# Submission form

### February 2025

## This document is a summary of the [discussion document](https://www.disabilitysupport.govt.nz/consultation/discussion-document-to-support-consultation).

## It is part of work to stabilise the Disability Support System (DSS). Later work will focus on strengthening DSS.

## The full discussion document (and a summary), as well as all the consultation details are available on our website: [www.disabilitysupport.govt.nz/consultation](http://www.disabilitysupport.govt.nz/consultation).

## This form includes consultation questions for you to respond to.

## You can choose which questions you want to answer as part of your submission.

## How to make a submission

The consultation is open from Monday, 10 February until Monday 24 March 2025 (at 5pm).

You can make a submission by:

* completing the submission form and emailing it to:
DSS\_submissions@msd.govt.nz
* completing an online survey at:
[www.disabilitysupport.govt.nz/consultation/complete-a-survey](http://www.disabilitysupport.govt.nz/consultation/complete-a-survey)
* mailing your submission to:

c/o Disability Support Services

Ministry of Social Development

PO Box 1556

Wellington 6140:

**How to make an NZSL submission**

Please email NZSL\_submissions@msd.govt.nz for more details if you would like to send us an audio or video response.

## Topic 1: Improving the way the needs of disabled people are assessed, and how support is allocated

This covers proposed changes to the way peoples’ needs are assessed and how decisions are made about what supports they receive.

It includes assessments through a Needs Assessment Service Co-ordination (NASC). Enabling Good Lives (EGL) assessments are not included.

### Make sure there is a consistent approach to needs assessment

**Question 1**:What changes can you suggest that would ensure the assessment tool and process is fair, consistent, and transparent? You might for instance wish to suggest it is: done in a different place; in person, or not; that it be supported differently; or that you receive different information about it before or after the assessment occurs.:

The purpose of this review is to stabilise DSS so they are more fair, consistent, transparent, and sustainable into the future. To ensure the assessment process is equitable and reflects the realities of the populations we represent, we recommend:

* Greater flexibility in the assessment setting – Individuals should have the option for in-person, virtual, or home-based assessments.
* Support person inclusion – Recognising that many individuals require advocacy and support when undergoing assessments.
* Pre-assessment information – Clear, accessible communication (in a variety of forms) about the process, expectations, and available supports.
* Diversity and disability inclusion – Ensuring that the tool accounts for fluctuating conditions, neurodiversity, and complex chronic illnesses.

### Improve how the assessment tool reflects the diversity of disability

**Question 2:** What information does the assessment tool need to gather about you and your circumstances to ensure it can identify the support you need?

The assessment tool should capture:

* The fluctuating nature of many conditions and how they impact daily life.
* Cognitive, sensory, and executive functioning challenges.
* Financial and social barriers to accessing care, education, employment and social/community engagement.
* The need for individualized support, such as specialised equipment, alternative communication methods, and accommodation in education and employment.

### Assess the needs of family/whānau and carers

**Question 3:** Do you support the needs of carers being specifically assessed alongside those of the disabled person? Why/Why not?

**Add your answer here:**

We strongly support the inclusion of carers' needs in the assessment process. Carers play a crucial role in the wellbeing of disabled individuals, and their capacity to provide care directly affects outcomes for the disabled person. Without formal recognition and assessment, many carers experience burnout, financial hardship, and mental health issues.

 **Question 4:** What considerations in respect to a carer’s situation should be taken into account in order to link them to, or provide, the support needed?

**Add your answer here:**

The financial, emotional, and physical toll of caregiving should be assessed. Access to respite care and mental health support should be incorporated into the assessment process. The impact of caregiving on employment and income should be recognised, and financial support should be considered where necessary. Taking a social investment approach, mitigating the stress and load on carers, should be a high priority of this review.

### Make sure the services and support a person receives continues to meet their needs

**Question 5:** How often have your needs and services / supports been reviewed or reassessed?

**Add your answer here:**

Needs should be reviewed at least every two years unless there is a significant change in circumstances. Conditions that fluctuate or deteriorate should trigger a review, when necessary, without placing undue burden on individuals to prove changes. Reviews should be streamlined and non-disruptive, ensuring continuity of care.

Any reviews undertaken should be done in such a way as to mitigate fear of losing supports and funding.

**Question 6:** What changes to your circumstances do you think should mean a review or reassessment of your services / supports would be needed?

**Add your answer here:**

Needs should be reviewed at least every two years unless there is a significant change in circumstances. Conditions that fluctuate or deteriorate should trigger a review, when necessary, without placing undue burden on individuals to prove changes. Reviews should be streamlined and non-disruptive, ensuring continuity of care.

**Question 7:** How often do you think your services / supports need to be reviewed or reassessed? (For instance, every year, every two years, every three years, or every five years.)

**Add your answer here:**

Needs should be reviewed at least every two years unless there is a significant change in circumstances. Conditions that fluctuate or deteriorate should trigger a review, when necessary, without placing undue burden on individuals to prove changes. Reviews should be streamlined and non-disruptive, ensuring continuity of care.

### Helping you access support that isn’t available through DSS

We propose that NASCs identify supports that are available through other agencies and provide guidance on how these can be accessed.

This will help ensure that DSS is only used for the supports that are not provided elsewhere.

**Question 8:** What information or support might NASCs provide that will help you access the services, beyond DSS, that you might be eligible for?

**Add your answer here:**

NASCs should provide clear pathways to support outside DSS, including:

Advocacy for access to social services, employment support, and housing assistance. Information on financial assistance programs. Guidance on accessing medical and rehabilitative care outside DSS funding.

