Re: Disability Support Services Bill

To: Social Services and Community Committee ssc.legislation@parliament.govt.nz
Date of Submission: 11 June 2026
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. This submission is in regard to the **Disability Support Services Bill**

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

Rare Disorders NZ opposes the Disability Support Services Bill in its current form. We support the intent of improving consistency, fairness, transparency and sustainability in Disability Support Services, but the Bill as drafted risks narrowing access, increasing uncertainty, and shifting more responsibility onto families and whānau without adequate safeguards, resourcing, or recognition. We are very concerned that the Bill does not recognise and support family carers and assumes families and whānau can and should absorb unmet support needs.

We ask that amendments are made to:

1) Address the uncertainty and erosion of trust created by this Bill's reliance on secondary legislation and limited consultation period by:
    a) Clarifying in the primary legislation that the Bill does not introduce, expand, or enable means testing or inappropriate consideration of family, whānau or "natural" supports as a substitute for funded support.
    b) Reducing reliance on secondary legislation by placing key eligibility, assessment, funding, complaints, review and safeguarding protections in the Bill itself.
    c) Requiring meaningful co-design with disabled people, including those living with a rare disorder, and their carers, including carers of people living with rare disorders.
2) Expand the definition of eligible disabled persons to include people with rare disorders, including those whose impairments arise from rare genetic, neurological, metabolic, immune, developmental, progressive or fluctuating health conditions.
3) Amend clause 8 to ensure that consideration of family or whānau support does not reduce, delay, or replace access to funded services, and that the rights of disabled people to autonomy, choice, and control over their care are explicitly protected.
4) Include explicit reference to New Zealand's obligations under the United Nations Convention on the Rights of Persons with Disabilities and to the Enabling Good Lives vision and principles, and require that these are actively upheld, embedded and operationalised in all aspects of decision-making, policy design, funding and service delivery.