Re: Disability Support Services Consultation March 2025

To: DSS_submissions@msd.govt.nz
Date of Submission: 24 March 2025
Submitted by: Rare Disorders NZ
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Declaration of interest

Rare Disorders NZ works with clinicians, researchers, allied health professionals, academia, government and industry to achieve better outcomes for people with a rare disorder in New Zealand and their whānau. We are funded by grants, donations, fundraising events, Pharma roundtable and a small Te Whatu Ora contract.

Rare Disorders NZ

Rare Disorders New Zealand is the respected voice of rare disorders in Aotearoa. We are the national peak body organisation, supporting the 300 000 New Zealanders with rare disorders and the people who care for them. We help those affected by rare disorders navigate the healthcare system, find information and resources, and connect with support groups specific to their condition.

We proudly advocate for public health policy and a future healthcare system that works for those with rare disorders – using a strong and unified voice to collaborate with Government, clinicians, researchers, and industry experts, to promote diagnosis, treatment, services, and research.

Our vision is for New Zealand to become a country where people living with a rare disorder are fully recognised and supported with equitable access to health and social care.

A rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 2,000 people in Aotearoa New Zealand. Rare disorders include, but are not limited to, rare conditions among genetic disorders, cancers, infectious disorders, poisonings, immune-related disorders, idiopathic disorders and various other rare undetermined conditions. An ultra-rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 50,000 people in Aotearoa New Zealand.

Our Submission

RDNZ has also fed into a wider group submission addressing the consultation questions compiled and submitted by the President of ANZMES.

We have also attached a submission form answering the consultation questions specifically from RDNZ's perspective, emphasising the aforementioned group submission's messaging and addressing the areas where we saw a need for rare disorders to be specifically considered.

In 2023, RDNZ conducted a survey of people living with rare disorders in Aotearoa NZ and subsequently published a White Paper titled Impact of Living with a Rare Disorder in Aotearoa New Zealand (available here: https://raredisorders.org.nz/media/pages/file/91/5295-rdnz-white-paper-layout-web.pdf). Overall, there were 1076 responses with a confirmed diagnosis included in the primary analysis. This represents the largest ever survey of consumer reported outcomes for people with rare disorders in NZ. Our responses in this submission draw on information gathered in this survey.

As part of our 2023 survey, we asked about Needs Assessments. The quantitative results are copied below and some examples of qualitative responses are also included. RDNZ would be happy to work with the Disability Support Services Taskforce to fully utilise these responses if there is an interest in doing so.

Has the person with a rare disorder had a Needs Assessment completed by a Needs Assessment Service Coordination Agency (NASC)?	Number of people	% total
No and I have not heard of a Needs Assessment	370	37.1%
No, but a Needs Assessment is not wanted	155	15.5%
No, but a Needs Assessment is wanted	82	8.2%
No, a Needs Assessment has been asked for but has not been completed	29	2.9%
Yes, but another Needs Assessment is required as needs have changed	76	7.6%
Yes and it is up to date	210	21.1%
Other	75	7.5%
Grand Total	**997**	**100.0%**

‘Other’ answers reflect confusion/not knowing about the process and eligibility criteria as well as frustration with the services. Many also noted they received a Needs Assessment in relation to a secondary diagnosis e.g. autism but the rare disorder was not considered.

Examples of ‘other’ responses:

- This is confusing as they say every 3 years …but there’s never follow up…patients must self-direct to get these assessments and the flow of whos whos and what’s next is non existent
- Just had done for the first time - we didnt know [child] was entitled to child disability allowance or lifelinks assessment until very recently!
- We had one early on, some help then applied when org went through change, they 'lost' paperwork, also didn't understand situation, became too difficult to keep following up or find someone for respite so we gave up.

Q35a: If the person with a rare disorder has undergone a Needs Assessment, did they qualify for funded services and supports?	**Number of people**	**%**
No and the person with the rare disorder does not require services or support	163	28%
No, and the person with the rare disorder has unmet needs	111	19%
Yes and the services and supports met the person's needs	167	29%
Yes, but the person with the rare disorder needs more than they were assessed as being eligible for	138	24%
Grand Total	**579**	**100%**

In our 2023 survey we asked respondents to comment on any successes and failures they experienced undergoing the Needs Assessment process and their thoughts on the outcome.

