



Submission to Pae Ora Health of Disabled People Strategy

Date of Submission: 17 March 2023

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 Ministry of Health contract that ends in 2023. This submission is in response to the Ministry of Health/Manatu Hauora Pae Ora Strategy for Health of Disabled People.

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.

Our Submission

While New Zealand does not have an official definition of what is considered a rare disorder, international definitions consider a disorder 'rare' when they affect less than 1: 2000. . However, though individual disorders may be rare, living with a rare disorder is not uncommon. Around three hundred thousand New Zealanders live with a rare disorder.

For most rare disorder patients, they experience forms of disability as a result of their condition. Unfortunately, the existing disability support system has proven unable to consistently meet the needs of the rare disorder community in New Zealand.

Typically, rare disorders are chronic illnesses and conditions that significantly impair normal activities of daily living, yet a major barrier to accessing support is the invisible aspect of many rare patients' disabilities.



These can include physical, mental or neurological impairments that are not visible from the outside, yet can limit or challenge a person's movements, senses, or activities. Unfortunately, the very fact that these symptoms are invisible can lead to misunderstandings, false perceptions, and judgments.

Living with these conditions can make daily life more demanding for many people. They affect each person in different ways and can be painful, exhausting, and isolating. Without visible evidence of the hidden disability, it is frequently difficult for others to acknowledge the challenges faced and as a consequence, sympathy and understanding can often be in short supply.

72% of rare disorders are genetic in origin and thus are present throughout a person's life even if the symptoms do not immediately appear. Approximately 50% of the people affected by rare disorders are children.

Being subjected to reassessment by social services to prove your limitations for disability support is incredibly stressful and degrading, and consideration needs to be given to waive this requirement for those who have been diagnosed with life-long disorders of a genetic origin of which medication or treatment to improve the condition is not available.

Retesting in social services for people with a rare disorder is incredibly stressful, with 72% being genetic and only 5% of rare disorders having a medication to treat the disorder, symptoms and disability do not get better over a lifetime they only get worst. Having to prove you have a disability over again to people in the system is degrading and stressful for these families.

Given the lack of any official data registry on rare disorders, these patients often fall through the cracks as they do not fit a 'tick box' to lead them on a pathway to receive the services and care they require. It is therefore essential that patients who do not fit a 'tick box' due to a rare condition are given individualised assessments to ascertain their needs for improved health and wellbeing.

Our 2021 survey and our 2022 Voice of Rare Disorders white paper found that for 60-75% of people, their disorder makes a number of everyday activities difficult. And the majority felt that communication and information exchange between different service providers was poor and that professionals are poorly prepared to support them.

70% had a decrease in income and limited employment options due to their rare disorder and one in three often felt unhappy and depressed and felt they could not overcome their problems.

We recommend that:

- New Zealand introduce personal care plans to cover an individual's health, education and disability care needs. These overarching integrated care plans would allocate responsibility for the delivery of services to specific levels of government.
- An urgent review of delays in access to equipment is undertaken to ensure that those with a rare disorder receive approved equipment in a timely manner.
- A 'fast tracking review' category for people with rare disorders who have been identified as having permanent and significant disabilities is incorporated. This would allow quicker access to additional support when required through consultation with clinicians.



- New Zealand recognise those with a rare disorder often have hidden disabilities yet still need to be categorised as Disabled.
- New Zealand recognises those with an undiagnosed rare disorder are still disabled and should have access to disability services.
- New Zealand recognises that people living with a rare disorder have complex medical issues as well as disability issues, it is not just one but frequently both exist.
- New Zealand recognises that due to the lack of an official data registry on rare disorders, people living with a rare disorder often do not fit a 'tick box' on a form and therefore may need personalised patient-centred care tailored to their circumstances.
- New Zealand recognises that given 72% of rare disorders are genetic and many rare patients will have these disorders for life, they should not have to be subject to reassessments of their condition.

ENDS

Rare Disorders NZ
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