Draft Mental Health and Wellbeing Strategy 2026-2036

Feedback by Prader-Willi Syndrome Association NZ Inc.

Submitted via email to: mhasp.engagement@health.govt.nz

Information about the person/organisation providing feedback

This submission was completed by:	Jo Davies
Email:	ceo@pws.org.nz
Organisation:	Prader-Willi Syndrome Association NZ Inc
Position:	CEO
This submission is made:	On behalf of a group or organisation.
Ethnic group:	Other - Prader-Willi syndrome affects all ethnicities equally and the association represents people of all ethnicities living with PWS in New Zealand, and their families / whānau.
Perspectives our submission represents:	Children/young people, Family/ Whānau, Lived Experience, Disability, Other – Rare Disorder

Summary of Submissions

☑ I wish to be informed when the summary of submissions is available.

Privacy

☐ Do not publish this submission.
☐ Remove my personal details from Official Information Act responses.
☐ This submission contains commercially sensitive information.

Consultation Questions

1. From your experience, what most gets in the way of people or whānau getting the mental health or wellbeing support they need, including support for addiction, substance harm and gambling?

   This could include things that affect people before they need help, when they are trying to get help or while they are recovering.

For people living with Prader-Willi syndrome (PWS), one of the greatest barriers is the lack of understanding and expertise within the mental health system about the syndrome. PWS is a rare genetic disorder associated with emotional dysregulation, challenging behaviours, and a very high

rate of mental health problems, including severe anxiety, mood disorders, and psychosis. Mental health problems are particularly common in people with the UPD subtype of PWS, where rates of psychiatric illness can be extremely high.
Despite these high prevalence rates, mental health symptoms in people living with PWS are often misunderstood, dismissed as "just part of the syndrome", or not recognised because presentations can be atypical. Families frequently report that clinicians do not understand PWS, resulting in delayed referrals, inappropriate treatment, over-medication, or people only receiving support once they have reached crisis point.

When patients with PWS are referred to mental health services, there are also long wait times and limited access to intellectual disability, specialist mental health services. This is a significant barrier because many people with PWS require clinicians who understand intellectual disability, atypical presentations, behavioural phenotypes, medication sensitivities and the relationship between physical and mental health in rare genetic disorders like PWS. These services are limited nationally.

Another major barrier is the lack of continuity and preventative care. Mental health problems in PWS commonly emerge during adolescence and early adulthood, yet this is also the period when paediatric services reduce, and adult services are often fragmented or difficult to access. The transition from paediatric to adult healthcare is associated with a significant loss of expertise and support at the time individuals are at highest risk.

Medication management can be challenging. People with PWS may respond differently to psychiatric medications, may experience significant side effects including weight gain and metabolic complications, and may require ongoing monitoring rather than brief intervention and discharge. Families report that medications can worsen agitation or behavioural symptoms. Treatments need to be carefully managed by experienced clinicians. Pharmacogenomic testing may also help guide safer and more effective prescribing in PWS, but this is not widely available.

There is insufficient recognition of the disability and rare disorder sectors within the draft strategy. While the draft strategy references links to suicide prevention, eating disorders, gambling and addiction strategies, it does not adequately connect with the Rare Disorders Strategy or Disability Strategy. For people living with PWS, mental health support must be embedded within coordinated rare disorder healthcare pathways and multidisciplinary care.

---

2. From your experience, what most helps people or whānau to stay mentally well or get the support they need for their mental health and wellbeing, including gambling and substance related harm?

The most important factor is receiving the right support at the right time — ideally before a crisis develops.

For people living with PWS, preventative and proactive care is essential. Mental health difficulties in PWS can be lifelong and linked to underlying neurodevelopmental and genetic factors. Waiting until a person reaches crisis point is both harmful and avoidable. Early intervention, regular monitoring, and ongoing multidisciplinary support can significantly improve wellbeing and reduce the likelihood of severe mental health deterioration.

Wrap-around care models are particularly important. People living with PWS benefit from coordinated multidisciplinary healthcare that includes medical, psychiatric, psychological, behavioural and social support across the lifespan. This support should begin in childhood and continue seamlessly into adulthood. Internationally, it has been demonstrated by specialist multidisciplinary PWS clinics, such as the adult clinic at Royal Prince Alfred Hospital in Sydney, that coordinated care including specialist psychiatric input can improve outcomes.

