



Submission to Pae Ora Women's Health Strategy

Date of Submission: 17 March 2023

Submitted by: Rare Disorders NZ

Contact person: Kim McGuinness, Rare Disorders NZ

Email: Kim.Mcguinness@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 Ministry of Health contract that ends in 2023. This submission is in response to the Ministry of Health/Manatu Hauora Pae Ora Strategy for Women's Health.

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. All childhood cancers are rare.

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.

We make the following comments and recommendations:

Rare Disorders affect women, in fact possibly more so than other groups of the population, especially due to women often taking the main carer role.

It should be noted the large population of women who become carers and/or the main navigators of the health, welfare, education and other public sector systems for those living with a rare disorder. This is often at the expense of their own health, wellbeing, career and employment.

Women face barriers to accessing care and greater stigma as Persons Living with a Rare Disorder. And as mothers, women are often the primary caregivers within the home.

A lack of public awareness means that Persons Living with a Rare Disorder and their challenges are often invisible and unrecognised.



RDNZ recommends an increase to existing supports and provide new ones for women who are carers for those living with a rare disorder– including services accessible for their own health needs, making respite services and funding more flexible across the diverse population of women carers and investing more to improve their wellbeing as a single vital way to safeguard and improve the wellbeing of this large population.

Carers provide significant economic value to New Zealand – an estimated \$16.8 billion per annum or 5.1% of Gross Domestic Product, as well as priceless social and family value. We must listen to them, and we must support them.

According to the State of Care Aotearoa 2022 report 84% of carers are woman. A high number of survey respondents (52.5%) reported having their own disability or ongoing health condition such as arthritis, heart conditions or diabetes. This was fairly consistent across survey respondent cohorts but was highest for carers of two or more people (62.6%). Respondents to the New Zealand survey were significantly more likely to report having a disability or health condition than respondents to Carers UK’s State of Caring survey (in which only 24% of survey respondents indicated they had a disability).

Female carers and young carers under the age of 35 reported the lowest levels of general mental health, at 50% and 46% respectively, and the highest levels of depression and anxiety, at 77% and 83% respectively. Mental health for those who care for older people and those with dementia was more positive than the overall rates.

Loneliness is very common amongst carers, with 66% of survey respondents saying they were sometimes or often/always lonely. This compares to 16% of the general population who identify as lonely. As a subpopulation, young carers under 35 experienced the highest rates of loneliness at 84%

Young carers aged under 35 and carers of people with intellectual disabilities reported the worst physical health, with 24% and 20%, respectively, reporting very bad or bad physical health. - This was followed by carers looking after two or more people, 21.4% of whom reported very bad or bad physical health, compared to 12% for carers assisting one person. - Higher rates of very bad or bad physical health were reported by carers who are Pacific (22%) or Māori (20%) compared to Asian (5%) or European (14%) carers.

Provide more effective navigation support (particularly around social welfare and support, health services and wellbeing services and respite care) and improve the promotion of information available to women carers about financial supports (including being paid to provide care).

Improve and simplify financial supports to reduce barriers to financial assistance, such as changing spouses’ inability to access the Supported Living Payment or family carers’ inability to be fairly paid for the significant efforts they make in areas such as Individualised Funding (often at the expense of other paid work opportunities).

Formally recognise the role of women as carers and the value they provide to their whānau and the system by directing government departments to ensure plans and strategies specifically include focus and actions that relate to women as carers.



Identify measurable ways to support women as carers wellbeing in areas such as employment, retirement planning, loneliness and social isolation, finances, and mental health; ensure programmes for wellbeing are adequately resourced and promoted.

Support specific initiatives and programmes that assist working age women carers whose earnings, life success, retirement savings, and financial wellbeing impact often adversely their ability to work, earn, save, and thrive.

People living with a rare disorder face a number of inequities in the health system, due to a lack of awareness and poor knowledge among health professionals on rare disorders, and few treatment or care options. These inequities are compounded for women due to pervasive gender inequalities.

