including autism, that arises before they turn 65, which lasts longer than six months and requires ongoing support to live independently[38]
DPMC	Department of the Prime Minister and Cabinet
DSS	Disability Support Services Includes goods, services, and facilities— a. provided to people with disabilities for their care or support or to promote their inclusion and participation in society and their independence; or b. provided for purposes related or incidental to the care or support of people with disabilities or to the promotion of their inclusion and participation in society and their independence[39]
EGL	Enabling Good Lives
EGL approach	In 2011, members of the disability community developed the EGL approach with the intent of shifting power and authority from government to disabled people and their families. The EGL approach is a foundation and framework to guide positive change for disabled people, families, communities and governance structures. The EGL approach has eight core principles, a vision and key components to guide positive change. The EGL approach is that *"through Enabling Good Lives, disabled people and their whanau can choose to increase the choice and control they have in their lives and supports"*[40]
EMS	Equipment and Modification Services

[37] New Zealand Disability Strategy 2016-2026, glossary, page 49
[38] DSS eligibility criteria were originally established through a 1994 Cabinet decision [CAB (94) M 3/5(1a) refers]
[39] Pae Ora (Healthy Futures) Act 2022, section 4
[40] Enabling Good Lives.co.nz, About enabling good lives New Zealand, accessed 25 June 2024

Flexible funding	Funding that enables the disabled person more choice and control about who provides support, and how and when they use it. The flexible funding service lines available nationally are: Individualised Funding (Personal Care, Household Management, and Respite) and Carer Support The additional service lines available in certain regions only are: Enhanced Individualised Funding, Personal Budgets, Choice in Community Living.
HNZ	Health New Zealand
Host department	A Public Service department which is the overarching legal entity for a departmental agency[41]
Host provider	An organisation contracted by the Ministry to assist people to purchase and manage their Individualised Funding or Enhanced Individualised Funding People with a personal budget may also work with a Host Provider
Impairment	A problem with the functioning of, or the structure of someone's body[42]
Individual rates	Relates to the prices paid for residential facilities-based care when banded rates are seen as inadequate to meet the costs of providing care Individual rates are agreed by the NASC/EGL demonstration site and the provider using an individual rate calculator and negotiation
Ministry	Ministry of Disabled People – Whaikaha[43]
MOH	Ministry of Health
MSD	Ministry of Social Development
NASC	Needs Assessment and Service Coordination organisation

[41] Legally defined in the Public Service Act 2020 Section 5 as "the host department of a departmental agency or a functional chief executive".
[42] New Zealand Disability Strategy 2016-2026, glossary, page 49
[43] Noting that the legal name is "Ministry for Disabled People" per Public Service Act 2020, schedule 2, part 2

Personal budget	A personal budget is the disability support funding that the disabled person can control and prioritise, used in EGL demonstration sites. People with personal budgets may use them to: a. purchase contracted disability supports, which are purchased through contracted providers; and/or b. individually purchase disability supports, such as by contracting directly with a provider, employing support workers, or purchasing goods that are disability supports
Phase One of the Review	*“what actions should be taken immediately in the 2024/2025 financial year to better manage the increasing cost pressures”*
Phase Two of the Review	*“what should be done to ensure the future sustainability of DSS”*
Purchasing guidelines	Guidance to support how people can spend disability support funding they are allocated
Residential facilities-based care	Residential care involves the Ministry contracting with providers to deliver board (e.g., accommodation, food and utilities), and disability support, to a disabled person 24 hours, 7 days per week
Service lines	Different categories of disability support services that the Ministry funds
Shared services	Corporate services required by a departmental agency that are provided by another agency. These could include Human Resources, Information Technology, Finance and other services
SPA tool	Support Package Allocation tool This tool is provided to NASCs assist in the determination of a person’s disability related need level and allocate services[44]
Support package	The cost of the disability support that is allocated to a DSS client

[44] *2016 Support Package Allocation (SPA) Guide*, Ministry of Health, page 2

Appendix 2: Terms of Reference

Terms of Reference: Independent review into the sustainability of Disability Support Services administered by Whaikaha – Ministry of Disabled People

As agreed by Cabinet on 29 April 2024 [CAB-24-MIN-0141]

1. Whaikaha – Ministry of Disabled People (the Ministry) was established on 1 July 2022 as part of the health system reforms enacted through the Pae Ora (Healthy Futures) Act 2022. It has a dual mandate to:
    a. lead strategic disability policy across government to improve outcomes for disabled people
    b. deliver and transform DSS, including the national rollout of the Enabling Good Lives approach (EGL).
2. The Ministry received the majority of funding, and responsibility for DSS and the Enabling Good Lives (EGL) portfolio from the Ministry of Health (MoH), and the Office for Disability Issues from the Ministry of Social Development.
3. Recent events have revealed that longstanding issues with DSS need urgent attention, in particular issues relating to increasing cost pressures.

Purpose

4. An independent review will provide advice on the immediate and longer-term sustainability of DSS, including what actions should be taken to strengthen the provision and certainty of support for disabled people into the future, and ensure strong fiscal management is in place.

Objective

5. Consistent with the Government's priorities for effective, efficient and responsive Public Services and improving fiscal management, the independent review will provide advice on what actions should be taken:
    a. immediately in FY 2024/2025 to better manage the increasing cost pressures of DSS
    b. to ensure the future sustainability of DSS.

Scope .

6. The independent review may provide advice on next steps on any matter it considers relevant to its purpose and objective.
7. To consider the future sustainability of DSS, the independent review will need to consider:
    a. eligibility for DSS, with a focus on entitlement to, and allocation of funding
    b. the purpose of different funding streams within DSS and the appropriate level of flexibility for each
    c. the capability and processes that need to be in place in the Ministry to manage DSS, including for risk management, commissioning, and organisational form and structure
    d. interactions between DSS and other systems (including health, welfare, and education)
    e. the legal framework for DSS c
    f. stakeholder relationships.

