

Submission to Disability Support Services Consultation 2026: Further Improvements to Services

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Executive Summary

Prader-Willi syndrome (PWS) is a rare, lifelong genetic disorder that affects multiple body systems and requires a coordinated, multidisciplinary approach throughout a person's life. While many people living with PWS have an intellectual disability, their support needs extend well beyond intellectual disability alone. Hyperphagia (an overwhelming biological drive to eat), behavioural and emotional regulation difficulties, metabolic complications, mental health vulnerabilities, and the need for lifelong environmental management all contribute to a level of complexity that is often not recognised within existing disability support systems.

People living with PWS can and do live fulfilling and meaningful lives when they receive the right support. However, too often the disability support system is fragmented, reactive and based on responding to crises rather than preventing them. Families frequently describe having to navigate multiple agencies, repeat their story numerous times, advocate for services, and wait until situations have deteriorated before additional support becomes available.

For people living with PWS, earlier intervention and coordinated planning are not simply desirable—they are essential. Appropriate support reduces the likelihood of health deterioration, mental health crises, safeguarding failures, family breakdown, interactions with the justice system and other avoidable crises. Investment in proactive and coordinated support should therefore be viewed not simply as additional expenditure, but as an investment that can improve outcomes for individuals while reducing the need for more intensive and costly interventions across the health, disability, and wider government systems.

The PWS Association supports the overall direction of this consultation and encourages Disability Support Services to place greater emphasis on proactive planning, coordinated multidisciplinary support, flexibility, specialist knowledge, and genuine collaboration across agencies. These changes would significantly improve outcomes for people living with Prader-Willi syndrome and their families.

About Prader-Willi Syndrome

Prader-Willi syndrome is a rare genetic condition caused by the loss of gene expression on chromosome 15. It is usually diagnosed during infancy and is a lifelong condition requiring ongoing medical, behavioural and social support.

PWS affects the hypothalamus, the part of the brain responsible for regulating hunger, metabolism, emotions, stress responses, sleep, temperature regulation and several hormonal functions. As a result, people living with PWS experience a complex combination of intellectual disability, developmental delay, hyperphagia, behavioural challenges, endocrine disorders, mental health vulnerabilities and physical health complications.

The hallmark feature of PWS is hyperphagia, an overwhelming biological drive to eat that cannot be managed through willpower alone. Without appropriate environmental supports and supervision, individuals are at risk of life-threatening food seeking behaviours, severe obesity and associated medical complications.

Importantly, people living with PWS often appear more capable than they actually are. However, this can mask significant executive functioning difficulties, reduced insight, cognitive rigidity and impaired judgement associated with the syndrome. Consequently, support needs may be underestimated, leading to insufficient supports that place the individual, their family and the wider community at risk.

International best practice recognises that people living with PWS achieve the best outcomes when care is coordinated across health, disability, education, mental health and community services throughout their lives. This submission reflects that evidence and focuses on opportunities to strengthen Disability Support Services by adopting a more proactive, collaborative and person-centred approach informed by specialist knowledge.

Outcomes that Matter

Supporting people to live full and meaningful lives

People living with Prader-Willi syndrome should have the same opportunities as other New Zealanders to participate in their communities, develop meaningful relationships, contribute through employment or volunteering where appropriate, pursue education and recreation, and live lives that reflect their own aspirations and goals.

However, achieving these outcomes often requires more than providing individual support hours. Many of the barriers experienced by people living with PWS arise from environments that have not been designed with their needs in mind.

Community activities frequently revolve around food. Social events, workplaces, recreational programmes and volunteering opportunities may all involve unrestricted access to food or expectations that individuals can independently manage situations that are unsafe for someone with PWS. Without reasonable environmental adaptations, many opportunities that appear inclusive in theory become inaccessible in practice.

Greater emphasis should therefore be placed on enabling participation through environmental adaptations, appropriate supports and collaborative problem-solving. This may include working alongside employers, education providers, community organisations and recreational groups to identify practical adjustments that enable people living with PWS to participate safely while maintaining inclusion and dignity.

