Re: Have your say on further improvements to Disability Support Services (DSS)

To: Disability Support Services, Ministry of Social Development
DSS_submissions@msd.govt.nz
Date of Submission: 31 July 2026
Submitted by: Rare Disorders NZ
Contact person: Chris Higgins (CE)
Email: Chris@raredisorders.org.nz

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. This submission is in regard to consultation on further improvements to Disability Support Services.

Rare Disorders NZ

Rare Disorders New Zealand (RDNZ) 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 living with rare disorders to navigate the healthcare system, find information and resources, and connect with support groups specific to their condition.

Our vision is for New Zealand/Aotearoa to become a country where people and whānau living with a rare disorder experience best possible health and wellbeing. We seek to achieve this by enabling and empowering people with rare disorders to best benefit from services and therapies available in New Zealand, and by championing their collective voice, advocating for provision of world leading evidence based health, disability, education and other services.

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

Submission

This submission draws on the experiences of people living with rare disorders and their carers and highlights the need for Disability Support Services to better recognise and respond to their needs.

Quotes used throughout this submission, and included in Appendix 1, are drawn from Rare Disorders NZ's 2025 Voice of Rare Disorders Survey, completed by more than 1,000 people living with a rare disorder and their carers. The survey findings show that many people with rare disorders and their whānau experience a disability support system that was not designed with their needs in mind and is not working for them. Our community's voices tell the story of a system that struggles to accommodate complexity, respond to fluctuating needs, and provide equitable access to support for people whose conditions and needs do not fit neatly within existing support service categories.

Our survey results demonstrate a significant failure of Disability Support Services (DSS) to adequately recognise and respond to the needs of people living with rare disorders. Among respondents who expressed a view, only 12% believed DSS takes the unique needs of people with rare disorders into account, including just 1% who felt this was done very well. Meanwhile, 58% reported that these needs were either not considered at all (29%) or not considered well enough (29%). The breakdown of responses to this question can be found in Appendix 2. These findings indicate that the current system is not meeting the needs of much of the rare disorder community and reinforces the requirement for recognition of the complexity, diversity, and variability of rare disorders within DSS systems.

The situation for carers of people living with rare disorders is also alarming. In our 2025 survey, in situations where a primary carer was involved, 77% had sometimes or often felt unhappy and depressed in the past 4 weeks, and 60% had sometimes or often felt they could not overcome their problems. This level of strain is not sustainable or safe. Our carers need more support that is easy to access and understand.

New Zealand was last examined by the United Nations Committee on the Rights of Persons with Disabilities in 2022. The Committee saw what our survey shows: people with rare disorders are not receiving equitable access to, and inclusion in, disability support services. This was reflected in Concluding Observation 54 (c). The recommendation calls on the government to *ensure that people with …. rare conditions have access to the disability support system and are included in disability policies and programmes*. The Human Rights Monitor records that implementation of this

recommendation is being progressed through Action CRPD-2022-A072: *MSD will consider the eligibility settings for who is eligible to be assessed for MSD-funded disability support services (DSS) as part of its strengthening DSS work*.

Rare Disorders NZ considers this consultation and the decisions that follow it a critical test of the Ministry of Social Development's commitment to acting on CO54(c) and to the UNCRPD. To give meaningful effect to this recommendation, the Ministry should ensure that DSS assessment processes, service design, and service eligibility and accessibility are based on a person's needs, circumstances, and the impact of their condition on daily life, rather than on diagnostic labels or artificial distinctions between "health" and "disability".

Failure to address these barriers risks perpetuating the exclusion that the UNCRPD Committee specifically sought to remedy. People with rare disorders should not be denied equitable access to DSS because their conditions are rare, fluctuating, difficult to diagnose, poorly understood, require different services or care solutions to more common conditions, or span both health and disability systems.

Where appropriate, consultation questions have been addressed by Rare Disorders NZ and quotes from our 2025 Voice of Rare Disorders Survey have been included as bullet points in italics. Some questions are not addressed as they are designed to be answered by individuals receiving services not an organisation.

Topic One: Outcomes that matter for disabled people

1. **What outcomes or wider benefits from our services are the most important to you? Are there any that we have missed?**

Access to support services and equipment needs to include outcome measures related to the timeliness of the service, flexibility of the service, equity of awareness and access to services, including for people with rare disorders.

Measures should also capture whether the service and support is responsive when needs change.

