

Summary of issues consultation findings

October/November 2024

Engagement on the issues experienced by disabled people and whānau using MSD's Disability Support Services (DSS) took place between 29 October 2024 and 22 November 2024.

We used a range of approaches to reach out to the disability community, including an online survey, written submissions, and hui with organisations representing disabled people and carers.

A total of 1,501 submissions were received. This summary gives an overview of the key findings from that engagement.

Our written survey had 15 questions across three sections:

- an overview of DSS
- assessment and allocation tools
- flexible funding.

Each question was analysed separately; however, this summary gives an overview of this analysis.

MSD would like to thank all the people who took time to share their views, insights and experiences with us, and thank those individuals and groups who helped us publicise and promote the consultation.

The following sections are not the views of DSS but are a representation of the views expressed to us during this consultation.

We sincerely hope that when those who participated in the issues consultation read this report, they will feel that we have provided a balanced representation of the range of different viewpoints.

This document provides a summary of the views we heard. Quotes included are verbatim and have not been corrected or changed for spelling or grammar.

Disability support services have variable outcomes for disabled people and their families

Some respondents valued the support they received from disability support services, particularly from Enabling Good Lives (EGL) sites.

However, others felt blamed and treated unfairly in their interactions with different parts of the disability support services which contributed to burnout, frustration, and poor mental health.

When you have a disabled baby there is so many different agencies to contact and be apart of that it's overwhelming. I'm scared to contact you to ask for help. You might say no, you might withdraw what funding we have, you might dismiss how hard it is – Family/Whānau, Wellington

this is all put on me as the parent, who has to work full time to pay for all therapy, equipment etc not supplied by government. Across the life course barriers exist, and they are changeable. Our kids grow, get heavier, become adults, we age alongside them. We have no respite, we get burnt out. Then there is our mental health. – Family/Whānau, Bay of Plenty

Some respondents commented on the experience of carers, who felt devalued and traumatised at their portrayal in public debate in 2024. They also felt burnt out because of the current settings.

Respondents highlighted the need for better respite options, both in flexible funding and more respite providers. They also stressed that family and carers should be listened to.

Re-instate FLEXIBLE funding. In other words, using allocated funds in the best way that suits the disabled person and their whanau. To look after the carers who have been trashed on in recent months. Burn-out is not just a myth, and its getting worse. - Family/Whānau, Auckland

Some DSS funded services and supports do not meet needs

Respondents shared their experiences of funding being inadequate to meet their disability related needs because of the inflexible support available.

Over 40% of respondents thought that support should be tailored to needs, not diagnoses, and should treat everyone as individuals, reflecting the diversity of disability.

egl in every Region and listening to what people need not just the diagnosis as everyone is so different with there needs. – Family/Whānau, Canterbury (including Chatham Islands)

Inconsistent practices and services across the country

Respondents shared feedback on inconsistent practices and access to services. They felt rules were not being applied consistently, which resulted in inequitable outcomes between services, regions, and impairment types.

Respondents mentioned barriers to services such as waitlists, regional gaps (particularly to residential care), cultural inappropriateness, and inability of providers to adapt to the circumstances of the disabled person and their Family/Whānau.

Have very clear information on what is funded, with national consistency, in equipment and modifications. Similarly for care provision, and do not reduce what is provided for home based care. Home based care services have been underfunded for years. Funded home based care providers need to provide better education of carers and improved supervision - it seems very hit and miss, at times, when it comes to quality of care. - Service provider, Auckland

Unique cultural and language requirements simply cannot be catered for under an inflexible model when residing in a remote location so family and close friends hve to step in. - Family/Whānau, Northland

Also, realistically, you can't employ someone else to do personal cares, at different times of the day, when you live rurally. You can't ask your disabled family member to use the toilet only at certain times of the day!! - Carer, Northland

The system is unclear and hard to navigate

Many respondents highlighted the need for better communication, which should be accessible, adaptable, and available across multiple channels.