Relatively small environmental adaptations can make a significant difference. People living with PWS have valuable skills and a strong desire to contribute to their communities, but success depends on the community they interact with understanding the syndrome, implementing appropriate routines, ensuring food security where necessary, and providing suitable levels of ongoing support.

Meaningful participation in community life depends upon opportunities that recognise both the strengths, and the support needs of the individual. People living with PWS should not be excluded because services or activities are unable to accommodate the syndrome. Instead, disability support should assist individuals, families and community organisations to work together to identify solutions that enable safe and meaningful participation.

Ultimately, success should not be measured solely by the amount of support a person receives, but by whether they are able to live a life that is safe, fulfilling, connected and aligned with their own goals and aspirations.

Safety must underpin all other outcomes

The PWS Association strongly supports Disability Support Services focusing on enabling people to connect and participate fully in their communities, to develop autonomy and experience growth. However, for people living with Prader-Willi syndrome, these outcomes cannot be considered in isolation from safety.

Many people living with PWS appear more capable than they are. They may communicate well, complete familiar tasks independently and present as more able than their underlying cognitive, behavioural and executive functioning challenges would suggest. This can result in support needs being underestimated, with decisions based on what an individual appears capable of doing rather than what is required for them to live safely and successfully over the long term.

For people living with PWS, insufficient support can have serious consequences. Poor supervision or a lack of understanding of the condition may result in life-threatening food access, significant deterioration in physical and mental health, family breakdown, safeguarding concerns, or interactions with the police and justice system. These outcomes are distressing for individuals and families and often result in substantially higher costs to the health, disability and justice systems than would have been incurred through appropriate early support.

Disability support should therefore recognise that maintaining safety goes hand in hand with promoting independence. Appropriate support provides the foundation that enables people living with PWS to participate in education, employment, recreation and community life while reducing the likelihood of crisis.

We encourage Disability Support Services to recognise that support requirements should reflect the complexity and risks associated with an individual's disability, not simply their apparent level of independence.

A Proactive and Coordinated Approach

Planning ahead prevents crisis

One of the strongest themes emerging from our community is that the disability support system often responds only after circumstances have deteriorated. Families describe having to reach crisis point before additional supports become available, despite concerns having been raised much earlier.

As Prader-Willi syndrome is a lifelong condition that is usually diagnosed during infancy, this provides a unique opportunity to adopt a proactive approach to planning throughout a person's life. Rather than waiting until significant challenges emerge, Disability Support Services should work alongside families to anticipate key transition points, identify likely future support needs and coordinate services before problems arise.

Earlier intervention has the potential to improve quality of life, reduce family stress, prevent avoidable crises and reduce demand for higher-cost services in the future.

Transition from school to adulthood

International literature consistently identifies the transition from adolescence into adulthood as one of the most vulnerable periods for people living with Prader-Willi syndrome, and one of the most challenging periods for people living with PWS and their families.

This stage often involves the simultaneous loss of established routines, educational supports and familiar relationships, while families are expected to navigate disability services, day programmes, employment opportunities, changing health services and future residential options. Adolescence is also a period during which behavioural, emotional and mental health challenges associated with PWS may become more pronounced, making coordinated planning particularly important.

Unfortunately, not all pupils living with PWS receive the same level of transition planning. Current ORS eligibility criteria do not always recognise the full complexity of PWS, meaning some pupils miss out on the coordinated planning processes that often accompany ORS-funded support. Families can therefore find themselves approaching the end of schooling without a clear understanding of available options or sufficient time to prepare.

PWSA(NZ) encourages Disability Support Services to strengthen transition planning for all young people with complex lifelong disabilities, regardless of whether they receive ORS funding.

Transition planning should begin well before school finishes and involve genuine collaboration between Disability Support Services, NASC services, education providers, Health New Zealand, mental health services, behavioural support teams and other agencies involved in the person's life. Families should not be expected to coordinate these services themselves.