We recommend that Outcome 1 – Daily Living is updated to include the text in bold "We provide disabled people with **timely and equitable access to** essential supports required for everyday life (for example, personal cares, residential care) **that are flexible and responsive to need**."

DSS includes Carer Support, but carer wellbeing is not currently reflected in the proposed outcomes. Meaningful impact on carer wellbeing should be treated as a core outcome of Disability Support Services, particularly where families are providing complex, sustained or lifelong care in the case of many rare disorders.

Community voice:

- *Services remain inflexible and focused on the short term rather than condition specific needs to promote QOL and full societal participation.*
- *it's a lack of support for whānau and carers*
- *DSS doesn't take into account how much work families must do to coordinate all the care, support and education needs of their family member with a rare disorder because most of the time no one know much about the condition. It requires a lot of skill and time to advocate effectively to get minimum services!*
- *They are too far removed from the day to day challenges we face and do not consider mental health of the careers to be a top concern. It should be fully funded!*

2. **We have two outcomes that we must achieve (Daily Living and Safety as described above). Can you please rank our five wider benefits in order of importance to you from 1 (most important) to 5 (least important)**

Rare Disorders NZ has not ranked the five wider benefits, as this question is best answered by individuals and whānau using DSS. However, we note it is important that benefits should be interpreted broadly enough to include people with rare, fluctuating, degenerative, complex and poorly understood conditions

4. **Do our outcomes and wider benefits reflect the needs of all people that access DSS support?**

The proposed outcomes and wider benefits do not yet adequately reflect the needs of all people who access, or should be able to access, DSS support. They need to better account for people whose disability is complex, invisible, episodic, degenerative, or fluctuating.

For some people, support may not result in long-term "growth" due to the complex, degenerative or fluctuating nature of their disorder. This does not mean it is less important or less beneficial to support them.

Community voice:

- *I have concerns around the changing nature of my rare disorder, in that every day is different and some days I require a lot of support and other days less support. I get concerned that DSS don't or are unable to have flexibility around this. It appears very black and white. It concerns me that my support will be reduced or cut and that I will struggle to maintain and get this support back if they take it away from me.*

- *I have found the service difficult to access if you don't fit in a box. Because my disorders are relapsing, sometimes I am of high need, unable to walk, and other times I am ok, therefore do not qualify.*

Topic 2: A more proactive approach to support

6. **In a more proactive system, what would you want to see happen differently from how the system or services work with you now?**

A more proactive system would manage the administration of shared and coordinated delivery with Health NZ-funded services where a person has both health condition and disability related support needs. DSS systems are too diagnosis and category driven and too siloed from other support. This does not adequately reflect the complex reality of multi-system rare disorders.

A proactive system would ensure people receive clear, accessible information upfront about what support is available, who is eligible, how to apply, what evidence is needed, and how DSS interacts with other government funded services.

The DSS systems should be linked with other government assistance to both ensure people are aware of it and also reduce the need for duplication of effort for people who are eligible for assistance having to constantly prove it across different departments.

A proactive system would have assessment processes that explicitly consider and plan for fluctuating, relapsing and degenerative conditions, including future trajectory and the likelihood that needs may change quickly. A more proactive system would identify, plan for and respond to changing needs earlier, rather than requiring people and whānau to wait until they are in crisis or repeatedly prove need.

Community voice:

- *They didn't know whether to classify [my rare disorder] as a "health problem" or a "disability", as it technically fulfils the criteria for both, yet they can only choose one for their funding streams. I asked what practical difference it would make for my care to be classified as one versus the other, and was told "I honestly don't know"*
- *Some rare disorders considered long term conditions are not covered by DSS NASC and because of other disabilities... Hospital long term service refer back to DSS causing bouncing between services*
- *Because rare disorders can have a variety of issues that can change over time, are not well known or widely understood the assessment for care and support can be quite rigid*

- *The time when disability support services are often needed most is when seeking diagnosis and this can take years and mean the patient is not earning, however without a firm diagnosis there is often no support.*

7. **What additional supports should DSS think about providing at the key transition points in people's lives (for example, one-off funding to invest in technology, facilitative support that aims to reduce over time, assistance with navigation, planning, and connection)?**

DSS should provide practical supports at key transition points, including navigation, planning, technology and equipment, and short-term facilitative support that can be scaled up or down as needs change. These supports should be available not only at age-based transitions, but also at diagnosis, deterioration, hospital discharge, changes in care arrangements, school-to-adult transitions, changes in housing, and when whānau or carers can no longer sustain the same level of unpaid care.