An initial review of the 510 responses to these questions showed themes of:

Successes:

- positive interactions with supportive and friendly staff
- receiving funding and/or equipment
- self-advocacy leading to eventual wins
- Largely positive about IF and EGL

Failures:

- What was provided was too little too late
- Poor communication
- Unclear eligibility, lack of information available and provided
- Not enough funding
- Long wait times
- Hard to find services even when funding approved and difficulty finding good caregivers
- Rare disorders don't "fit"

Some examples of responses are noted below (some details have been removed to maintain anonymity):

- Our son is now under PACT so we have no idea of the extent of his funding other than he is left with $77.00 for social expenses, toiletries, haircuts etc
- We did an online assessment and got an increase in carer support days and respite funding
- Able to get funding for all required services, and care needed, feel supported
- Conversations around care in the event of total dependence and how to juggle till funding for this comes through relieved some worry for myself and my son(main caregiver)
- Having a nasc who has lived experience is vital.
- I feel that our Needs Assessor listens and does her best to organise the funding which will support us as best she can. In the past we have had not-great needs assessors, so I hope we can hold on to this one for as long as possible.
- Individualized funding outcome means better outcomes for persons needs
  Initially very hard to get support but now with individual funding which is very successful
- The success was how we battled with NASC in order to get the right package. The NASC are not mana enhancing and we had to really fight for it. So we succeeded despite their best/worst efforts.
- Success in having a good relationship with the IF manager who is my 'go-to'. She is good at making annual contact to review needs. Last year she felt that more support was best and was happy to back an application for the higher supply. She read the situation well at the time, as then I thought we could manage continuing on, but now we have the increased funding, I can see why she pushed for me to accept it.
- I'm not sure if this has Improved as I now understand the system better, but it's still appears to depend on who you get on the day and there mood.

- Being in the enabling good lives prototype areas we are very fortunate and you can see the differences versus before this system came in to play. It has provided investment for equipment that otherwise would not be funded. It has provided support for respite and cares along with therapeutic services. Had we not been in this area we would not be getting the support we are now. It is an unfair system that benefits you by where you live - this is not right.
- He only has funding that covers 3 days at a day provider so I can only work part time
- I appreciate individualised funding, but challenging to find carers to provide respite care due to workforce shortages.
- I had a better experience with EGL, they funded more than just respite. Looked at the holistic picture. I don't think the respite funding is enough - there is a carers shortage and the money we have to hire a carer is embarassing.
- I like that the way things are assessed now are not based on the negatives. But now around helping them to have a better life with the right supports etc. Writing a Living Well plan is so much better and empowers us to set the scene for what it would mean for my son to have exactly that - enabling good lives! We have recently gone through a meeting with the NASC and [my son] also took part. The person put in place ways for [my son] to partake using visuals etc which was great. Through the NASC I was able to learn of some wee organisations out there that could help my son (for example Lego based therapy) that I would not have known of otherwise. Also broadening my view of how to use the funding and where. I feel a bit more in control now that I did before. They are still in learning phase I think though, so there is still room for improvement.
- I requested under the OIA the assessment tool they used and found this helpful the use the terminology they needed the hear as opposed to a different word with the same meaning
- I was assessed mainly for my other illnesses although my rare disease likely caused those illnesses. I'm a very strong advocate for myself which I think helped in my outcome to receive support
- It is divided into medical and disability. This is a problem since some medical problems are effectively disabilities. It took three years of fighting to be allowed an ASD assessment. The care and support

needed is reliant on this assessment. We couldn't do it under paediatric because we were fighting for her life and mental health issues that arose from the stress. Since the surgeries the health has improved to the point that we can now focus on ASD and mental health. The complexities of a rare syndrome means that NASC falls behind in their ability.