Planning should also recognise that support needs do not reduce simply because a person has left school. Families often expect disability support funding to increase to replace the structured hours previously provided through education. Instead, many discover there is a significant gap between leaving school and the availability of meaningful daytime opportunities. Future planning should therefore consider how individuals will spend their day, what supports will be required to participate safely and meaningfully, and how those supports will be sustained over time.

Transition should be viewed as an ongoing process rather than a single event. The months and years following leaving school are often a period of significant adjustment for people living with PWS and their families, and plans may need to be reviewed as circumstances change. Adolescence and early adulthood are recognised as particularly vulnerable stages of life for people living with PWS, and support should remain responsive to changing needs rather than ending once a transition plan has been developed.

In addition, families often need assistance to identify community activities that are genuinely suitable for people living with PWS. Many programmes unintentionally create barriers through food-centred activities or environments that cannot safely accommodate the people with PWS. Skilled navigation and advocacy can help families identify opportunities that promote inclusion while appropriately managing risk.

Planning for future residential support

Planning for future residential support should also become significantly more proactive.

PWSA(NZ) is regularly contacted by families seeking advice about residential options because they are uncertain where to begin or have found few suitable options available through existing processes.

Many families report joining waiting lists for residential services without any indication of likely timeframes. When a vacancy finally becomes available, they often feel pressured to accept the placement regardless of whether it is the best long-term option, fearing they may otherwise return to the bottom of the waiting list. This can result in placements that are less stable or appropriate than they might otherwise have been.

A more proactive approach would involve earlier discussions with families, better forecasting of future demand, greater collaboration between regions, and strategic planning to develop capacity

where unmet need has been identified. Consideration could also be given to compatibility between prospective housemates and the development of specialist residential options for people whose needs are unlikely to be met within generic services.

By planning earlier and more collaboratively, Disability Support Services have an opportunity to reduce crisis placements, improve long-term stability and provide greater certainty for individuals and their families.

Developing specialist residential capability

While some people living with PWS continue to live successfully with their families or in mixed community residential services, other individuals require more specialised environments to achieve positive outcomes.

PWSA(NZ) continues to hear from families who struggle to find residential services with sufficient understanding of Prader-Willi syndrome. Staff turnover, limited knowledge of the condition, inconsistent food security practices and insufficient behavioural support can place both residents and staff under considerable pressure.

Sadly, New Zealand has experienced situations where inadequate understanding of PWS within disability services has contributed to tragic outcomes. These experiences reinforce the importance of ensuring that providers supporting people living with PWS have appropriate knowledge, training and systems in place.

Internationally, specialist residential models have demonstrated that people living with PWS can thrive when they receive full-time support within environments specifically designed around the syndrome, such as those referenced below in Ireland and Australia. These services provide consistent routines, appropriate environmental controls, skilled staff and positive behaviour support while enabling residents to develop greater independence within safe boundaries.

PWSA(NZ) would welcome a more strategic approach to developing specialist capability within New Zealand. This does not necessarily require all people living with PWS to access specialist services, but there should be pathways for individuals whose needs cannot safely or effectively be met within generic services. Developing specialist expertise within the disability sector would improve outcomes for individuals while strengthening the capability of the wider support workforce.

Supporting Families and Carer Respite

Supporting families sustains positive outcomes

Families provide the foundation of support for many people living with Prader-Willi syndrome. Supporting family wellbeing is therefore an investment in the long-term wellbeing of the individual.

One of the most significant challenges reported by families is accessing respite that is safe, appropriate and sustainable. Although respite funding may be available, finding carers with the knowledge, skills and confidence to safely support someone living with PWS can be extremely difficult. Families would benefit from greater assistance to identify, recruit and retain suitable support workers. Finding carers with the right skills and experience can be time-consuming and stressful. Practical support with recruitment and workforce development would improve access to respite and reduce the burden on families.