Any additional supports should be flexible and easy to understand and access. Pathways and eligibility need to be very clear and administrative load on the individual and carers as low as possible.

Community voice:

- *The system is very time consuming and draining to navigate. Someone to walk you through the application processes and help you understand your entitlements across the board would be incredibly helpful.*

8. **Can you provide us with any additional thoughts you have about the questions you have just answered, or on how can we get better at providing the right support at the right time?**

We would love to see DSS provide the right support at the right time by shifting from a reactive model to one that anticipates complexity and change. This will require clear pathways between health and DSS, recognition of and planning for fluctuating and degenerative conditions and needs.

We need an accessible, flexible system with assessors who listen so our community are not having to advocate for services from crisis point.

Community voice:

- *That they will not fund my increasing needs in a timely manner due to over work and underfunding and my life will be extremely difficult while my request makes its way through the system*

- *Slow to respond to changing needs; seem to have a cookie-cutter approach / one size fits all mentality.*

Topic 3: Feedback and complaints processes

9. **Thinking about the support you receive from a DSS provider, what matters to you when you are being supported? How do you know when you have received a quality and safe service?**

Quality and safe support for people with rare disorders requires assessors and providers to listen, learn, and avoid inappropriate comparisons with more common conditions. People with rare disorders and their carers need to feel believed, respected and involved in decisions about their support.

For many rare disorders there is not a traditional evidence bank or care pathway, and the people living with the rare disorder need to be recognised and respected as the experts in their disorder and what they need.

Community voice:

- *For rare conditions there is little support or understanding or willingness to learn. So insulting when they don't listen or compare with conditions they think are similar.*
- *Rare Disorders are complex and I have found myself explaining time and time again how this disorder affects my disabled person. DSS attitude can be somewhat blasé*
- *They haven't heard of our Diagnosis and try to lump it with others which doesn't work.*

11. **Would a short, regular feedback survey be a good way for my DSS provider, and national agencies, to monitor how well my supports and services are working and respond where improvements are needed?**

    How would you prefer to give feedback on the support or services you get from DSS providers?
    What would give you confidence in a DSS providers' complaints process?

Feedback and complaints processes should be treated as an important source of system learning, not only as individual issue resolution. Repeated feedback about poor understanding of rare disorders, inflexible assessments and support, inaccessible information, or service gaps should trigger national-level review and improvement.

Processes to identify themes should be built into any feedback/survey/complaints system.

Topic 4: Better support for carer respite and breaks

13. **Can you tell us about the issues you, or your carers, face when accessing respite care, day programmes, or other DSS services that support carers?**

In our 2025 Voice of Rare Disorders Survey, we asked "If you qualify for respite care, are there barriers that prevent you from accessing it?" Below are a representative selection of responses covering the main themes.

Lack of staff and facilities available, particularly rurally and in smaller communities

- *There is no respite house in Palmerston North*
- *Only in the ability to find temporary carer support while taking respite. There is close personal care requirements from time to time making this difficult*
- *Not able to find a person to cover nights*
- *Can't find people to do the care*
- *Can't find the staff to provide at present*
- *No qualified Support Workers available in our region.*
- *Not enough experienced support workers.*
- *the cities are better equipped, the regions dont have the same opportunities to use the respite care.*
- *Difficult to find a suitable facility*
- *No facilities available with the required gear or staff available*
- *Finding appropriate carers and pay structure does not always help maintain them.*
- *Live in small community that doesn't provide any or is hard to access it*
- *Because we live rurally and due to some of our son's requirements, we really struggled to find a suitable carer.*

Complexity of care needs limiting options

- *Barriers are finding people that are aware of their disability and not scared of needles. I don't trust my children with anyone but close family, their eldest sibling is the only person I'd trust in their care because of the nature of the disorder.*
- *Don't like the options to send her away. She is not verbal and vulnerable. Due to the equipment she needs, she can't sleep anywhere but at home.*

- *I was told there isn't a respite facility that would take him as his needs are too high*

Inflexibility of Disability Support Services (we appreciate that since the survey flexibility has increased but feel it is important to share this perspective as future changes could have similar impacts)