## Topic 2: Accessing flexible funding, and how it can be used

There are two options for changing how flexible funding can be used:

### Option 1 – Link flexible funding to the person’s plan, with oversight of how it is used

### Option 2 – Adjust current lists of what can and can’t be funded using flexible funding.

**Question 9:** Do you prefer Option 1 (link flexible funding to the person’s plan, with oversight of how it is used) or Option 2 (adjust current lists of what can and can’t be funded using flexible funding)? Why?

**Add your answer here:**

We would reluctantly support Option 2 (adjusting current lists) as it allows for greater responsiveness to individual needs. However, we believe that:

* safeguards should be in place to ensure equitable access and prevent misuse.
* A clear process for an application for funding for something not on the list. Some conditions have very unique needs, and funding should be allocated on a ‘needs’ basis.

 **Question 10:** Do you have any suggestions on how flexible funding can be used to allow disabled people and carers as much choice, control and flexibility as possible, while still providing transparency and assurance the funding is being used effectively, and is supporting outcomes?

**Add your answer here:**

Funding should be person-centred and flexible to adapt to real-life challenges.

Transparency can be maintained through simple reporting mechanisms without creating excessive administrative burdens.

There should be clear pathways for appeals and reassessments if funding decisions do not meet the individual's needs.

### Introduce criteria to access flexible funding

**Question 11:** Do you support the introduction of criteria for receiving flexible funding? Please let us know why, or why not?

**Add your answer here:**

We support the inclusion of criteria that ensure funding is used effectively while allowing for maximum choice and control. But must address points outlined in 12a.

**Question 12:** Which of the following criteria for receiving flexible funding do you agree or disagree should be included and why? (Choose all that you think should apply.)

**12a.** Use of flexible funding is part of an agreed plan and linked to a specific need.

Agree/Disagree

Why/Why not?

**Add your answer here: Agree**

* Agreed plan linked to specific needs – Ensuring funding addresses individualised disability-related support.
* Recognition of fluctuating and complex conditions – Funding should accommodate people whose needs vary over time.
* Addressing service gaps – Flexible funding should be prioritized for areas where standard services do not meet needs.
* Cost-effectiveness without unnecessary restrictions – The focus should be on ensuring that individuals receive meaningful support rather than rigid cost-cutting measures.

**12b.** Disabled people and/or their family / whānau / carers are able to manage the responsibilities of flexible funding.

Agree/Disagree

Why/Why not?

**Add your answer here: Agree**

No decisions should be made about disabled people without their input – giving them this responsibility alongside family/whānau/carers enables them to allocate funding in ways that meaningfully help their quality of life.

**12c.** Flexible funding will be used to purchase a service or support that DSS provides through its contracted services/supports, that will address a person’s disability-related support, and there is an advantage to using flexible funding to purchase it (such as greater flexibility for scheduling, it is closer to where the person lives etc).

Agree/Disagree

Why/Why not?

**Add your answer here:**

Agree – with a caveat.

If the service is not available in their area – this creates inequity – therefore, service users should be allowed to utilise services and supports outside of DSS contractors, in instances where, they are unable to use DSS contracted services/supports.

**12d.** Flexible funding will address a service gap, where the service is not otherwise available, or suitable for the individual.

Agree/Disagree

Why/Why not?

**Add your answer here:**

Agree, if the answer to 12c is addressed.

**12e.** The cost of the support or service that will be funded is not more expensive than other ways to get that support.

Agree/Disagree

Why/Why not?

**Add your answer here:**

Disagree. That all depends on availability of services. We want to move away from the postcode lottery – that enables particular services in some areas but not others. It may be more expensive in smaller areas based on usage levels versus economy of scale in larger areas. Therefore, regardless of the cost if the support/service is needed, it should be funded. This should be allocated on a ‘needs’ basis not ‘cost’ basis.

**12f.** The flexible funding will enable the person to purchase or access a service that is expected to reduce a person’s future support needs.

Agree/Disagree

Why/Why not?

**Add your answer here:**

In an ideal world, early intervention and support, reduces burden on health and support services. However, this is not all the case for long-term conditions, or degenerative conditions where services may increase over time. Again, services should be provided on a ‘needs’ basis.

**Question 13:** Can you suggest other criteria for accessing flexible funding in addition to, or instead of, those above? If you have suggestions, please explain why you think they will be helpful for those who are accessing flexible funding.

**Add your answer here:**

Recognition of underfunded conditions – **Populations that currently receive minimal or no government funding should be prioritised for flexible funding allocations.**

Inclusion of technology and accessibility supports – Many people require assistive technology, home modifications, or communication aids not covered under current funding models.

Simplified administrative processes – Reducing complexity in applications and reporting requirements will ensure accessibility for all.

This response highlights the urgent need for an equitable, inclusive, and responsive assessment tool that truly reflects the diverse experiences of disabled individuals and their carers. The populations represented in this submission require more flexibility, transparency, and recognition within disability support systems to ensure they receive the assistance they need to live fulfilling and independent lives. We include a report “Critical Issues and Challenges in current DSS: A Consumer Perspective” sent in July 2024 to a review panel, which outlines all of our collective concerns, insights, and experiences.

**Compiled and Submitted on behalf of the members of:**

ADHD New Zealand

ANZMES (The Associated New Zealand Myalgic Encephalomyelitis Society)

Autism New Zealand

Complex Chronic Illness Support

Ehlers-Danlos Syndromes New Zealand

Epilepsy New Zealand

FACS-NZ (Foetal Anti-Convulsant Syndrome New Zealand)

FASD-CAN Incorporated Aotearoa (Fetal Alcohol Spectrum Disorder - Care Action Network)

Rare Disorders NZ

Stroke Foundation of New Zealand

Tourettes Association of New Zealand