Timeframe

8. The independent review will meet the following timeline:

Stage	Output	Deliverable	Deliverable due
Immediate priority	Advice on: choices for making immediate changes to DSS in FY 2024/2025 trade-offs and implications of the choices mitigations for critical risks.	Report to Minister with recommendations for responding to cost pressures on DSS in FY 2024/2025.	Week 6
Future sustainability	Advice on future fiscal sustainability and certainty for disabled people: choices for making changes to DSS in FY 2025/2026 and beyond eligibility for DSS with a focus on entitlement to, and allocation, of funding purpose of different funding streams within DSS and the appropriate level of flexibility for each the capability and processes that need to be in place in the Ministry to better manage DSS, including for risk management, commissioning, and organisational form and structure interactions between DSS and other systems (including health, welfare and education) the legal framework for DSS stakeholder relationships.	Final report to Minister	Week 14

9. During the review, the lead reviewer will keep the Minister for Disability Issues and Minister for Social Development and Employment updated on the progress of the review and the approach. This will include the scale and shape of anticipated recommendations.

10. If the lead reviewer becomes concerned about the timeline for the review, and considers that the timeline will compromise the quality of the findings and recommendations, they will raise this with the Minister for Disability Issues and the Minister for Social Development and Employment urgently. When doing so, they will provide an explanation and a proposed timeline.

Membership and appointment

11. The independent review will be undertaken by a lead reviewer and two advisors appointed by the Minister for Disability Issues and the Minister for Social Development and Employment as agreed by Cabinet.

Conflicts of interest

12. Members of the independent review should identify, disclose, manage, and review situations that might compromise their integrity or otherwise lead to actual or perceived conflicts of interest. The Secretariat will put in place appropriate procedures, including a register of interests, to ensure that any potential conflicts of interest are identified and managed effectively.

Cost and operational matters

13. The Minister for Disability Issues and the Minister for Social Development and Employment will determine remuneration for the lead reviewer and two advisors. Additional funding may be required to pay relevant disbursements such as flights and accommodation.

14. The independent review will be supported by a Secretariat made up of officials provided by key agencies and agreed with the relevant portfolio Minister. Its primary role is to provide advisory and analytical support to the independent review. The Secretariat will also provide advice to the reviewers on project management and planning, and their public engagement strategy.

15. The Secretariat will be hosted by the Public Service Commission. However, the advice of the secretariat will be independent of the Public Service Commission.

16. All costs arising from the independent review (but not including officials provided by relevant agencies for the Secretariat) will be met by the Ministry.

Appendix 3: List of people spoken to by the Reviewers

Government officials

Agency	Official	Role
Whaikaha – Ministry of Disabled People	Amanda Bleckmann	Deputy Chief Executive (DCE) Commissioning, Design and Delivery
Whaikaha	Ben O'Meara	DCE Policy Strategy and Partnerships
Whaikaha	Hayley Evans	DCE Corporate Services
Whaikaha	Helen Walter	Group Manager, Policy
Whaikaha	Maria Morunga	Head of Finance
Whaikaha	Paula Tesoriero	Chief Executive
Whaikaha	Philip Berghan-Whyman	Principal Advisor, Strategic Finance
Whaikaha	Trish Davis	Group Manager, Quality and Insights
Accident Compensation Corporation (ACC)	Amanda Malu	DCE Service Delivery
ACC	Karen Craven	Manager Partnered Recovery
MOH	Emma Prestige	General Manager Family & Community Health Policy
MOH	Victoria Manning	Manager Health of Disabled People Policy
Ministry of Social Development (MSD)	Brad Young	Group GM Finance and Chief Financial Officer
MSD	Debbie Power	Chief Executive
MSD	Melissa Gill	DCE Organisational Assurance and Communication
MSD	Nadine Kilmister	DCE People and Capability
MSD	Sarah Palmer	Manager Disability Policy
MSD	Simon MacPherson	DCE Policy

Others

Organisation	Representative	Role
Australian Government – Department of Social Services	Ray Griggs	Secretary
EY New Zealand (EY)	Adam Naiman	Director Strategy and Transactions
EY	Herwig Raubal	Associate Partner
EY	Sophie Dawson	Partner
Manawanui Support Limited	Sir Bill English	Chair
Spectrum Group	Sean Stowers	Chief Executive
Taikura Trust	Sonia Hawea	Chief Executive
Taikura Trust	Tony Wai	Chair

Appendix 4: Suggested list of Phase Two considerations

The broad themes below were observed while undertaking Phase 1, and we believe warrant further investigation in Phase 2. This is not an exhaustive list:

(1) A social investment and outcome approach including the role of behavioural support

(2) Cross-government system strategic leadership including simplifying the pathways for disabled people

(3) Legislation and policy settings regarding eligibility, services, allocation and prioritisation

(4) Service design and delivery models, including:

- (a) Role and effectiveness of NASCs and NASC national structure
- (b) Role and effectiveness of hosts and national structure
- (c) Taking the best learnings from the EGL demonstration sites – e.g. connectors

(5) The primacy of natural supports

(6) Provision of services for disabled people after they turn 65

(7) Provision of respite care

Appendix 5: Estimated financial impact of recommendations as assessed by the Ministry

Recommendation 2: Freeze current levels of funding for residential facility-based care for 2024/25	s9(2)(j)
Assumptions:	
s9(2)(j)	

Recommendation 3: Take no action on a price increase for providers in 2024/25	s9(2)(j)
Assumptions	
s9(2)(j)	

s9(2)(j)

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