- *Child is unable to stay overnight at other houses as sleeps in an enclosed bed and our house is "[child's name]" proof, since the change in funding we can no longer pay with our IF funding for a hotel so have not had a night away for years*
- *EGL goals seem to have disappeared so we no longer have flexibility to use funding in ways that suit our child*
- *Extremely rigid on what it can be used for.*
- *Unfortunately, the things that would give me true respite are not covered in what I can claim for.*
- *We were unable to use all of our respite funding, despite wanting to, resulting in it being reduced. The restrictions around how respite funding can be used is very challenging.*

Insufficient funding

- *The cost to pay these carers outweigh the funding pool we are allocated. There is no balance.*
- *Carers to support as no one will get paid 80 dollars a day respite and they shouldnt*
- *The fact we have to top up the funding contribution. It's costly.*
- *Cost!! Carer Support payments are a joke! No-one will care for a highly vulnerable medically fragile child for $80 a day!! That's what is allowed per day. Individual Funding picks up the slack financially, but finding people suitable to look after [child] is bloody hard! We have one teacher aide from her school that does overnight respite for us but it's $400-600 depending on the hours. It's a big chunk of our funding for a much needed night off!!*
- *Difficult to find someone who is willing to care for the person for such a little amount of money - less than half the minimum wage.*
- *The subsidised amount provided for 8hours care ($80) is cost prohibitive for accessing care from anyone other than a family member (as it does not cover the cost of anywhere near 8 hours of care).*
- *The fact we have to top up the funding contribution. It's costly.*

Difficulty with processes and understanding the how DSS works

- *Cumbersome process to use. Too many rules. Might as well not have it.*
- *Was a battle to get the hours we have.*
- *I actually still don't understand how it all works. Minimum wage to how much you get to pay for someone so you can get respite simply doesn't add up in the slightest.*
- *Lack of understanding how it works*
- *I don't know about my entitlements to respite care*
- *Do not know who does respite care*
- *We're not actually sure if we qualify for respite care, and we don't know how to access it if we do*

15. **Can you provide us with any additional thoughts you have about the questions you have just answered on the support DSS provides for carers?**

DSS should recognise carer workload, mental health, coordination burden, and the need for genuine respite.

Topic 5: How we offer more choice and control in our services

16. **Currently there are two main options for DSS support - flexible funding budgets or a fixed range of services available from the providers that DSS funds. What could DSS do to give you more flexibility, choice and control in accessing services; without full responsibility for managing a flexible funding budget?**

17. **How could DSS improve, or add to the services we provide, so they work well for all users?**

DSS should provide a wider range of flexible options between fully self-managed budgets and fixed provider services. People with rare disorders and their whānau need flexibility and choice without being required to take on a large administrative burden.

We would like to see DSS improve services by designing them around functional need rather than diagnosis, and by recognising fluctuating, relapsing, degenerative and variable conditions.

Services need to allow for changing levels of support, timely access to essential equipment, streamlined growth-related equipment replacement, and better integration with Health NZ services for people who have both disability and chronic health-related needs.

Community voice:

- *Still the funding isn't flexible enough. We have struggled to find respite caregivers? I haven't used all our funding and yet am not allowed to spend it on modifications or devices that would help keep our son safe.*
- *The options for equipment isnt good enough, and the process and systems to get the funding and equipment are too slow and too hard to navigate.*
- *Access to equipment will become more vital as our boy gets older, and I'm not confident it will be provided in a timely manner (or at all). We also don't know what support of any our son will qualify for - no one seems to be able to tell us. It's so hard to navigate*
- *They can't find us on their drop-down menus, therefore we are ignored.*

18. **Are there specific considerations, or different types of services, we should have for children and young people?**

Children and young people with rare disorders often have complex, changing and highly individual needs that do not align with common disability categories. Flexibility and listening to carers about the needs of their children is essential, especially for rare disorders where there is unlikely to be information about their needs or an assessor familiar with the disorder.

DSS needs to consider the cumulative impact of caring responsibilities for families with genetic disorders affecting multiple members and for those who are going to be life-long carers of their child.

19. **Are there any services that DSS doesn't currently provide, that we should consider adding, to help deliver better outcomes for disabled people?**

DSS should add a service to provide joined-up responses for people whose needs sit across health and disability systems and take responsibility for ensuring this group of people are receiving equitable support.

In addition, the needs of people with one of the more than 7,000 rare disorders will never fit neatly into a list or tick-box system, so flexibility and ability to override tick-box categories must always be built into service design.

