

Women as caregivers for those with rare disorders

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Around the world, some 30 million people live with a rare disease. Together they would make up the size of the world's third most populated country, the United States. In New Zealand, we have nearly 400,000 people with a rare disorder or 9 percent of our population. Half of them are children.

While individual disorders are rare, collectively they are not. In total there are over 6,000 different rare diseases or disorders.¹ Some people with rare disorders are assessed as having a disability, while others are not. That assessment makes a significant difference to their lives and their family's - *Will a parent or partner receive a carer's allowance? Will the state provide a wheelchair, or support the adaptations needed for a home so that all family members can do the everyday things that most of us take for granted?*

There's no cure for the majority of rare disorders and few treatments. Most are genetic. Judging from the first EURORDIS Rare Diseases survey across Europe, we can expect that 8 in 10 of those with rare disorders will have difficulties carrying out everyday tasks. And, not surprisingly, in spite of their determination and courage, 7 out of 10 patients and caregivers will give up work as a result of their own or their family member's rare disease.

When all of this is put together it's not surprising that people living with a rare disease, and their carers, are three times more likely to report that they feel unhappy or depressed than the general population.²

A 2017 Rare Barometer report in Europe showed that 97 percent of the primary carers for people living with rare disorders are parents. Another survey showed that the primary caregiver for 64 percent of people living with rare diseases was their mother, and in yet another recent survey, 71 percent of those living with a rare disease identified their mother as the main carer.³ A recent smaller survey in New Zealand indicated a similar percentage. The European survey showed that the time required varied with 62 percent spending more than 2 hours a day on illness-related tasks, and a significant percentage providing intense caring, with 30 percent spending more than 6 hours a day helping the patient.

¹ There are over 6,000 rare diseases, and a number of groups including metabolic, neuro-muscular, autoimmune, developmental anomalies, bleeding disorders, cardiovascular, respiratory, skin diseases and rare cancers. Rare Barometer Voices, "Juggling care and daily life: the balancing act of the rare disease community", extract from <https://www.eurordis.org/voices#studies>

² Juggling care and daily life: the balancing act of the rare disease community, extract from <https://www.eurordis.org/voices#studies>

³ ENSERIO study FEDER: Huee Garcia, A and D Velasquez, <http://www.enfermedades-raras.or/index.php/actualidad/publicaciones/1281...>, Madrid, 2009

This needs to be considered in the wider context of women's unpaid work. Some readers will have read Marilyn Waring's recent, short and very readable book, *Still Counting: Wellbeing, Women's Work and Policy-making*,⁴ and some may also have read her 1994 *Counting for Nothing*, which revealed the invisibility of women's many contributions to society.

In economic terms, this resulted from the accounting framework used in New Zealand and in every other country, based on GDP and the UN System of National Accounts. As a result, "unpaid work of all kinds-voluntary and community work, unpaid productive work. and household work," was omitted from the national accounts. Many of these activities, such as household cleaning, preparation of meals, training of children, the care of the sick, tending home vegetable gardens, and family transport were considered "non-productive" and, therefore, not to be counted. Instead they continued to be seen as "women's work," in line with traditional gender stereotypes and norms rather than "productive work" as categorised by the National Accounts. Washing done by machine, for example, is counted as productive, washing by hand is not!

In 1998 New Zealand ran its own Time Use survey. This showed that time spent on 'unpaid work' as a primary activity equated to 2 million full-time jobs, compared with 1.7 million full-time jobs in the paid labour force. The survey hasn't been repeated since 2009-10, and while some relatively minor changes have occurred, the lack of real recognition of women's unpaid work has continued. The 2009 -10 data which the National Council of Women has on their Gender Equality webpage, citing StatsNZ showed that men and women worked the same number of hours in a day, but women were paid for 35 percent of their hours and men for 63 percent.⁵

This lack of recognition for unpaid work has been particularly difficult for women who are the caregivers for children with disabilities or rare disorders, or for their spouses in a similar position. Many studies show that the effects of providing care over the long term lead to anxiety and stress, as well as loss of confidence and self-esteem. One study investigates the possible "pathway through which chronic caregiving stress may influence susceptibility to infectious illness and other immune related conditions."⁶ A study by the UK All Party Parliamentary Group on Rare, Genetic and Undiagnosed conditions found that 36 percent of patients and 19 percent of carers had suicidal thoughts, 95 percent of parents/carers felt that worrying about their child's quality of life and emotional wellbeing affected their own mental health. Yet 46 percent of patients and 48 percent of caregivers reported never being asked by health care professionals about their mental and emotional well being.⁷

Yet when parents raised the issue of the number of hours involved in caring for their children with disabilities or rare disorders, some policymakers and others saw this as part of the natural duties of parenthood-parents were expected to care for their children, as a part of their role, or, similarly, to care for their partners, "for richer or for poorer." That meant, therefore, that these caregiving roles should not require any payment. In line with this view, the Ministry of Health prior to 2013, had a policy of never paying carers of adults, if they were related to each other.