Unfortunately, due to New Zealand's considerable data gap in the health system when it comes to rare disorders, we are unable to back up with concrete data what we hear anecdotally every day from patients and caregivers and what the international evidence tells us – that there is a disproportionate delay in women's access to diagnosis, treatment and care compared to men, and that women overwhelmingly bear the brunt of the informal primary caregiver role for rare disorder patients.

Studies from Europe on gender bias in health care for rare diseases show that women tend to be diagnosed later than men, referred to hospital later and their systems managed later to men. While the reasons for this are unclear, women's testimonies strongly suggest women feel they are taken less seriously and that their symptoms are often attributed to hormones, or they are gaslighted to believing it is all in their head.

Furthermore, women largely take on the brunt of the caregiving when someone in the whanau has a disability or is diagnosed with a rare disorder. This disrupts their own professional life, putting them under financial strain, not to mention the added stress, emotional strain and pressure of the 24/7 caregiving demands.

Through our organisation, RDNZ, we are well aware that the majority of voluntary patient support groups are set up and run by women, extending their unpaid support and care work to others in similar circumstances to themselves. 84% out of the 150 rare disorder support groups in our collective are run by woman.

Women face barriers to accessing care and greater stigma as Persons Living with a Rare Disease. And as mothers, women are often the primary caregivers within the home.

Gender bias in care for rare diseases starts early. Within the complex and long process to receive an accurate diagnosis – the "Diagnostic Odyssey" – women tend to be diagnosed later than men. A report from Alliance Maladies Rare indicates that French women are directed to a hospital and specialists later than men following the onset of symptoms, which delays diagnosis.

That same report further shows that on average symptom management starts before diagnostic confirmation for men, and after confirmation for women. As a result of delayed diagnosis, the uptake of appropriate treatment and care is also deferred. This often leads to a rapid progression of the disease, severely impacting the quality of life, socioeconomic status, and mental health.



The recent European Care Strategy acknowledges that informal care suffers from a strong gender bias. This exposes women to higher risks of socioeconomic and wellbeing challenges and perpetuates the gender stereotypes that typically assign women to care-related tasks. According to the Juggling Care Survey for carers of people with a rare disease, 30% of carers spend more than 6 hours per day in care-related tasks. The majority of these carers were women, mostly mothers (64%) or spouses (25%) of people living with a rare disease. With intensive and time-consuming care needs for people living with a rare disease, female carers face a higher risk of unemployment, vulnerability in the labour market and social exclusion, while also impacting wellbeing and limiting time for other responsibilities. Furthermore, the care they provide is often unpaid, contributing to the gender pay gap.

The World Health Organization's definition of health includes "complete physical, mental and social wellbeing and not merely the absence of disease and infirmity. Women's Health involves their emotional, social and physical wellbeing and is determined by the social, political and economic context of their lives, as well as biology". Aotearoa New Zealand has high levels of violence against women and children, there is a significant income gap between men and women, and women are often held responsible for the health of their families. Women are also subjected to societal pressures about appearance and body size, and the effects of sexism, all of which impacts on their wellbeing.

Women are overrepresented amongst lower income New Zealanders, and are more likely to be receiving a benefit, providing unpaid care, sole parenting and receive lower incomes than men. Issues such as poverty, homelessness, transportation, and accessibility impact on women's health service use. Women on a low income are less likely to prioritise their own health and dental care and have a poorer nutritional intake.

Recent studies note women in rural and remote areas and women who experience socio-economic disadvantage have poorer health, economic disadvantage, limited access to services and inadequate housing, are directly associated with reduced life expectancy, premature mortality, injury and disease incidence and prevalence, and biological and behavioural risk factors. In general social exclusion and the effects of stigma and discrimination have also been found to have negative impacts on health.

The past 50 years have seen significant change in women's social roles. Women today balance the stresses of multiple roles, including family and childcare responsibilities, paid employment, and community and voluntary activities. Despite many gains, women in New Zealand continue to experience persistent inequities, including higher rates of poverty.

Rare Disorders NZ

15 March 2023