Community voice:

- *It should all be a result of need (not which brand name condition, alignment, disability they have). Seeing my son miss out where kids who have a known condition (ie CP) get instant free access to things that all of my sons symptoms suggest he would benefit from is totally unfair*
- *They don't recognise that we do not fit into a one box fits all, that each disease is different. We have seizures but don't fit general epilepsy, we have autism but*

don't fit general autism, we are non mobile but don't fit cerebral palsy, we are a round peg trying to fit into a square peg

20. **and you provide us with any additional thoughts you have about the questions you have just answered about the flexibility and range of services that DSS provides?**

For people living with rare disorders, flexibility is essential because needs may be unusual, unfamiliar to providers, and not easily matched to standard service options.

Choice and control should not depend on a person or whānau having the time, confidence, capacity and resources to manage complex systems themselves. Many people and families living with rare disorders are already coordinating and navigating many other areas such as health and education. DSS needs to provide respite and needed supports, not add more complexity to their lives.

Topic 6: Improving our information and advice

21. **Where do you currently get information about disability supports from?**

People with rare disorders and their carers often rely on a mix of informal networks, condition-specific organisations, peer groups, health professionals, community organisations and online searching to understand disability supports. This means access to information can be uneven and depends heavily on personal networks, capacity, and whether someone happens to find the right pathway.

22. **What are the biggest challenges you face when trying to access information about DSS?**

The biggest challenges we hear about from our community are not knowing what support exists, who qualifies, how to access it, what evidence is required, and how DSS interacts with other services. Information can be difficult to find, fragmented, unclear, and hard to apply to rare or complex conditions that do not fit standard examples and are a mix of disability and what DSS refers to as 'personal health conditions'.

Community voice:

- *Didn't even know it existed which shows they are not viable to the ones who Need the support services the most*
- *It is very difficult to access*
- *It is hard to find what is available*
- *Don't know what support is available*

23. **What information do you want, or need, to know about the services DSS provides?**

People need clear information about what services DSS provides, who they are for, eligibility criteria, referral pathways, assessment processes, evidence requirements, review rights, complaint pathways, funding options, and how DSS-funded supports interact with Health NZ and other services. Information should include practical examples for fluctuating, rare, complex and undiagnosed conditions, as well as conditions that span both the health and disability support systems.

Community voice:

- *The funding model is complex. No one has ever talked to me about IF.*
- *I don't know about my entitlements to respite care*
- *Do not know who does respite care*

24. **What else could DSS do to make it easier for you to understand and access information about disability supports?**

25. **What would make it easier to navigate the support for disabled people provided by DSS and other government agencies or community groups?**

Navigation assistance would make it easier for people to access support across DSS, Health, Education, Work and Income etc. Ideally agencies should refer on and ensure people who may be eligible are receiving all the support they are entitled to across government rather than in silos.

Worked examples of forms, and coordination support so people do not have to repeatedly work out which agency is responsible or how to describe their needs or fill in forms in the right way would also make navigation easier.

Community Voice:

- *Being a rare disorder you don't receive the information or same support as those with a known disorder/ illness, you feel left out in the cold often*
- *I find it hard to get any help without jumping through hoops I don't have the energy to jump through*

26. **Can you provide us with any additional thoughts you have about the questions you have just answered about the information and advice that DSS provides?**

Information and advice should be treated as a core access issue. If people do not know what exists, whether they qualify, or how to apply, then the support is not genuinely accessible. Improving information available and access to it must therefore be part of improving equity, timeliness and effectiveness of DSS.

Demographic Questions:

27. **Are you responding to this survey as a (please select all that apply):**

    ☐ **Other (please write)** NGO

28. **Which of the following best describes your ethnicity? (please select all that apply):**

N/A

29. **Which region do you live in most of the time? (please select one)**

National organisation based in Wellington

30. **What services and supports do you receive from DSS (or provide)? (please write)**

N/A

31. **Can DSS publish your name, or any other personal information that might be contained in your submission, in a summary document on the DSS website?**

    ☐ **Yes** Rare Disorders NZ

32. **Are you Deaf?**

N/A

33. **How would you best describe your disability? (please select all that apply):**

N/A

Appendix 1

Quotes from Rare Disorders NZ's 2025 Voice of Rare Disorders Survey regarding Disability Support Services, themed by category.

