



## **Submission of the Prader-Willi Syndrome Association New Zealand on the Disability Support Services Bill**

**To:** Social Services and Community Committee

### **About PWSA(NZ)**

Prader-Willi Syndrome Association New Zealand (PWSA NZ) is the national organisation supporting individuals and families affected by Prader-Willi syndrome (PWS). We provide advocacy, education, support, and Disability Information Advisory Services (DIAS) to families throughout New Zealand.

Prader-Willi syndrome is a rare, lifelong genetic disability that affects multiple aspects of physical health, cognitive functioning, behaviour, emotional regulation, and independence. Support needs vary significantly between individuals, but people living with PWS require ongoing support throughout their lives. Many adults living with PWS require intensive support through family care, residential services or supported living arrangements.

### **Summary Position**

PWSA(NZ) supports the intent of establishing a clear legislative foundation for Disability Support Services (DSS). Disabled people and their families benefit from certainty, transparency, and consistency in the delivery of disability supports.

We acknowledge that the Bill has been developed in response to the Supreme Court decision regarding family carers and the Crown's relationship with those providing care. The issues raised by that decision are complex. The level and intensity of caring experiences vary considerably between families, as do their personal, financial, and employment circumstances. The Supreme Court decision raises important questions deserving of careful consideration. Therefore, rather than commenting on a legal model for recognising family care, PWSA(NZ)'s interest in this submission is ensuring that people with PWS and their families have genuine choice, appropriate support, and long-term certainty within the disability support system.

Our primary concern is that, whilst responding to the Supreme Court decision, the Bill introduces broader provisions that create uncertainty about the future direction of disability support services. We are particularly concerned that aspects of the Bill could reduce choice and autonomy for people living with PWS and their families, and it could enable significant future changes to eligibility and support arrangements without sufficient parliamentary scrutiny or community input.

For these reasons, PWSA(NZ) does not support the Bill in its current form. We recommend that the Bill be substantially amended before proceeding so that it better protects the rights, choice, and long-term interests of disabled people and their families.

### **Consultation and Confidence in the System**

PWSA(NZ) is concerned that legislation with such significant implications for disabled people and their families has been developed with limited consultation prior to introduction.

The disability community relies heavily on trust and certainty. Many families already feel unsettled following recent changes and reviews within the disability support sector. The speed

at which this legislation has progressed, combined with the broad powers it creates, has contributed to considerable anxiety amongst disabled people and family carers.

Disability support services should be based on disability-related need rather than assumptions about what unpaid support may be available from family members. They should also be grounded in the rights, dignity, participation, and self-determination of disabled people, consistent with New Zealand's commitments under the United Nations Convention on the Rights of Persons with Disabilities.

### **Clause 8 – Reliance on Family, Whānau and Community Supports**

PWSA(NZ) is concerned about the principle established in clause 8 that a person's own resources, including support available from family, whānau, and community, should be considered before disability support services are provided.

Families play an essential role in supporting people with Prader-Willi syndrome and many already provide extraordinary levels of unpaid care. However, the existence of family members does not necessarily mean that support is available, appropriate, sustainable, or desired.

There are many reasons why family support should not be relied upon as a substitute for funded disability supports. These include not only the financial impact of full-time caring on families, but also the effects on the mental wellbeing of family members, including siblings. Research consistently demonstrates elevated levels of stress, caregiver burden, and mental health challenges among family carers of people with Prader-Willi syndrome.

For people living with PWS, support needs continue throughout adulthood. Many parents provide extensive care well beyond the years typically associated with parenting, often while managing employment, ageing, health challenges, and financial pressures of their own.

While some adults with PWS continue to be supported by ageing parents, this should not be relied upon. It is also not always possible for adults living with PWS to live with or near their family. For example, families may need to relocate for employment, housing, or other reasons, potentially disrupting established support networks and services. In some parts of New Zealand, specialist disability supports and residential options may be limited or unavailable, meaning families already face considerable challenges in accessing appropriate supports. Given the variability of family circumstances, it is not realistic, safe, or sustainable to assume that family, whānau, or community support will always be available when determining eligibility for disability support services.