Respondents also suggested staff need a better understanding of disability support services, disability knowledge, and the rights and needs of tāngata whaikaha and Māori.

Some respondents requested more disabled people be employed at all levels across the disability support system.

Train staff continuously on Deaf Culture and basic sign language. increase awareness of Disability especially Deaf community- not enough awareness there. Always book at NZSL interpreter for a Deaf Person. Assigned a Deaf Culture understanding Person for Deaf Community. Lots of Deaf NZ European Māori/Pasifika People struggle with communication and written language due to lack of Education!!! - Disabled person, Auckland

Employ disabled people to review and change the systems that currently dont work for them - Disabled person, Wellington

Respondents:

- Shared feedback on the need for simple policies and consistent processes across the disability system to support a greater diversity of needs.

- Mentioned the need for improved coordination and information sharing between agencies and organisations.

We shouldn't have to 'navigate' we should have access, different parts of government needs to be more accessible. - Disabled person, Wellington

Recent changes were hard to understand

Many respondents highlighted the impact of inadequate and inaccessible communication. 44% of service providers and over half of carers, family/whānau and disabled people were not clear what flexible funding could be used for.

Especially since the March 2024 changes, many respondents did not understand the rules or know where to go to find out.

Respondents felt there should have been consultation prior to the March 2024 changes and requested better representation of disabled people as decision-makers for DSS, reflecting the mantra “nothing about us, without us”.

We as disabled people have a better understanding of our needs and requirements than the government. - Disabled person, Wellington

Respondents emphasised the need for transparent, logical, simple, and practical rules that accommodate the diversity of disability, provide efficient support, and are consistently applied and well communicated.

A large proportion of respondents asked for the ‘March 2024 changes to be reversed’.

What is cost-effectives differs for each person. What is a disability support differs for each person. What is the point of filling out a purchasing support form and providing evidence that it fits the purchasing criteria if the goal posts are continually being shifted to ensure that it can be rejected as not being "cost-effective" or "a disability support". - Disabled person, Auckland

Assessors play a big role in understanding needs

Many respondents mentioned the assessment experience as being critical to match service coordination to needs. Respondents shared feedback on the impact of assessors’ capability to understand disabled people and the needs of their family/ whānau.

Respondents wanted assessors to have more qualifications or experience, greater understanding of disabilities, empathy, cultural sensitivity, and training to recognize unconscious bias.

Strong communication was highlighted with respondents emphasising the need to be listened to and treated with respect, and have complaints acknowledged.

Respondents mentioned workforce capacity, recommending more staff, especially connectors, better wages, and employing more disabled people. Interactions with EGL sites, particularly with connectors, were often mentioned in a positive way.

I would hire more staff to the NASCs with a reasonable case load to ensure that each case is given proper care. - Family/Whānau, Wellington

They should not have the child present for the interview. I didn't want to be negative about my child in front of him, like expressing how much stress he causes me or how my health is affected by caring demands. - Family/Whānau, Southern

Assessments are not as good as they could be

Respondents suggested taking a whole-of-person approach that considered a disabled person and their family/ whānau in their entirety.

They also suggested taking a stronger person-centred approach to service coordinations, where disabled people and their families are listened to, provided options, and given time to understand and decide what is best for them.

36% of respondents said the assessment experience is vitally important, and suggested flexibility in where and how the assessment is done.

They also recommended improving communication prior to, during, and after the assessment, with 41% of respondents stressing the importance of interpersonal communication to improve service coordination.

They had no understanding of the condition, did not meet in person, did not have an interpreter for the online call, were pushed for time so dint cover everything, were unavailable for days on end, did not send draft of plan, etc etc – Family/Whānau, Wellington

Respondents:

- Found assessment criteria vague and overly strict and suggested clarifying the criteria and eligibility to improve transparency in how these are applied.
- Noted the length of time between a needs assessment referral and actually receiving support. They also outlined points of information overload and needing more time to process it all to enable informed decision making.
- Spoke about the frequency of reassessments, with some requesting more frequent reassessments as their circumstances change, and others requesting fewer or no reassessments where disabilities are permanent.