Equity/rare issues

- *DSS is very geared to a set of criteria would 'boxes' disability needs. I do not use these services any more due to an inability to create understanding of my child's individual needs.*
- *It should all be a result of need (not which brand name condition, alignment, disability they have). Seeing my son miss out where kids who have a known condition (i.e. CP) get instant free access to things that all of my son's symptoms suggest he would benefit from is totally unfair*
- *Theres no funding if you don't fit criteria but there's no criteria that takes into account the variables*
- *They don't recognise that we do not fit into a one box fits all, that each disease is different. We have seizures but don't fit general epilepsy, we have autism but don't fit general autism, we are non mobile but don't fit cerebral palsy, we are a round peg trying to fit into a square peg*

Needing a diagnosis

- *Disability services tends to focus on a diagnosis rather than individual needs, for people struggling to get diagnosed, there is no support.*
- *It takes too long for the actual diagnosis for the support to kick into place early enough*
- *My NASC assessment was based on my diagnosis of [rare disorder 1], because i was not formally diagnosed with [rare disorder 2] at the time. No one can provide me with information about whether i would qualify for care work support under my [rare disorder 2] diagnosis. It's left me feeling vulnerable and duplicitous, even though the disorders are related. I don't think the disability support services well enough informed about rare disorders and there seems to be a lack of internal communication and transparency also.*
- *The time when disability support services are often needed most is when seeking diagnosis and this can take years and mean the patient is not earning, however without a firm diagnosis there is often no support.*

Lack of understanding of the rare disorder and needs

- *Because our son's diagnosis is extremely rare (only one other case in NZ), there is no real understanding of his needs or future trajectory. This makes conversations about the support he needs really difficult and you often feel completely unheard*

- *They do not take into account enough the physical disabilities related my child's diagnosis. How much extra care that needs, we do not get the personal cares or respite support needed for that level of disability. They are more focused on the disabilities such as autism that is more common*
- *For rare conditions there is little support or understanding or willingness to learn. So insulting when they don't listen or compare with conditions they think are similar.*
- *I don't believe they even have an understanding as to what a rare disorder is. Let alone how it affects an individual*
- *Lack of knowledge around anything that is not in their box*
- *Lack of understanding. Often rare disease does not fit into box.*
- *More understanding is needed by nasc*
- *Disability Support Services using NASC to do needs assessments make a person list a primary diagnosis. Our son's rare disorder get's relegated to #3 on the list, because ID and Autism are recognised as disabilities whereas his health condition is not. But it is his health condition that affects his sleep, energy and makes him physically unable to do a lot of things. I have never met a needs assessor who knows this condition and what it does, so it makes it useless to give it as a diagnosis. As an aside, we receive funded support for overnight care via the DHB because without this he would have stayed in hospital for his life.*
- *Rare Disorders are complex and I have found myself explaining time and time again how this disorder affects my disabled person. DSS attitude can be somewhat blasé*
- *There isn't a lot of guidelines of rare conditions so you have to get them to believe you that you need help*
- *They don't understand just how disabled you can be with an invisible disability.*
- *They haven't heard of our Diagnosis and try to lump it with others which doesn't work.*

Lack of pathway/process

- *Being a rare disorder you don't receive the information or same support as those with a known disorder/ illness, you feel left out in the cold often*
- *Being rare we seem to fall through the cracks.*
- *I feel they are not set up for rare disorders at all*
- *Cookie cutter methods , which do not always work the same for all*
- *I find it hard to get any help without jumping through hoops I don't have the energy to jump through*

Fluctuating conditions

- *I have concerns around the changing nature of my rare disorder, in that every day is different and some days I require a lot of support and other days less support. I get concerned that DSS don't or are unable to have flexibility around this. Its appears very black and white. It concerns me that my support will be reduced or cut and that I will struggle to maintain and get this support back if they take it away from me.*
- *because rare disorders can have a variety of issues that can change over time, are not well known or widely understood the assessment for care and support can be quite rigid*
- *I have found the service difficult to access if you don't fit in a box. Because my disorders are relapsing, sometimes I am of high need, unable to walk, and other times I am ok, therefore do not qualify.*
- *Home help, eg Enliven and other providers appear to have quite narrow criteria for funding. This reduces their ability to tailor home help. For eg, 'house work' is not really prioritized, but eg helping shower the patient is. With a muscle weakness, I can get out of bed, shower myself and get breakfast. But then I usually need to rest from that exertion. (repetitive muscle use quickly tires me). This means I can't lift groceries into pantry cupboards, I cannot vacuum more than half a lounge before being fatigued.. so IF house work was able to be included, then I can conserve energy eg, to prepare meals etc. Therefore flexibility is important. Also some days I may feel fine and just as easily have days with almost no capacity. Explaining why I can walk one day and the next need a walker, is challenging. Thankfully the carers I've had, have been able to understand this dilemma.*