Families and whānau also need support, education and inclusion in care planning. The family members of individuals living with PWS are often central to maintaining safety, structure, emotional regulation and health management. Supporting carers is therefore also preventative mental health care. However, we note that despite carers and whānau facing substantial emotional and psychological strain, they are largely absent from the strategy. Caring for someone with complex mental health and behavioural needs can be exhausting and isolating, particularly when families are left to manage crises without adequate support.

Access to clinicians with expertise in intellectual disability and rare disorders is extremely important. People with PWS require professionals who understand atypical mental health presentations, behavioural drivers, medication sensitivities and the specific psychological profile associated with PWS. As mentioned previously, we have limited PWS expertise in New Zealand, but clinicians who are learning about PWS as they work with patients could be encouraged to share their expertise.

Psychological and emotional regulation programmes can also be very beneficial. Programmes such as “Stepping Stones” and adapted psychological supports may help individuals develop emotional management and coping skills. However, these services are often only available after people have entered forensic or high and complex framework services, rather than earlier when they could prevent escalation.

Flexible service delivery would also help. Given workforce shortages, online appointments, national specialist clinics, outreach support, group sessions for people with PWS, and nurse navigator models should all be considered.

---

3. Which parts of the strategy feel the most right or important to you? Why?

We support the strategy’s emphasis on prevention, early intervention, and improving access to care before people reach crisis point. This is particularly important for people with PWS, who are at high risk of developing serious mental health problems but often do not receive support until situations become acute.

We also support the strategy’s recognition that some groups are at higher risk and require more tailored approaches. People with rare disorders and intellectual disabilities, including PWS, clearly fall within this category and should be explicitly recognised within the strategy and implementation planning.

The focus on more coordinated and holistic care is also positive. For people with PWS, physical health, mental health, behavioural wellbeing and social supports are deeply interconnected. Fragmented systems do not work well for people with complex neurodevelopmental conditions.

The strategy's intention to broaden the workforce and consider new ways of delivering care is also encouraging. Given the shortage of expertise in PWS and intellectual disability mental health, innovative approaches including telehealth, national specialist services, multidisciplinary clinics and workforce development will be important.

4. What changes would make the strategy work better for people and whānau? Why?

The strategy should explicitly refer to disability and rare disorders throughout the document. Currently, these groups are largely absent despite having high mental health needs and significant barriers to accessing appropriate care.

The strategy should also align more clearly with the Disability and Rare Disorders Strategies. Mental health care should form part of coordinated rare disorder healthcare pathways.

There also needs to be stronger recognition that some mental health conditions are driven by underlying neurodevelopmental or genetic conditions and cannot be addressed solely through general wellbeing initiatives or self-management approaches. While improving mental health literacy and self-management is valuable for many people, this approach is not always appropriate or sufficient for people with PWS and other genetic disorders.

We are concerned that generic models of care are increasingly replacing individualised specialist support. For example, families report that one-to-one dietetic support has been replaced with generic group programmes that are not suitable for people with PWS. Mental health services must avoid repeating this pattern.

The strategy should include stronger commitments to:

- specialist intellectual disability and rare disorder mental health expertise
- better transition services from paediatric to adult care
- multidisciplinary lifelong care pathways
- prevention-focused services for at risk groups (PWS)
- access to adapted psychological therapies
- ongoing psychiatric monitoring where clinically required
- access to new medications or treatment approaches
- support for carers and whānau

There should also be national workforce development initiatives to build expertise in rare disorders and intellectual disability mental health. New Zealand currently lacks recognised PWS mental health specialists. Training partnerships, conference opportunities, international collaboration and clinician mentoring could help build expertise over time.

5. This strategy will come with a plan that sets out what needs to happen to bring it to life. The first plan will have a three-year focus. What are the most important steps we should take in the next three years to make the biggest difference to people's mental health and wellbeing? Please tell us why.

The most important steps over the next three years are:

1. Develop specialist multidisciplinary care pathways for people with PWS (rare disorders and intellectual disabilities), including mental health support embedded within those pathways.
2. Improve transition services from paediatric to adult healthcare so people do not lose support during adolescence and early adulthood — the period of highest psychiatric risk in PWS.
3. Invest in workforce capability and specialist training in intellectual disability and rare disorder mental health, including psychiatry, psychology and behavioural support.
4. Increase access to preventative and early intervention services, rather than waiting until people reach crisis point or enter forensic and high and complex services.
5. Expand access to adapted psychological supports and counselling for people with intellectual disabilities and neurodevelopmental disorders.
6. Support carers and whānau as part of the mental health response.
7. Improve access to evidence-based medications, including consideration of pharmacogenomic testing for high-risk patient groups such as PWS.
8. Develop national or regional specialist clinics, including telehealth options, to improve equitable access to expertise.