For many people living with PWS, routine, predictability and trusted relationships are essential. As a result, traditional overnight respite models are not always appropriate. Frequent transitions to unfamiliar environments may increase anxiety and behavioural challenges, reducing the benefit for

both the individual and their family. PWSA(NZ) encourages Disability Support Services to consider longer-duration respite.

There is also a need to increase specialist knowledge among respite providers. Families frequently tell us they are reluctant to use respite because they fear the potential consequences of support workers not understanding the condition, particularly the importance of food security and consistent behavioural approaches. Greater flexibility to pay appropriately for experienced and trusted support workers could improve recruitment and retention of carers with the skills needed to safely support someone living with PWS.

International examples demonstrate what can be achieved through specialist facility-based respite services. In Ireland, Áit Shona has been developed specifically for people living with PWS, providing families with confidence that their family member is being supported by staff with expertise in the condition. While such models may not be immediately achievable in New Zealand, they illustrate the value of developing specialist capability and should inform future service planning.

Supporting families also requires better access to clinicians with expertise in Prader-Willi syndrome, particularly mental health professionals. Families often report significant challenges accessing specialist medical, psychiatric and behavioural support, particularly following the transition from paediatric to adult health services. Earlier access to appropriate expertise can help prevent situations from escalating and improve outcomes for both individuals and their carers.

Choice and Flexibility

Flexible supports that respond to changing needs

Disability support should recognise that the needs of people living with Prader-Willi syndrome are not static.

Behavioural, emotional and health needs may fluctuate throughout a person's life and can change rapidly during periods of stress, illness, major life transitions or changes in routine. As a result, the level and type of support required may vary over time.

Families therefore need flexibility to determine how funding can best be used to meet current needs. There may be periods where support requirements increase significantly and other times where fewer supports are required. Expenditure is unlikely to be evenly distributed throughout the year, and there may be occasions where one-off or establishment costs are necessary to achieve better long-term outcomes.

Families may also choose to use disability funding to access supports outside Disability Support Services where appropriate services are unavailable through other systems, thresholds are too restrictive, or waiting times are excessive. Until there is greater integration between disability, health, education and mental health services, this flexibility remains important.

People living in rural and regional communities face additional challenges because specialist services, allied health professionals and disability programmes are often concentrated in larger centres. Greater flexibility, including assistance with travel where appropriate, would improve equity of access and enable people living with PWS to benefit from services that are not available locally.

Improving Information, Advice and Navigation

Coordinated assessment, planning and navigation

Prader-Willi syndrome requires a multidisciplinary approach to support. Effective planning cannot occur through disability assessment alone.

Families currently navigate multiple assessment processes across disability, health, education, mental health and social services, often providing the same information repeatedly to different agencies. This creates unnecessary stress, increases administrative burden and can delay access to essential supports.

Disability Support Services should move towards a more coordinated model in which assessments and planning occur collaboratively across agencies wherever possible. Greater involvement from Health New Zealand, allied health professionals, behavioural support services, education providers, mental health services and Disability Support Services would provide a more complete understanding of an individual's needs and reduce duplication for families.

Because Prader-Willi syndrome is uncommon, it is unrealistic to expect individual NASC assessors or navigators to have detailed expertise in the condition. While assessors will sometimes actively seek information and work collaboratively with our Association, a more consistent approach is needed.

PWSA(NZ) would like to see the development of nationally coordinated navigation for rare and complex conditions, enabling specialist knowledge to be shared across the country rather than relying solely on regional experience. This approach could also support greater consistency in assessment and planning regardless of where a person lives.

Families should not repeatedly be required to demonstrate that their child continues to have a lifelong genetic condition. Assessments should instead focus on understanding changing support needs and identifying the most effective supports to achieve positive outcomes.

Working together across government agencies

People living with Prader-Willi syndrome interact with many government systems throughout their lives. Disability Support Services alone cannot achieve the best outcomes.

