

*“to champion and amplify the collective voice of New Zealanders with rare disorders”*

Submission to: Finance and Expenditure Committee (FEC)  
Subject: [Budget Policy Statement 2024](#)  
From: Rare Disorders New Zealand (RDNZ)<sup>1</sup>  
Date: 24<sup>th</sup> April 2024

## Recommendations

Rare Disorders New Zealand (RDNZ) recommends that BPS 2024:

1. Includes a set of authentic wellbeing objectives as required by the 2020 amendment to the Public Finance Act
2. Demonstrates how the Budget 2024 priorities contribute to the Government’s overarching goals for its term of office, including improved health outcomes in particular
3. Includes “improving the health, wellbeing and quality of life for all New Zealanders” as a priority for Budget 2024
4. Amends the operating balance and government spending commentary to include analysis of the extent to which government expenditure can be considered an investment in New Zealanders’ future health, wellbeing, quality of life and productivity
5. Amends the commentary on debt so that there is recognition that high quality investments that provide benefits to New Zealand over time should include investment in New Zealanders’ health, wellbeing and quality of life, which will increase the productive capacity of the economy.

## Introduction

At RDNZ our mission is to champion and amplify the collective voice of New Zealanders with rare disorders, advocating for access to world class and world leading health, disability, education and other services. We do this so that people and whānau living with rare disorders experience their best possible health and wellbeing.

About 300,000 New Zealanders have one or more of the estimated 7000 rare disorders which are thought to be prevalent in New Zealand. Approximately 50% are children, 78% of respondents to a recent RDNZ survey said they experience rare disorder-related difficulty with seeing, hearing and/or moving, and 72% of disorders are genetic in origin. People with rare disorders are high users of the country’s health and disability services, yet they frequently report dissatisfaction with the interactions and outcomes that they experience.

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<sup>1</sup> <https://www.raredisorders.org.nz/>

As a result of RDNZ's advocacy over more than two decades the Pharmac Review Report<sup>2</sup> recommended development of a Rare Disorders Strategy (RDS). Manatū Hauora/Ministry of Health has recently submitted its final draft RDS to Minister of Health Hon. Dr Shane Reti. Our hope and expectation is that following the Minister's formal agreement government agencies including Te Whatu Ora/Health New Zealand, Whaikaha/Ministry of Disabled People, Te Pātaka Whaioranga/Pharmac and others will be tasked with the Strategy's implementation.

It is likely that there will be some resource implications associated with implementing the RDS's requirements and it will be important for people living with rare disorders to see these provided for in the 2024/25 and successive budgets. On their behalf RDNZ is making this submission on the BPS 2024 in an effort to ensure that their requirements and expectations won't be overlooked - and indeed will be met - in the budget setting process.

## Wellbeing objectives

Previous years' BPS documents have explicitly set out their underpinning wellbeing objectives, as derived from successive versions of Treasury's Living Standards Framework (LSF). RDNZ supports the overall intent to explicitly link Budget allocations to improving New Zealanders' health and wellbeing.

RDNZ is concerned to see, therefore, how nonchalantly the wellbeing objectives in BPS 2024 have been conflated with the "Government's overarching goals for its term of office". We consider it disingenuous that this has been justified on the grounds that meeting these objectives "is the most important contribution the Government can make to the long-term social, economic, environmental and cultural wellbeing of New Zealanders". Although elements of wellbeing may be discernible in the first two of the three stated objectives, RDNZ fails to see how getting "the government's books back in order and [restoring] discipline to public spending" can be construed as a wellbeing objective.

All of the above notwithstanding we may have been less concerned if the Budget 2024 priorities could be seen to be contributing to the second of the Government's overarching goals for its term of office which in particular includes the intention to bring about improved health outcomes. None of the five Budget 2024 priorities are obviously relevant to improving health outcomes, and if the government's belief is that they are then the BPS would benefit by having this clearly spelled out.

### **RDNZ therefore recommends that BPS 2024:**

- Includes a set of authentic wellbeing objectives as required by the 2020 amendment to the Public Finance Act
- Demonstrates how the Budget 2024 priorities contribute to the Government's overarching goals for its term of office, including improved health outcomes in particular
- Includes "improving the health, wellbeing and quality of life for all New Zealanders" as a priority for Budget 2024:

RDNZ's supporting context for the above recommendations is our fundamental belief that it is a basic duty of the New Zealand government to support its citizens to live well for as long as possible. For New Zealanders with rare disorders this means that they have the same rights as all

<sup>2</sup> Pharmac Review Final Report 2022. <https://www.health.govt.nz/system/files/documents/publications/pharmac-review-final-report.pdf>

other citizens to be supported to the best extent possible to not die prematurely, and to live well to at least the “ripe old age” of seventy five years<sup>3</sup>. This basic duty should be a key driver of how it allocates resources and distributes wealth through successive annual Budgets.