My clients have waited for up to eight (8) months for agreed supports to be written & approved! By the time I get to see them, they are in need of much higher supports. What a waste of extra resources that could have been an easily prevented – Service provider, Central

Many disabilities don't "go away" which could be better recognised by the system, which carries a burden of proof. This carries strain on disabled people, whanau, and on the health centre and network of professionals that are required to reconfirm needs – Family/Whānau, Canterbury

Flexible funding was viewed as a work-around to issues in disability support

Flexible funding was seen by many as a key pathway to support needs that were either not properly understood by disability support services or not provided for.

Over 50% of respondents from every region, except for one, indicated that there are situations where they can only access what they need through flexible funding.

Needs assessments are not holistic or accessible enough to capture the needs of disabled people, subsequently, adequate services were not coordinated for this.

Disabled people are each unique, as all members of our communities. There cannot be a 'one-size-fits-you' approach. Each disability manifests in unique ways and as such needs must be assessed accordingly as well as the funding mechanisms. The current funding and service restrictions reduce a person into 'parts', never being able to function as any other person would expect to do. - Service Provider, Auckland

Flexible funding was seen as an alternative to provider funded services where these were otherwise unavailable, had long waitlists, or were not appropriate to meet the disability related needs in some circumstances.

flexible funding allows me to hire specialised carers, arrange therapy sessions, and manage his unique behavioural and emotional support—all tailored to what works best for him. Traditional funding doesn't typically cover these personalised options, leaving families like mine without the vital resources we rely on. Flexible funding gives us the freedom to make decisions based on real needs rather than predefined, limited services, ensuring my nephew receives the right support for his well-being. - Carer, Canterbury

Every area has the access to the same flexible funding. If the funding is flexible and can be used to purchase community based, uncontracted support options then the support can be tailored to the opportunities available in the community. – Service provider, Nelson/Marlborough/West Coast

Flexible funding was also used as an alternative to provider services where staff were not always reliably available; not a good fit (either personally or culturally); lacking specific expertise; or not affordable.

Choice over staff (whether family members or not) provided a greater level of trust between the disabled person and their staff, and greater control in setting their schedules. This is particularly important for accessing respite care.

Going to the gym for my mental and physical health. He was able to play lego and be content. Play video games when i needed an hour to myself . Having something as a behaviour reward system. Equipment required to help him burn energy, self sooth, to

support him in his sport. My son refused to stay with anyone other than my Mum or Sister. Paying for her to come from Aus and care for him and give me a whole week. After 10 years. Ive been able to have 4 days away since while he stayed with my Sister. Now all of these are not available. - Family/Whānau, Auckland

Respondents:

- Shared frustration with current purchasing guidelines that prevented access to practical methods of respite.
- Emphasised the need for flexibility in how the service is used, where traditional respite provision in many cases is not appropriate or accessible, or where it is not the most cost-effective way to provide rest for carers in ways that work for disabled people and their families/whānau.

There are situations where disabled people and their whanau cannot easily find support workers or they require supports from people who are part of their own culture and language. Carer support hours and respite hours often limit what can be achieved as the funding cannot easily be bundled - for example, the set fee for 24 hours is usually vastly insufficient to hire a person or agency for that period of time. However, being able to fund a family/whanau or similar for the same period can work at a reduced rate (even though this is inequitable). Also, flexible funding may pay for a club or group that can both create a period of respite for family/whanau and a valued activity for the individual. - Service Provider, Wellington

Flexible funding was used to purchase goods and services that respondents did not believe were funded elsewhere. These included consumables for self-regulation, access to participate in community activities, and supports to build or maintain independence.