⁴ "Still Counting: Wellbeing, Women's Work and Policy-making, BWB, 2018

⁵ NCWNZ www.Gender Equal citing Stats NZ

⁶ Prathe A.A. Brain, Behavior, and Immunity (2018).<https://doi.org/10.10.16/j.bbi.2018.06.019>

⁷ Living with a rare condition:the effect on mental health, Rare Disease UK, May 2018

In 2013, in a much needed and dramatic change, the Funded Family Care policy allowed family members to be paid for caring for their loved ones with high or very high needs, except their spouses. In a strange reversal of roles, the family member for whom they were caring, virtually became their employer. At the same time, Part 4A of the Public Health and Disability Act banned families from challenging the policy on grounds of discrimination. While this 2013 change was seen as a step forward in that parents could now receive payment for caring for their children, it was also regarded as insulting.⁸

Currently, spouses are not entitled to be paid for the care of their disabled or ill loved ones. Today, in mid-2019 there are “around 480,000 unpaid New Zealanders whose lives had been severely impacted as a result of caring for a disabled or ill loved one without any financial support.” Some who have been funded for only 40 minutes to an hour of caregiving a day have had to give up work, others have taken mortgages. Many experience feelings of loss and isolation. And it is surely not surprising that a 2017 University of Otago study revealed a high number of unpaid carers had elevated symptoms of depression and anxiety.

With over 600,000 New Zealanders over 65 in 2013, it is expected that this group will double to 1.2million by the mid 2020s. Likewise, the 48,000 New Zealanders with Alzheimers in 2010 are “forecast to jump to 75,000” by the same date.⁹ The result is likely to be an increase in older people requiring care.

At the beginning of July this year, the Government announced details of a previously promised policy which will pay caregivers \$20.50 to \$22.50 an hour, depending on their years of service. This would be particularly valuable to those who have given up work in order to care for their child or partner. The Government expects that 640 people will qualify for payment at a cost of \$32m over four years. The pay rates will be similar to the new pay rates for care and support workers in New Zealand ‘s aged and disability residential care sector.¹⁰

But for those with rare disorders, who are sometimes considered disabled and sometimes not, even if they use a wheelchair, the future of care will depend on the assessment. A mother of a child who had a late diagnosis of a rare disorder, describes her child as having 300 seizures a day, fully tube fed and medicated, and requiring regular suctioning and a cough assistance machine, and cannot attend school, but has over 25 medical appointments a month, and therapy three times a week. Her child’s needs assessment stated that she would require less than 6 paid hours a week.

She and other parents believe that assessments are not being done when the situation changes, but on a calendar basis, although this may not be the formal policy. “This is not equitable for the person needing care, or their carers.”

While she and others welcome this recent decision to include funding children’s parents as caregivers, within Funded Family Care, they believe that the assessment of hours for payment must reflect the hours of care that they are currently providing to their child. This should not be a tick the box assessment exercise - careful consideration and skill are needed to ensure people have the ability to assess rare conditions that are highly complex and not well understood by medical professionals. In

⁸ The New Zealand Herald, 8 July 2019, pA3

⁹ Ibid p.A8

¹⁰ ibid

addition she understandably believes that, *“Our children deserve to have someone they know, trust and love caring for them and this should be a parent if that is what the family choose. Paying them and allocating hours fairly will allow a better quality of life for the child and the parent.”*

Given all this, it is not surprising that the Welfare Expert Advisory Group Report Whakamana Tangata – Restoring Dignity to Social Security in New Zealand, concludes that *“Inequities exist in the provision of financial assistance for people with health conditions and disabilities and carers across the social sector.”*¹¹ They consider the different approaches of the Ministry of Health, Ministry of Social Development and Accident Compensation Corporation (ACC), and conclude that differences have led to disparate and inequitable outcomes for disabled people regardless of whether their condition is medically diagnosed or the result of an accident. It also concludes that, *“The stress of coping with ill health, disability or caring responsibilities on a low income is often exacerbated by dealing with an overly bureaucratic income support system and trying to navigate the supports and treatments they need to access...primarily the health system.”*

They also recognise that *“New Zealand relies heavily on family carers ...As in other OECD countries demand for such carers is expected to rise...However, family carers especially women can become trapped in a role where they receive a very low income. Economically disadvantaged families are more likely to be family carers, because they are less likely to be able to afford formal care. These families are also more likely to struggle to meet the additional costs associated with caring. This means the impact of caring, and the costs, are felt more intensely by those who are already disadvantaged.”*

For women who are the major caregivers for those with rare disorders, and who may not qualify for the new funding for carers, their conclusion is particularly apt, *“For those with a health condition or disability....High-intensity caring is associated with negative impacts on income, physical and mental health, family functioning and social networks and these are experienced more intensely by those who are already disadvantaged.”*

The mother of a child with a rare disorder sums up the ongoing situation for many who care for children with rare disorders, *“I am needed at home to care for our eldest son (now 11) who is severely autistic. If we were not caring for him he would have to be in full time residential care. This would medically qualify us for the Supported Living Payment. However, I am not eligible for any assistance like the Supported Living Payment because my husband has a paid job.”*

In a recent relatively small survey of New Zealand Carers for those with Rare Disorders, the respondents were asked:

How does living or caring for someone with a rare disorder impact on mental health?

Respondents were provided with the choices to answer the question:

- *Have you ever felt worried or anxious because of the impacts of the rare disorder?*
- *Have you ever felt emotionally exhausted because of the impacts of the rare disorder?*
- *Have you ever felt at breaking point because of the impacts of the rare disorder?*

¹¹ “Creating a fairer deal for people with health conditions or disabilities and carers in Whakama Tangata- Restoring Dignity to Social Security in New Zealand pp142-155

- *Have you felt isolated or ignored by the health system?*
- *Have you felt disbelieved by your health professional?*

The answer, **“all of the above”** was repeated 15 times.