



Re: The future of Disability Support Services

To: DSS_submissions@msd.govt.nz

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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

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.

1. What is the role and purpose of Disability Support Services in disabled people's and their whānau / families', aiga and carers lives?

Rare Disorders NZ supports the key characteristics of Enabling Good Lives (Outlined here: www.enablinggoodlives.co.nz/about-egl/egl-approach/key-characteristics/) and believes these are essential to the role and purpose of Disability Support Services.

1. Self-directed planning and facilitation

All supports and services are led by the preferences, strengths, aspirations and needs of disabled people and their families. An aspiration-based personal plan is the central document to design and measure paid supports. While the core components of plans may be similar, plans make take different forms. Unique and changing aspirations are to be expected. Supports and services will need to continually adapt in the way they assist people to build and maintain a good life.

An Independent Facilitator (Navigator) can assist disabled persons and family/whanau to consider existing options and create new possibilities. The degree of involvement an individual or family has with a Navigator is negotiated between the parties.

2. Cross-government individualised and portable funding

Disabled people and family/whanau have control of funding i.e.bulk funding, according to service type, will be replaced with individualised funding where people can choose how they create a good life for themselves. All government funders will contribute to one funding pool that is determined through a simple process of self assessment (or supported self assessment) and confirmation.

Disabled people and family/whanau will be able to move their funding as their preferences and needs change.



3. Considering the person in their wider context, not in the context of 'funded support services'

Disabled people and family/whanau belong to networks e.g. family, friends and community. These networks are respected as being fundamental to identity, belonging and citizenship.

4. Strengthening families or whānau

There is direct investment in the networks of disabled people and their family/whanau. Resources are provided to assist understanding, educate and promote increased knowledge of options and how to maximise choice and control.

5. Community building to develop natural supports.

Disabled people are active and valued citizens with an everyday life in everyday places. Enabling Good Lives supports people to achieve desirable outcomes such as education and training; employment; being with friends; having relationships and a family; and taking part in community and cultural activities. Community (generic, mainstream) opportunities and assets are educated and supported to be inclusive and valuing of diversity.

In addition to this, One of RDNZ's seven priority areas is *Access to disability and social supports, including support for carers.*

We continue to advocate for health and other government entities to implement mechanisms to ensure appropriate access to disability and social supports for those living with a rare disorder, including support for carers. We see the role of Disability Support Services including:

- Ensuring those with unusual co-presenting undiagnosed symptoms are included. This means that not having a diagnosis is not a barrier to accessing funding and support.
- Developing an easily accessible pathway to information on support services available to those with a rare disorder.
- Removing the administrative burden of proving the disorder is ongoing for conditions that are lifelong.
- Ensuring that 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.



2. Is the role of government agencies in supporting disabled people clear?

No

3. If no, please provide examples.

RDNZ's 2023 survey found that people did not feel informed at all around the rights related to the consequences of their rare disorder (79%), relevant social services that can help them (73%), or financial help they could be entitled to (66%).

The survey also found over 50% of respondents felt that communication and information exchange between different service providers was poor.

A majority of people said that professionals from social, local and support services are not well prepared to support their family, nor informed about the disorder and its consequences.

Even if people are aware of support available, the definition of 'disability' that will receive support that is used across different government agencies differs and Disability Support Services definition excludes what is referred to as personal health conditions. It is unclear to much of our community whether for the purposes of Disability Support Services, they are 'disabled' enough, or if they have a personal health condition and will not be eligible.

People cannot be split in half but the current system wants to separate their disability from their health condition, which for many with a rare disorder is actually all part of one syndrome or disorder.

4. How do you find navigating between different parts of government?

- 1 = Very hard

Quotes from RDNZ's 2023 survey responses:

- We have also stumbled on support and additional funding by accident and no one person/body ever sits you down and discusses what you are eligible for which is very frustrating so we have probably missed out on some stuff
- No one can give me any information on what services I qualify for

5. What supports would help make this easier?

RDNZ advocates for:

- Developing an easily accessible pathway to information on support services available to those with a rare disorder.



6. What short-term actions, over the next one to two years, do you think would improve disability support services?

RDNZ supports the feedback of Awhi Ngā Matua as follows:

- flexibility for funding spend must be returned to what it was before 18 March 2024. The removal of flexibility is an attack on the dignity of families who know what their tamariki need to thrive.
- Carer support is meant to support carers and parents - this Government must recognise and value carers and apologise and build trust with the community.
- Tamariki with low to moderate needs still need funding. Providing funding now to tamariki with lower support needs is a form of early intervention and prevention that often reduces the severity of need later.
- Many disabled, medically fragile, and neurodivergent tamariki are not in mainstream schooling, refusing requests for funding allocations and supports during school hours is not fit for purpose for most of these tamariki. Return flexibility for funding to pre-18 March levels.
- Disability Support Services policies need to match and enact Enabling Good Lives principles.

7. What short-term actions, over the next one to two years, do you think would help better manage the cost of disability support services to the Government?

The government needs to budget better for the increasing need in the disability community. If the government cannot balance their budget then they need to be transparent about this rather than creating a narrative that paints disabled people and families as greedy or misusing funds.

Delays in and lack of access to support and early intervention often leads to worse (and more expensive) outcomes. Reframing the cost of Disability Support Services to how it can be an investment is needed.

8. Longer term, what changes do you think would help improve disability support services?

RDNZ calls for change that will ensure that 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.



Many rare disorders have a fluctuating course and needs can increase and decrease rapidly, the current system is not well set up for this.

Better data is needed for the government to make budget decisions, lack of data collected on rare disorders contributes to this.

9. What changes do you think would make disability support services fairer?

RDNZ advocates for the following:

- Ensuring those with unusual co-presenting undiagnosed symptoms are included. This means that not having a diagnosis is not a barrier to accessing funding and support.
- Developing an easily accessible pathway to information on support services available to those with a rare disorder.
- Removing the administrative burden of proving the disorder is ongoing for conditions that are lifelong.
- Ensuring that 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.

In addition to this, clear published criteria for eligibility for different types and levels of support with staff well trained to apply the criteria is needed. Many members of the rare disorder community currently feel that support received is dependent on the staff member's willingness to help and their advocacy efforts rather than transparent criteria.

Our community report there is currently a post code lottery/ inconsistency across the regions and this needs to be addressed.

Currently our community report that a lot of advocacy is needed to get what you need and it shouldn't be like this, what you get shouldn't depend on health literacy, having an advocate and presenting well.

The second half of the survey questions relate to specifics about needs assessment and services coordinated at NASC or EGL sites for disability support services received.

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 embarrassing.
- 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 received 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 their 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