Siloed approach

- *DSS are not taking a holistic approach to what people with rare disorders lives actually look like. DSS are siloing what is going on with the individual or body part rather than looking at the true impact.*
- *I got turned away from support because it's more special needs, the I get turned away from that because he is more physically impaired. Then we can't leave him because of his medical, I can't see a box we fit in*
- *I had to battle to get home help through Whaikaha; I was sent through a gauntlet of professionals who invariably told me that they had no idea how to access this system, maybe this other person can, but it would be very unlikely unless I were elderly or terminally ill. When I got through to Capital Support I learned all of this was untrue; nonetheless, my referral got stuck for some 8 months, and I was told that this was because they didn't know whether to classify [my rare disorder] as a "health problem" or a "disability", as it technically fulfils the criteria for both, yet they can only choose one for their funding streams. I asked what practical difference it would make for my care to be classified as one versus the other, and was told "I honestly don't*

know" - this was from the person supposedly most qualified to know within that system. I still reel at the inexpressible Kafkaesque stupidity involved in such a bureaucratic limbo. They can't find us on their drop-down menus, therefore we are ignored.

- *It's a bureaucratic mess. Looks good on paper, but in practice it sh*t for us because of the silos.*
- *My child also has Autism so we use Disability Support Services for this, they were clear (there are activities he can not do because of [their rare disorder]) that they could not include anything to do with his [rare disorder] or this couldn't be a part of the rationale behind a decision for funding*
- *Some rare disorders considered long term conditions are not covered by DSS NASC and because of other disabilities the MoH Hospital long term service refer back to DSS causing bouncing between services*

Equipment

- *The system for getting equipment is a joke. We waited for nearly 18 months to get shower chair for our son at school, due to Enable dragging the process out. Basic Equipment that needs replacing due to growth is being held up in the enable process. This has happened on numerous occasions which then causes a regression in his therapy due to lack of equipment.*
- *Equipment Services and other private companies are not client focused. I sometimes feel it is about making money and ticking boxes.*
- *Funding for equipment slow or non existent*
- *The options for equipment isn't good enough, and the process and systems to get the funding and equipment are too slow and too hard to navigate.*
- *Access to equipment will become more vital as our boy gets older, and I'm not confident it will be provided in a timely manner (or at all). We also don't know what support of any our son will qualify for - no one seems to be able to tell us. It's so hard to navigate*

Service issues

- *A lack of Holistic Care, along with clear communication*
- *Compared to support for people over 65 years, there is very little support but worse, access to support is obscured with information barely accessible*
- *DSS has got no idea about what it takes to recruit, train, lead and manage a person centered support team. Their controlling third party tactics are creating barriers to our employment relationships. Training needs and business expenses ie recruitment company , HR, health and safety and payroll services. are not taken into account when deciding on budget levels. Intergenerational care is not taken into account. Shifting sands keep us in survival mode, we need to be able to make long term plans including employment contracts etc. family governance costs are not understood.*