New Zealanders with rare disorders are not currently afforded either the best possible or the same rights as other citizens to be supported to live well for as long as possible - let alone to a ripe old age. RDNZ’s White Papers<sup>4 5</sup> reporting on the experiences of New Zealanders living with rare disorders, together with a wealth of patient stories, demonstrate that this is because:

- There is an underdeveloped approach to rare disorders prevention
- New born screening arrangements are becoming increasingly anachronistic and falling behind international best practice
- For some conditions there is misalignment between availability of screening tests and availability of treatment resulting in delays in treatment which in turn militates against its effectiveness
- Inadequate funding is resulting in life saving, life extending and life enhancing medicines being denied to those who would benefit
- Demand for modern genetic testing technology and expertise is outstripping supply and availability, resulting in delayed diagnoses and access to effective treatment
- Clinicians, including both general practitioners and specialists are often not sufficiently equipped or resourced to accurately diagnose rare disorders
- Clinical responses to rare disorders are often based on inaccurate diagnoses which means that patients’ health outcomes either fail to improve or become worse because they receive inappropriate or harmful treatment
- There is a dearth of coordination services to support people to navigate the complexities of the health system, which are especially challenging for people living with rare disorders
- Disability support is experienced as discriminatory, insufficient, difficult to access and not enabling people with rare disorders to live good lives
- New Zealand underinvests in the health research<sup>6</sup>, including rare disorders research, which could identify new and better interventions, treatments and cures.

RDNZ expects the addressing of these issues to be initiated in the context of implementing the Rare Disorders Strategy, and that there will be capacity built in to the 2024/25 budgetary allocations for vote health, vote disability and vote Pharmac to enable this to occur. We are concerned that the absence of clear wellbeing signals in the BPS will result in service compromises which will be deleterious to the quality and length of life of New Zealanders living with rare disorders.

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<sup>3</sup> Deaths prior to attaining the age of 75 years old are classified as premature mortality. See, for example, <https://www.health.govt.nz/system/files/documents/publications/health-and-independence-report-2017-v2.pdf> p.8

<sup>4</sup> RDNZ. Impact of living with a rare disorder in Aotearoa New Zealand in 2024. [https://www.raredisorders.org.nz/assets/Documents/5295\\_RDNZ\\_White-Paper-Layout\\_WEB.pdf](https://www.raredisorders.org.nz/assets/Documents/5295_RDNZ_White-Paper-Layout_WEB.pdf)

<sup>5</sup> Impact for Whānau Māori of Living With a Rare Disorder in Aotearoa New Zealand 2024. [https://www.raredisorders.org.nz/assets/Documents/5295\\_RDNZ\\_Whanau-Maori-White-Paper-Layout\\_WEB.pdf](https://www.raredisorders.org.nz/assets/Documents/5295_RDNZ_Whanau-Maori-White-Paper-Layout_WEB.pdf)

<sup>6</sup> NZHR. April 2024. FEC Submission re BPS 2024. <https://nz4healthresearch.org.nz/wp-content/uploads/2024/04/NZHR-Budget-Policy-Statement-submission-220424.pdf>

## Investment

BPS 2024 is silent on investment.

Investing in New Zealanders' health, wellbeing, quality of life and standard of living will result in big productivity gains and less expenditure on mitigating the effects of poor, or suboptimal, health, wellbeing and quality of life outcomes. BPS 2024 would be improved if when it talks about expenditure it draws a distinction between:

1. expenditure as an investment to achieve future productivity gains,
2. expenditure to necessarily preserve the status quo, and
3. expenditure which achieves neither of these things and can therefore be identified as potential savings for reallocation elsewhere.

In focusing on the first of these distinctions RDNZ's submission recommends that BPS 2024:

- Amends the operating balance and government spending commentary to include analysis of the extent to which government expenditure can be considered an investment in New Zealanders' future health, wellbeing, quality of life and therefore productivity.
- Amends the commentary on debt so that there is recognition that high quality investments that provide benefits to New Zealand over time should include investment in New Zealanders' health, wellbeing and quality of life, which will increase the productive capacity of the economy.

RDNZ submits that the costs of addressing the service deficits experienced by people with rare disorders, as outlined above, should more properly be regarded as investments in their future health and wellbeing, and in New Zealand's future prosperity as a result of the productivity gains that would result.

To illustrate the point the so called economic burden of rare disorders is huge, as reported in a 2023 Berl Insights<sup>7</sup> report, as follows:

- The total cost associated with rare disorders-related hospital discharges in Western Australia during 2010 was AU\$173,322,256, or 4.6 percent of the total WA inpatient hospital expenditure
- A study conducted in the United States (US) estimated the overall economic burden of 379 rare disorders to be greater than US\$966 billion in 2019, including US\$418 billion in direct medical costs, and US\$548 billion in indirect and non-medical costs absorbed directly by patients and their families

Furthermore, NZIER<sup>8</sup> estimates the value of lost production in New Zealand due to premature deaths from what are currently considered to be all non-amenable causes of mortality to be between \$3 billion to \$4 billion annually. Assuming that rare disorders comprise, say, just 5% of this total, the potential economic benefits of people living with rare disorders being supported to live well to a ripe old age are up to \$200m per year.

Clearly considerably more analysis needs to be done but the point remains that investing in the future wellbeing of people with rare disorders (and others) has the potential to result in significant reductions in the economic burden both to the country and its citizens, and to gains in national productivity and prosperity. RDNZ submits that a BPS which values an investment approach to

<sup>7</sup> BERL. March 2023. Rare Disorders Insights Report. Pathways towards better health outcomes.

<https://www.raredisorders.org.nz/assets/Documents/Rare-Disorders-Insights-Report-2023-Final-1.pdf>

<sup>8</sup> NZIER. 2022. Valuing health research in New Zealand. Feasibility Study.

informing its expenditure decisions will be an important enabler of realizing these gains.

A handwritten signature in black ink, appearing to read "Chris Higgins".

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