- After a needs assessment they could see the need for a wheelchair and were able to initiate and support us through this process.
- After selling our soul to the devil, saying we were boarding mental health breakdown, worst parents in the world etc we were finally given 28 hours of individual funding per week, and 40 hours of respite a year
- we had to break before funding we reassessed and an advocate from CCS Disability spoke for us before adequate funding was given. We can employ several carers to be available so we hv some breaks during weekend days. External respite has been a lifesaver.
- Continuity of care with the same needs assessor for many years. She has been excellent.
- NASC strips Mana and no flexibility. Mana whaikaha restores Mana, but Te Whatu Ora is blocking most with Ehlers Danlos because they have stripped our identity as disabled people. Those in our hapori that Mana Whaikaha support are lucky. The rest have nothing because Te Whatu Ora would rather destroy our Mana, our identity and any chance of getting support than see anyone with Ehlers Danlos be treated well. Te Whatu Ora/Ministry of Health have instructed Mana Whaikaha to stop taking on anyone with Ehlers Danlos syndrome, no matter how bad their disability is. There is no such thing as patient rights or
- It took me years to find it it was available and I had many years without support and with inadequate support.
- It was an awful experience, hard to get help, and a total lack of understanding of what we are going through.
- It was one of the most demoralising things we have ever done. Resulting in trauma / an inflexible outcome and consequently we have chosen (possibly poorly) to support this outside the system.

- It’s great if you have a helpful assessor who understands your situation. We have been lucky with this.
- My daughter was assessed as having very high needs. Through Individualised funding I am able to pay myself for some of her care. This takes a lot of financial strain off the family as its hard for me to find work that fits with her care. Greater flexibility with purchasing for carer support has been good and means if we can't find carers we can instead purchase hase items that support carers to take a break.
- Needs to be clearer guidelines perhaps an email prior to explain what happens after the assessment and what the choices for care help are
- Still trying to navigate this! It is a help but you don't get much support, they are not proactive in helping you
- As the condition changers the assessment does not take that into consideration.
- They will not do a needs assessment without being diagnosed!
- Using the phone to do reviews is helpful
- We successfully advocated for a significant package of Individualise Funding 11 years ago which got providers virtually out of our lives which was great. The package has not been changed (although has increased in line with pay equity etc) which is a relief. NASC's are a flawed approach, and in Northland it is even worse as they are a huge provider of services and there are huge conflicts of interest and client capture.
- NASC were terrible to us on the first 2 assessments. They implied that we shouldn't get anything, we were greedy and should care for our child without help. They would not help when we needed it, we had to complain about them a lot. It was so much unnecessary fighting for services we are entitled to.
- When he was younger it was horrible and traumatic.
- Needs assessor did not visit us at our home. Did not understand and did not offer any ideas of what we could benefit from so we did not know what was available or how to access supports. Very very very poor job done!
- Seems to depend on the advisor you get on the day as to what you're eligible for.

- There seems little transparency on what supports are available. It’s very hit and miss dependent upon the assessor initially, and then the funds are held by a profit driven third party (commercial entity) which has no incentive to facilitate independence. I only find out about supports and changes to the support or welfare system via chance conversations with others.
- Upon moving regions we have found it incredibly challenging to engage with these services and understand who should be conducting the needs assessment so that we can access the appropriate resources.
- NASC referrals need to be coded urgent or not. Urgent means urgent. Not months later.
- We haven’t heard from our NASC coordinator since it was done. The forms don’t match what we were told we could claim for, the forms are very generic
- We have asked for an assessment with an assessor but have been waiting over 18 months
- People not understanding the restrictions owing to the condition. Not understanding how it can change from one day to the next therefore there are days when I'm incapacitated and need way more support.
- Rare disorder not understood or catered for.
- They don’t seem to know about conditions, or have any medical knowledge or understanding of rare disorders look differently than more mainstream ones
- Tired of knowing what I need but not being listened to.
- Being made to continually feel beneath "normal" ppl
- They are not particularly proactive. I only find out about things because I know to ask about them through support groups for example IF
- Before EGL it was very hard to get support
- Carer Support at $80 a day is a ridiculously low amount

  Complete lack of understanding about the 2 disorders affecting our family members
- Due to understaffing we have not had an updated needs assessment - it has just rolled over since covid.
- Even though hand delivered paperwork (because it was important) they 'lost' it, then went through org changes & simply didn't/wouldn't

follow through. Seemed they could not find a suitable person, solution during changes, amongst everything have to deal with, it was one too many agencies letting us down so we let it go - gave up.

