PRADER-WILLI SYNDROME
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Submission on the Draft Carers Strategy Action Plan

Submitted by: Prader-Willi Syndrome Association New Zealand (PWSA NZ)

The Prader-Willi Syndrome Association New Zealand (PWSA NZ) appreciates the opportunity to provide feedback on the draft Carers Strategy Action Plan.

PWSA(NZ) is a national organisation supporting individuals and families affected by Prader-Willi syndrome (PWS), a rare and complex genetic condition associated with intellectual disability, lifelong health challenges, behavioural challenges and significant support needs. Most individuals with PWS require full-time supervision and structured support to ensure their safety and wellbeing. This need continues throughout life, as adults living with PWS need to be supported by a suitably trained and experienced residential service or to receive ongoing support from parents and family members.

Family carers therefore play a critical role in enabling people with PWS to live safely and participate in their communities. However, our members consistently report that the systems intended to support carers are not easy to navigate and do not adequately reflect the intensity and long-term nature of their caring responsibilities.

We welcome the focus of the draft Action Plan on the three priority areas of recognition and appreciation, health and wellbeing, and financial security. The immediate deliverables outlined are well intentioned and provide a starting point, but we would like to see an implementation plan, and feedback from our members is that these generalised statements do not reassure of a meaningful difference being delivered to carers supporting people with complex disabilities.

Recognition of the caring role

For many families supporting a person with Prader-Willi syndrome, caring is effectively a 24-hour responsibility. Individuals with PWS often require full-time support due to complex health, behavioural, and communication needs.

Greater recognition of the intensity and long-term nature of caregiving is important. While initiatives that raise awareness of carers are valuable, many carers would like to see this recognition reflected in practical support systems that acknowledge the scale of the role they perform.

Improving service access and navigation is important, but this needs to go a step further by ensuring that government funded supports and services have a **wider understanding of disability-specific support needs** so that they can more effectively engage with carers.

Health and wellbeing – access to appropriate respite

Access to suitable respite is one of the most significant challenges reported by families in our community.

Families often struggle to find services that are safe or appropriate for the complex needs of their family member with PWS. Standard respite options may not always be suitable for children or adults with the behavioural and health challenges of PWS, particularly where **providers lack the capacity or willingness to accommodate their needs**.

While some respite funding may be available, families can experience difficulties finding and retaining suitable carers to employ due to the potentially challenging nature of supporting someone with PWS, limited funding and low pay rates, and the time needed to search for suitable carers. As individuals with PWS have a preference for routine and consistency, short-term respite care can cause additional problems and stress for carers.

Families have identified several areas where improvements would help:

- **More flexible respite options**, including in-home respite and sufficient funding that provides the ability to employ reliable, well qualified and trusted carers or trained family members.
- **More assistance with finding suitable carers** to provide respite.
- **Longer-duration respite opportunities**, such as multi-day stays or supported breaks rather than only short overnight options. For carers of an individual with PWS, frequent transitions, unfamiliar routines and the time and effort involved in traveling to and from the facility and settling in can make overnight respite unhelpful, often adding stress rather than providing relief. Longer-duration, suitable respite is essential to provide carers with a meaningful break.
- **Training for respite providers** to better understand complex conditions such as Prader-Willi syndrome. Families are often scared of what can go wrong and lack trust in the quality of support.
- **More facility-based respite options** across Aotearoa New Zealand. Families need respite opportunities that are suitable for people with PWS and include respite for carers of adults.
- **Specialised respite**. We would like to highlight Áit Shona, an innovative model in Ireland which is a dedicated respite facility designed specifically for people with PWS, where families can confidently leave their child knowing they are supported by staff who understand the condition. While such models may be viewed as aspirational, they demonstrate the potential benefits of specialised respite options and represent the type of initiative the Strategy should be working toward. We note that the immediate deliverable of assessing current levels of available respite services does not include specialised respite.

Families also report challenges accessing **specialised health and mental health support**, particularly when their child transitions from paediatric to adult services. Access to clinicians with knowledge of Prader-Willi syndrome, including psychiatric expertise, is limited. Improving access to appropriate medical and mental health support would benefit the wellbeing of both the individual and their carers.

Improving respite access and specialised mental health support would significantly support the wellbeing of carers and the whole family. We often hear stories of families reaching breaking or crisis point by which time irreversible damage has unfortunately occurred, altering the trajectory of individual lives and relationships. We would like to see a focus on **earlier intervention** to help sustain long-term family wellbeing, which is also likely to reduce the additional costs associated with more intensive, high-level support needs when situations have deteriorated.

Financial security and participation in work

Some carers of people with PWS are able to balance caregiving responsibilities with employment. However, this is often dependent on the availability of reliable family support networks and the flexibility of their employment. The intensity of caregiving usually limits carer ability to work full-time.

Families report several issues:

- Carers receive **very limited financial support,** especially when unable to work and caring full-time.
- Respite budgets are insufficient.

- Carers can be required to **repeatedly reapply for benefits, services and support**, despite supporting someone with a lifelong condition.
- Many carers **can only work part-time**, yet flexible and well-paid part-time roles are difficult to find. Carers may have to abandon a previous career path.
- Where families are able to work, their carer role is carried out in addition to and alongside their employment commitments, and the two must be balanced around each other. Carers can feel like they are doing neither job well.
- Attending **frequent medical appointments** can make maintaining employment challenging.

Some families have also highlighted related challenges, such as finding and affording **accessible housing**, particularly in areas such as Auckland where suitable one-level housing can be limited and difficult to financially secure.

Better support for **flexible work arrangements**, clearer pathways back into employment, and financial support that appropriately recognises the contribution of carers would make a meaningful difference for many carers.

However, the immediate deliverables for this priority area do not promise action and only focus on assessment of the current situation. We feel that carers have been expressing the same messages for a long time and we would like to see some of these issues addressed through tangible action and concrete measures.

Data and information - working with communities and specialist organisations

Community organisations such as PWSA(NZ) play an important role in supporting carers and providing condition-specific information. We encourage government agencies to **engage with organisations representing rare and complex conditions** to ensure the specific needs of their communities are understood when implementing the Carers Strategy Action Plan.

Carers' experiences can vary significantly depending on the disability or condition involved, and policy design should reflect these differences.

Looking ahead

The immediate deliverables in the draft Carers Strategy Action Plan provide a starting point. However, it will be important that future actions go further to include meaningful measures to address systemic gaps in services and supports for carers, particularly those supporting people with complex disabilities.

We would also like to see a multi-agency, holistic approach to supporting carers and people with disabilities such as PWS. The Carers Strategy Action Plan should have strong links with other strategies such as the Rare Disorders Strategy and the Disability Strategy. The experience of families in our community is that **government systems are far too siloed, with deficiencies in support from one system often increasing support needed from another**. Families also report having to repeatedly apply for support across multiple agencies, undergoing reassessments and navigating complex referral and funding processes to secure disability, health, educational and other services for a condition with lifelong, evolving needs. **Families can be overwhelmed by bureaucracy in an inefficient system**. Simplifying, streamlining and better coordinating these processes would reduce the administrative burden on families and enable government resources to be directed more efficiently toward services. In previous government submissions, we have advocated for a **'Standards of Care' approach** for rare disorders like PWS, providing a framework that maps out required or recommended assessments, care interventions, and key considerations guiding support throughout a person's life. We need to see the Ministries of Social Development, Disabled People, Health and Education working more collaboratively to improve services and support for disabled people and their carers.