Currently I cannot participate fully in society because the only funding for interpreters is health or employment related. How would YOU like to be only able to understand things in the workplace or a health setting but not at a whanau gathering like a wedding, tangihanga, or socially like a movie, party, theatre, community support group, or inspirationally like a night class, hobby group, volunteer work to name but a few. - Disabled person, Wellington

Both greater accountability and trust are wanted to make flexible funding work

Respondents:

- Want clearer and simpler accountability and compliance mechanisms to improve flexible funding access and availability, with suggestions including auditing and peer support.

- Requested they be trusted to manage their allocations appropriately with support available to follow the rules and trusted to know how to spend the money in ways that suit their needs and circumstances.

35% of respondents wanted to see greater choice and control in the purchasing rules than was currently allowed.

budget. Timesheets hold us accountable, receipts and purchase guidelines support accountability. We are all individuals living in a family, and community. Trust us as best carers and disabled people to know what we need to make the budget we have work for best outcomes – Family/Whānau, Auckland

The role of DSS is not well defined

Views on the role and purpose of DSS varied substantially between respondents. Many people thought DSS held multiple roles.

Respondents suggested DSS roles include stewardship of the disability system, safeguarding of disabled people, implementing EGL and the United Nations Convention on the Rights of Persons with Disabilities, providing advice and guidance on disability services, assessing eligibility and support needs, and providing disability support services.

To help people with disabilities and neurodiversity be accepted and understood. – Disabled Person, Auckland

link services and support. enable the flow of information and services. It is all disjointed today and nothing available. - Family/Whānau, Waikato

Respondents provided feedback on the three methods by which DSS provides support; funding services, flexible funding, and equipment and modifications.

However, responses varied about the degree to which DSS should play a role in providing support and services to disabled people and carers.

to provide ANY kind of help a disabled person might need – Disabled person, Bay of Plenty

to support them to live meaningful lives and participate in society on an equal basis with non-disabled people – Disabled person, Bay of Plenty

DSS requires better planning and stronger investment

Respondents:

- Felt strongly that DSS required further investment and greater efficiency in managing funds.

- Highlighted growing populations and the critical need for system planning and funding certainty to prevent sudden disruptions to critical services.
- Were frustrated with the Government's funding choices, requesting that funding for disability services be prioritised.

Fund services fully. Meet the needs. It is a matter of human rights and of equity. It is foolish to think cost can be "managed" (aka reduced) without it having consequences, some dire. We know supports and services can improve wellbeing for disabled people and their whānau, increase engagement in education and employment and improve mental health. – Service provider, Southern

13% of respondents felt that structural reform was required, with some suggesting DSS be returned to the administration of Whaikaha, while some suggested it be administered by the Ministry of Health or ACC.

Return management to whaikaha and fund their budget appropriately. Whaikaha were done a disservice when handed the budget from MOH. – Disabled person, Wellington

DSS must consult with and value the disability community

Some respondents stressed the need for genuine consultation with disabled people, family/whānau, and service providers.

Disabled people need to lead change to ensure it is fit for purpose. Respondents also mentioned their frustration at poor consultation by government in the past paired with inaction to resolve longstanding issues.

Having consistently and really listening to the needs of the community and acting on it not just asking for feedback as a formality – Family/Whānau, Wellington

The recent apology from the Royal Commission means nothing if these people are not cared for in an appropriate manner. – Family/Whānau, Central

Respondents:

- Felt disabled people were devalued throughout society and within various agencies across the disability system, and subsequently experienced inequitable treatment.
- Wanted a system that embodies empathy, respect, and empowerment in a culturally sensitive way.
- Discussed the value of EGL in supporting disabled people and their families to better navigate different parts of the government.

A full commitment to Enabling Good Lives. Better resources for auditing and monitoring – Family/Whanau, Canterbury

Long term increased investment that ensures disabled people's human rights are, particularly under Article 19 of the UNCRPD. - Disabled person, Auckland

What happens next?

The findings from this, and consultation in early 2025, will support and inform the development of options for Government to stabilise disability support services so they are fairer, more consistent, more transparent, and sustainable into the future.

Our next community consultation takes place from 10 February until 24 March 2025 and builds on the responses we received in our first round of consultation as summarised above.