- *Expecting in person meetings*
- *Families that struggle to communicate outside the home*
- *Funding offered only goes toward covering the costs slightly, there are other hidden and unseen costs associated with disabilities such as buying specialised food or sensory equipment*
- *It's all very well to allocate "respite hours" when there are no carers available or willing and no agency who provide carers*
- *It's not sufficiently funded and hard to access*
- *Just look at the past 18months and the decisions that were made, and continue to be made that have a detrimental effect of the person and their caregiver*
- *Lifelong impacts not taken into account*
- *Services remain inflexible and focused on the short term rather than condition specific needs to promote QOL and full societal participation.*
- *Situations change so quickly and yearly assessments are not good enough*
- *Slow to respond to changing needs; seem to have a cookie-cutter approach / one size fits all mentality; and who on earth thinks it's ok to give a disabled person a wheelchair with the brand name Karma?!*
- *Still the funding isn't flexible enough. We have struggled to find respite caregivers? I haven't used all our funding and yet am not allowed to spend it on modifications or devices that would help keep our son safe.*
- *That they will not fund my increasing needs in a timely manner due to over work and underfunding and my life will be extremely difficult while my request makes its way through the system*
- *The anxiety I feel close to every DSS review date with my NASC organisation (every June)*
- *The current guidelines are related more to children or adults with ASD*
- *only helping a small portion of disabilities and should be funding more*
- *The last couple of years with disability funding have been a minefield of admin, paperwork and fluffery with a lot of rehashing conditions that are incurable and huge amounts of frustration with the limitations. The current guidelines are dehumanising, patronising, infuriating and infantilising....Their scope is hugely skewed by autistic accommodations and leave huge gaps for other physical or intellectual conditions. The guidelines were clearly written without diverse input from the disability community, with glaring gaps in care and huge assumptions made on the capacity individuals have to make decisions in their own supports - far too vague in some aspects and way too specific in others. If I did not have the very lovely fund manager I have now, or the parents I have, the entire process of Individualised Funding would have overwhelmed and intimidated me to the point of inaction. Especially as my first attempt accessing the funding with [Host] was awful - they were entirely incompetent, with absolutely no understanding of any of my conditions, and non-responsive. It took me emailing 6 times without reply, needing to explain my conditions and their effects repeatedly to the same staff members, and*

calling IT Support (where I was immediately yelled at before I could even greet the other person) before I decided to give up and ask for a different host. They had no consideration for the fact that phone calls were taxing for me, or that in-person appointments are nigh impossible, video calls were scheduled with very little notice and my requests for general correspondence to be in text instead of calls was ignored. Their onboarding was FULL of fearmongering tactics aimed at scaring their users into paying for additional services [the Host] offered in regards to staff/employment management, accounts and financial management, legal representation and insurance. There should be much more oversight into the hosts to where that kind of transparent exploitation of at-risk individuals, already struggling with symptomology and navigating the system, is dealt with swiftly.

- *The funding we receive through the Kaikaranga (needs assessment) is very limited and does not fit with our sons needs e.g. they will pay for a consultation to see a podiatrist as it falls under the respite care support as someone else looking after my child, but they will not fund the orthotic insoles that aid my son in walking everyday as it does not fall within their rules.*
- *There is no consideration for multiple disabilities within the household, everything I based on the single person to have one disability.*
- *They barely approve funding for known disabilities let alone rare disorders*
- *They dont understand the effect it has on the whole whanau*
- *they haven't explained the process well and managed expectations (they asked if he wanted to go into care, but that is not an option)*

Awareness/information

- *It is very difficult to access*
- *It is hard to find what is available*
- *Don't know what support is available*
- *Didn't even know it existed which shows they are not viable to the ones who Need the support services the most*
- *The funding model is complex. No one has ever talked to me about IF.*
- *The system is very time consuming and draining to navigate. Someone to walk you through the application processes and help you understand your entitlements across the board would be incredibly helpful.*

Carer needs

- *it's a lack of support for whānau and carers*
- *DSS doesn't take into account how much work families must do to coordinate all the care, support and education needs of their family member with a rare disorder because most of the time no one know much about the condition. It requires a lot of skill and time to advocate effectively to get minimum services!*

- *[rare disorder] syndrome is a complex disorder that requires 24/7 care, plus highly specialised medical treatments when there is a hospitalisation. Patients are also non-verbal with intellectual disability. DSS provides support based on the person's 'need', not for the carer or parent overseeing their medical care. There should be more supports for coordinated care. This becomes a lifelong commitment.*
- *They are too far removed from the day to day challenges we face and do not consider mental health of the careers to be a top concern. It should be fully funded!*
- *I have had no support and my daughter is like the only one in NZ with the disorder. So no help with my mental health, no counselling, no support other than what I have found for us*
- *Because she is younger they say that she is 24/7 care anyway. However, no Sleep, constant anxiety, her not being at the mental and physical age of a 3 year old has its impacts*

Appendix 2

Results from Question 34(a) of Rare Disorders NZ's 2025 Voice of Rare Disorders Survey

Do you think that Disability Support Services take into account the unique needs of the rare disorders population?	Number of people	% of total
I haven't thought about it	253	24%
No, not at all	305	29%
Not applicable	59	6%
Not well enough	298	29%
Yes very well	10	1%
Yes, as well as I believe they are able to	117	11%
Grand Total	**1042**	**100%**