We believe these steps would reduce crisis presentations, improve quality of life, reduce inappropriate forensic involvement, and create more sustainable long-term outcomes for people and families.

---

6. If you could choose just one thing for us to do to make the biggest difference in the next three years, what would it be?

Invest in preventative, specialist multidisciplinary mental health support for people with complex neurodevelopmental and rare disorders before they reach crisis point.

For people with PWS, timely access to knowledgeable clinicians and coordinated care could prevent many individuals from deteriorating to the point of requiring forensic services, high and complex care, or repeated hospital admissions. Prevention is also bound to be more cost-effective than crisis management.

---

7. To make space for new or better ways of doing things we might need to stop doing other things. What do you think we should stop doing, or do less of, so we can focus on what would work better? Please tell us why.

We need to stop relying on crisis-driven models of care that only respond once people become severely unwell.

For people with PWS and other complex neurodevelopmental conditions, waiting until someone reaches crisis point often leads to poorer outcomes, greater trauma for families, increased use of restrictive environments, and greater long-term cost to the health system.

We also need to stop assuming that generic approaches work equally well for everyone. General population programmes are often not appropriate for people with intellectual disabilities, rare disorders or genetic syndromes with distinct behavioural and psychiatric profiles.

The system should also move away from fragmented care and repeated short-term discharges without ongoing monitoring. People with PWS often require long-term follow-up, careful medication review and coordinated support.

Finally, we need to stop overlooking carers and whānau. Supporting families should not be viewed as optional — it is a critical part of maintaining wellbeing and preventing crisis.

---

8. We want to make sure that the things we do are making a difference for people. What should we be checking, measuring or keeping an eye on to know if the strategy is making a difference?

You might want to think about or share what you would be seeing, hearing or experiencing in your own community if the strategy was changing things for the better.

Measures should include not only service activity, but whether people and whānau are actually experiencing improved wellbeing, earlier support and better quality of life.

Important measures could include:

- reduced mental health crisis presentations
- reduced use of forensic and high and complex services
- reduced hospital admissions
- shorter wait times for specialist mental health support
- improved continuity between paediatric and adult services
- increased access to psychologists, psychiatrists and counselling
- improved support for carers and whānau
- patient and family satisfaction with services
- improved access for disabled people and people with rare disorders
- workforce capability in intellectual disability and rare disorder mental health.

It is also important to collect meaningful data for patients with intellectual disabilities and rare disorders. We note some concern regarding the wellbeing data presented in Figure 3 of the draft strategy, as it does not appear consistent with experiences reported by many disability organisations and families. People with PWS often experience restricted independence, social isolation, difficulties with employment and housing, and significant mental health challenges that can substantially affect wellbeing.

Success would look like people getting help earlier, families feeling supported rather than abandoned, fewer people reaching crisis point, and clinicians having greater confidence and expertise in supporting complex conditions such as PWS.

---

9. Are there any other thoughts, concerns, or ideas you want to share?

People with rare disorders and intellectual disabilities are largely invisible within the current draft strategy despite often having some of the highest unmet mental health needs.

PWS is a lifelong, complex neurodevelopmental disorder associated with significant mental health vulnerability. People with PWS require tailored, specialist and preventative approaches that recognise the interaction between genetics, brain function, behaviour, physical health and mental wellbeing. They need a system that understands them, supports them early, and works with them across the lifespan rather than only responding once crisis occurs.

The Prader-Willi Syndrome Association of New Zealand would welcome opportunities to work collaboratively with Health New Zealand, the Ministry of Health, Te Pou and mental health services to help improve workforce capability and access to expertise in PWS mental health care.

There is also an opportunity for New Zealand to build specialist leadership in this area through international partnerships (centres of expertise), clinician education, conferences and multidisciplinary models of care.

However, changing models of service delivery are unlikely to sufficiently improve access to support unless New Zealand attracts more specialists to working in the field of intellectual disability psychiatry. The Ministry of Health may need to consider incentivising working in this challenging but rewarding area.