- First NASC was declined, we were struggling terribly and when we rec8eved the NASC it did not accurately reflect our son's conditions or his needs. It took a formal complaint to get a new NASC and finally some funding
- From the experience of others with the same rare disorder, they have been turned down because their rare disorder isn't on the list of conditions considered as a disability.
- Having different assessors each time and having extreme differences in options & outcomes. Having to be constantly contacting the NASC to complete a review even when it was overdue & the funding had not ticked over.
- I can't get a handle on what we could be eligible for, or how I could get further support for my daughter. I was disappointed that there was no home help
- I feel it is very unfair. If my daughter had ASD (on the cards later) she'd instantly get IF, but because we have a rare disorder we are only getting carer days.
- I find the most frustrating thing is finding out the person who is your point of contact at the NASC has left but this is not communicated to you. I still feel communication is not the best.
- I only knew about carer support early on and found out about respite and IF approximately 4 years after diagnosis
- I reached out not long after diagnosis 1yrs old and was told we weren’t entitled to anything, it wasn’t until my daughter was 6 that someone mentioned them again and they said we should be entitled to funding, I reached out and turns out all along we could have had this! Getting the respite care funding finally was great, not so great experience reaching out for more respite hours sometimes feeling like you are stealing out of there own wallet or having to jump through hoop after hoop, still being on waiting lists for things like horse riding for kids with disabilities a year later. Feeling like when you ask about certain things for your child, getting shut down with a no you don’t qualify but never really getting an understanding of why

and of at some point you will…do I have to remember and reach out again or do they etc.

- If you were not good at writing to describe the need, it would be hard to get the support. A person should be funded on their need, rather than a NASC budget divided up amongst people in their area. A person should be able to access what they need wherever they are in NZ, not limited by what address they have.
- It varies greatly in different regions. I discovered this after moving.
- It's too subjective - it's up to the coordinator as to what you are "eligible" for but it's too inconsistent and everyone ends up with a different amount.
- Just not enough funding. No help to find services – again, back to my own resources to try to find services and cobble something together.
- Lack of knowledge about the rare disease
- My daughter underwent several needs assessments as a toddler. Shortly before beginning school it was determined she required a motorised scooter to help her get around school, as she was yet unable to walk. The motor scooter arrived when she was in year 5.
- My only issues were way back in the beginning where my two didn’t fit the mould but advocacy is the answer here.
- NASC did not consider the syndrome a disability and only picked up on some of the smaller areas that were part of the syndrome. It was definitely not a holistic approach for the person or their whānau.
- They don't look at the family as a whole unit

Disability
Support Services

MINISTRY OF SOCIAL DEVELOPMENT
TE MANATŪ WHAKAHIATO ORA

Submission form

February 2025

This document is a summary of the discussion document.

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.

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
- 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.:

Add your answer here:

- **Qualified Assessors** – Needs Assessments should be conducted by professionals with training in rare disorders and the additional challenges people living with rare disorders face.

- **Flexible Assessment Settings** – Individuals should have the option for in-person, virtual, or home-based assessments to accommodate diverse needs.

- **Support Person Inclusion** – Recognising that many individuals require advocacy and support when undergoing assessments, the presence of a support person should be allowed and encouraged.

- **Clear Pre- and Post-Assessment Information** – Accessible information should be provided in multiple formats before and after assessments, outlining the process, expectations, available supports, and eligibility criteria.

- **Diversity and Disability Inclusion** – The assessment process should account for fluctuating conditions, neurodiversity, and complex chronic illnesses. Criteria should be needs based not diagnosis based.

- **Transparent Decision-Making** – Consistent and clear processes should be implemented across all NASC agencies to reduce inconsistencies. These processes need to be publicly available.

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?