Importantly, adults with disabilities should have the same rights to autonomy, privacy, and independence as other New Zealanders. Many adults living with PWS seek increasing independence from their parents and family as they mature. They may prefer support from trained disability support workers, supported living services, or residential care providers rather than relying exclusively on family members.

People living with Prader-Willi syndrome require support from individuals who understand the unique behavioural, cognitive, social, and health-related aspects of the condition. Effective support often depends not only on the availability of assistance but on the availability of appropriately trained and knowledgeable support providers. This should be recognised within any framework for disability support services.

We are concerned that clause 8 could, intentionally or unintentionally, create future pressure to shift responsibility away from formal supports and onto families. It could also create uncertainty about whether access to support may depend on the availability of family members rather than the assessed needs and preferences of the disabled person.

**Recommendation:**

Amend clause 8 to clearly state that family, whānau, and community supports may complement disability support services but must not replace an individual's entitlement to supports based on assessed disability-related needs. The legislation should also explicitly recognise the disabled person's right to choice, autonomy, and independence in determining who provides their support.

**Clause 11 – Ministerial Programmes and Future Eligibility Criteria**

PWSA(NZ) is concerned about the breadth of powers contained within clause 11, particularly the provisions that appear to enable future change to regulations or programme rules relating to financial circumstances, income, assets, or other eligibility criteria.

We acknowledge the Government's assurances that there is currently no intention to introduce means testing of disability support services. However, legislation should be assessed on the powers it creates rather than on the intentions of any current government. Future governments may take different approaches to disability support policy and funding, making it important that appropriate safeguards are embedded within the legislation itself.

PWSA(NZ) is concerned that significant aspects of eligibility, access to supports, and service delivery could potentially be determined through ministerial programmes rather than primary legislation. Decisions with substantial implications for disabled people and their families should be subject to appropriate parliamentary scrutiny and transparency.

The Bill currently creates uncertainty about what future governments may be able to introduce through ministerial programmes or regulations without the same level of scrutiny that would accompany amendments to primary legislation.

While there may be circumstances where a person's financial resources are relevant to particular support arrangements, disability support services exist because of disability-related needs. Any future unconsulted move toward income or asset testing could have significant consequences for disabled people and their families.

For people living with Prader-Willi syndrome, disability-related support needs are lifelong and do not disappear because family circumstances change. The intensity of support required may fluctuate across a person's life, but the need for specialist disability support remains.

**Recommendation:**

Remove the provisions that enable future income or asset testing through ministerial programmes or regulations. At a minimum, the legislation should contain clear safeguards requiring parliamentary scrutiny and public consultation with the disability community before any such changes can be implemented.

Ensure that the detail of eligibility, funding, and decision-making is in primary legislation and not left to secondary regulation.

**Supporting Family Carers While Preserving Choice**

PWSA(NZ) recognises the enormous contribution made by family carers throughout New Zealand. Families affected by Prader-Willi syndrome frequently provide support that extends across an individual's entire lifespan.

We acknowledge the Government's stated intention to develop alternative approaches to recognising and supporting family carers. Family carers make an essential contribution to the

wellbeing of disabled people. We welcome further information about these proposals and encourage meaningful engagement with carers and disabled people as they are developed.

Whatever approach is ultimately adopted, we believe that flexibility and choice should remain central principles. Families differ greatly in their circumstances. A sustainable disability support system should accommodate these differing circumstances rather than assuming a single model of care.

### **Conclusion**

PWSA(NZ) supports the establishment of a legislative foundation for Disability Support Services and recognises the need for clarity and certainty within the disability support system.

However, we believe the Bill should be amended to provide stronger protections for disabled people's autonomy, choice, and access to support based on assessed need. In particular, we recommend amendments to clause 8 and clause 11 to reduce uncertainty and ensure that future changes to disability support settings cannot occur without appropriate consultation and scrutiny.