Improved collaboration between Disability Support Services, Health New Zealand, education, mental health services, behavioural support teams and other agencies would create a more seamless experience for individuals and families. Rather than operating as separate systems with separate assessments and plans, agencies should work together to develop coordinated, person-centred support that evolves as needs change.

This collaborative approach is consistent with international clinical guidance, which recommends multidisciplinary management throughout life because Prader-Willi syndrome affects endocrine, nutritional, behavioural, psychiatric and social functioning. Many countries have also developed specialist multidisciplinary clinics and coordinated care pathways to ensure support is integrated across sectors.

This approach would also align with the direction of the Rare Disorders Strategy and its recently released Implementation Plan, which recognise the importance of coordinated, person-centred care, improved navigation and greater collaboration across health and support systems for people living with rare disorders. There is a significant opportunity for Disability Support Services to work alongside Health New Zealand and other agencies to ensure these initiatives complement one another and deliver a more seamless experience for people living with Prader-Willi syndrome and their families.

The PWS Association encourages continued work towards nationally recognised standards of care and coordinated care pathways for people living with rare disorders like Prader-Willi syndrome. As outlined in the Rare Disorders Strategy, these would provide a stronger framework for consistent, evidence-informed assessment, navigation and service delivery across New Zealand. Disability Support Services and partner agencies would better understand expected supports throughout the lifespan and facilitate more consistent, evidence-informed decision-making.

This approach is particularly important during key life transitions, when coordinated planning can prevent avoidable crises and ensure supports are in place before problems develop.

A more collaborative system would not only improve the experience of families but also reduce duplication, improve efficiency and support better long-term outcomes across government.

Summary of Recommendations

PWSA(NZ) recommends that Disability Support Services:

- Place greater emphasis on proactive, preventative support rather than responding after families reach crisis point.
- Recognise that independence and meaningful participation must be supported by appropriate safeguards and inclusive environments that enable people living with PWS to participate safely.
- Improve transition planning from school to adulthood for people with complex lifelong disabilities, regardless of ORS eligibility, recognising that transition is an ongoing process requiring continued support and review.
- Develop more coordinated approaches to future residential planning and increase specialist capability within residential services for people with complex needs such as PWS.
- Improve access to flexible, appropriate and specialist respite options for people living with Prader-Willi syndrome and their families.
- Support greater flexibility in disability funding so families can respond to changing needs and circumstances.
- Improve equity of access for people living in rural and regional communities, including consideration of travel assistance where specialist services are unavailable locally.
- Explore nationally coordinated assessment and navigation to improve support pathways for people living with rare and complex conditions.
- Reduce duplication by promoting coordinated assessments and shared planning across agencies.
- Strengthen collaboration between Disability Support Services, Health New Zealand, education, mental health services, NASC services and other agencies involved in supporting individuals with Prader-Willi syndrome.
- Support the development and use of nationally recognised standards of care and coordinated care pathways for Prader-Willi syndrome.

Conclusion

People living with Prader-Willi syndrome can lead meaningful, fulfilling and connected lives when they receive the right support at the right time.

This consultation presents an important opportunity to strengthen Disability Support Services by moving towards a model that is proactive, coordinated, flexible and informed by specialist knowledge. For people living with PWS, success depends not only on the availability of disability support, but on how effectively services work together, anticipate changing needs and build specialist capability. The greatest opportunity is not simply to increase support, but to improve the

way support is designed and delivered through stronger collaboration, specialist knowledge and earlier intervention. This will enable people living with Prader-Willi syndrome to live safer, more meaningful and fulfilling lives while improving long-term outcomes for families and making better use of public resources.

PWSA(NZ) appreciates the opportunity to contribute to this consultation and looks forward to continued engagement as Disability Support Services evolve to better meet the needs of disabled people and their whānau throughout Aotearoa New Zealand.

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- Interaction Disability Services: [Prader-Willi Syndrome Specialist Services](#) (Australia)
- AMA Community Services: [Prader-Willi Homes](#) (USA)
- Consensus: [Prader-Willi Syndrome services](#) (UK)