Add your answer here:

- **Holistic Understanding** – A full view of the individual, including progressive, fluctuating, and complex symptoms and needs.

- **Family/Whānau Impact** – Recognising the broader effects of rare disorder on family members and caregivers.

- **Access Challenges** – Understanding barriers to care, including physical, geographical, financial, and social obstacles that limit access to healthcare, education, employment, and community engagement.

- **Recognition of Undiagnosed or Complex Conditions** – The ability to accommodate individuals with rare, undiagnosed, or overlapping conditions. The assessment tool needs to be based on symptoms and need with recognition this may not fit with the assessor's understanding of the diagnosis.

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:

Yes. Carers play a critical role in supporting individuals with rare disorders, and their well-being directly impacts the quality of care they can provide. Many carers face significant physical, emotional, and financial strain, yet their needs are often overlooked in the assessment process.

This is particularly important as approximately half of people living with a rare disorder are children, meaning many parents and family members take on full-time caregiving responsibilities with little formal support. Carers often experience burnout, loss of income, and difficulty accessing respite or tailored assistance. Assessing their needs alongside those of the disabled person ensures they receive appropriate resources, respite care, and support, ultimately benefiting both the carer and the individual with the rare disorder.

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 physical, emotional, and financial cost of caregiving.
- The need for respite care and mental health support and the barriers to accessing this. We have heard a lot from our community that while respite is funded, they cannot access it.
- The impact of caregiving on employment and financial stability.
- Access to training and support networks.

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:

Community feedback indicates that reassessments are often delayed or only occur when individuals are in crisis.

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:

- Changes in health status or progression of a rare disorder.
- Significant life transitions, such as starting school or employment.
- A change in family or carer circumstances.
- Conditions that fluctuate or deteriorate should trigger a review, when felt necessary by the individual and their whānau or care team.

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:

The emphasis needs to be that reviews occur at appropriate intervals without placing undue burden on individuals to prove changes or be administratively difficult. Reviews should be streamlined and non-disruptive, ensuring continuity of care. Reviews should be managed in a way that there is not a fear of suddenly losing needed support.

The administrative burden of proving the disorder is ongoing for conditions that are lifelong needs to be removed.

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:

- Processes and supports should be in place to support those approaching times of transitions (e.g starting school, leaving school, starting employment, entering adulthood).
- There should be processes to ensure people with rare disorders that include both health conditions and disabilities and/or hidden disabilities are able to access support that is comparable to people who have an isolated or more visible disability.
- Individuals and whānau should be connected with support networks where possible.
- NASC's should have information about accessing support for e.g. Work and Income, Education, Housing, Transport, and the Health system. They should have cross agency contacts who they can ask about difficult situations (with consent) and a way to pass this information on to the individual.

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:

Whichever option is chosen, there must be a clear process for an application for funding for something not on the list/not in keeping with a previous plan. This process needs to be well known about, transparent, accessible, not administratively burdensome and have reasonable timeframes for decisions to be made, as well as an appeal process.

Some disorders and individuals have very unique needs, and funding should be allocated on a ‘need’ basis not based on a pre-set list or criteria.

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 allowing maximum choice and control for individuals and whānau who want this.

Criteria needs to allow for individualised decision-making and do not create unnecessary barriers for those with rare disorders who often don't fit tick box criteria due to their unique conditions that are often not thought about while the criteria are designed.

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:

- If there is an agreed plan it needs to have the ability to recognise fluctuating and complex conditions – Funding should accommodate people whose needs vary over time.

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 – With the provision of support and guidance for those who want assistance in managing funds.

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:

This needs to be approached cautiously such that it does not limit access to services that may better suit individual needs outside of DSS-contracted providers.

There also needs to be consideration of access to services for those that are not in an area with a DSS-contracted provider for that service, but another provider is available.

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:

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:

Cost should not be the sole factor; access to appropriate services and meeting needs should take priority.

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:

Many rare disorders are degenerative or fluctuating and lifelong. Criteria that expects improvement or reduced dependency on support does not take this into account. Support should be needs based.

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:

The funding should allow for non-traditional supports, including innovative solutions tailored to rare disorders.