

# DSS Community Consultation

**February / March 2025**

## **Submission by Prader-Willi Syndrome Association NZ**

Email: [enquiries@pws.org.nz](mailto:enquiries@pws.org.nz)

Website: [www.pws.org.nz](http://www.pws.org.nz)

Phone: 021791391



# Topic 1: Improving the way the needs of disabled people are assessed, and how support is allocated

## Make sure there is a consistent approach to needs assessment

**Question 1:** What changes can you suggest that would ensure the assessment tool and process is fair, consistent, and transparent? You might for instance wish to suggest it is: done in a different place; in person, or not; that it be supported differently; or that you receive different information about it before or after the assessment occurs.:

Families often tell us there is a lack of information about needs assessments – what to expect from and during the assessment, what will be assessed, and what supports they might be able to access. This is particularly the case amongst families with newly diagnosed or young children. We often hear families say that they did not know a support or fund was available to them / their child. Over time, families hear from other families about supports they have been provided and make comparisons – sometimes realising that they would have been eligible for support they have not received because they were not informed about it. As part of our role as a DIAS provider, we aim to share such information, but we are not trained service coordinators, and our knowledge of public supports and services is gleaned from conversations with families. We are also not necessarily connected with families from diagnosis and are therefore sometimes unaware that a family is not accessing supports, services or treatments that are available to them. Assessments should not rely upon a person being aware or knowledgeable about what they can ‘ask for’. There needs to be more detailed information available for families in addition to standardised and specialised training for NASC assessors so that families are all offered the supports and services that should be accessible to them.

Sometimes the needs assessor will have no understanding of Prader-Willi syndrome. PWS is a rare and complex disorder, and we cannot expect every assessor to have extensive knowledge of all rare disorders, but they should be able to easily seek appropriate professional advice. [Ideally, assessments would be multi-disciplinary (see q.2) which would ensure against gaps in understanding.] One suggestion is that assessors / navigators for a disorder such as PWS are part of a national rather than regional service. Upon diagnosis, families would be connected to someone that helps them navigate the system and ensures that timely supports and treatments are provided. This is achieved overseas through Centres of Expertise and nurse navigator roles.

During the assessment process, families tell us that they are provided with a clear message that there are budget constraints. There is a focus on balancing these budget constraints with needs. This means that parents must make decisions about how to prioritise support needs and a potential support allocation. This is not conducive to assessing a true, consistent, or fair reflection of need.

## Improve how the assessment tool reflects the diversity of disability

**Question 2:** What information does the assessment tool need to gather about you and your circumstances to ensure it can identify the support you need?

Assessments can be quite focused on the support needed to complete tasks or activities, but support requirements for people with PWS can be multifaceted and perpetual. For example, once a person living with PWS has developed hyperphagia, families must maintain a constant high level of vigilance over their dietary intake and all food environments. PWS is also associated with a complex behavioural profile which requires a high level of skilled support to prevent the escalation of anxiety and

deterioration of behaviour. As people with PWS are extremely stress sensitive and prone to outbursts which can at times result in destructive or aggressive behaviours that are detrimental to the person with PWS and others around them, it is essential that proactive rather than reactive behaviour management strategies are used. The continual assessment of mood and being mindful of potential triggers can place relentless stress upon parents, siblings and support providers.

Prader-Willi syndrome is not just an intellectual disability – it is an extremely complex disorder which requires a multi-disciplinary approach to providing support. Ideally, assessments and allocations would have inter-agency input from health, allied health, education, behavioural support teams, transition services, mental health teams, social services etc. Currently, families need to make multiple applications to access the supports their child needs, but with the adoption of an inter-agency strategy based on a person's diagnosis, this would not be necessary and supports could be more collaborative and coordinated. A holistic support approach has been proven in studies to have improved health and wellbeing outcomes for the person with PWS, but this would also reduce dependence on government services / systems in the long term. This approach would also reduce unnecessary administration for both families and services.

Prader-Willi syndrome is a lifelong disorder caused by a chromosome abnormality that is usually diagnosed shortly after birth, yet families find themselves frequently having to prove that their child still has their PWS diagnosis and associated symptoms.

Assessments are quite deficit focused, rather than focusing on what is needed to help a person thrive.

Needs assessments need to be more responsive to crisis, risk, and safeguarding. When a family has reached crisis point, standard assessment questions may be irrelevant.

It is also not possible to future predict and crisis may occur 'out of the blue'. In these circumstances, an urgent assessment needs to be prioritised.

The needs assessment should consider the safeguarding all family members.

Needs assessments should consider what would be most helpful and what is realistic or attainable. Unfortunately, some community services designed for people with intellectual disabilities are inappropriate or inaccessible for people living with PWS due to their hyperphagia and food security requirements. It is not uncommon to hear that people with PWS have been turned away from services due to a refusal or inability to make the relevant changes that would make it safe for them to attend. Sometimes people with PWS are not accepted into services because they are deemed too high risk. A NASC assessment should consider whether services suggested will be appropriate and could be made safe. They should have a role in advocating for a person with PWS when a service has been made inaccessible to them. If a family is provided with an allocation so that they can use it in a particular way, there needs to be help and support provided to ensure that they are able to use it, as well as guidelines for the service providers.

When families are allocated an IF package, help should be offered with initial set up and the utilisation of funds – fund management can be a complicated and highly administrative process. An assessor / navigator should follow up whether the allocation is being used and provide support as needed. The assessment should consider whether the family are able to make good use of the funds allocated, for example, if they need to find a support worker, what assistance will they need and receive with this?

## Assess the needs of family/whānau and carers

**Question 3:** Do you support the needs of carers being specifically assessed alongside those of the disabled person? Why/Why not?

Yes. There are numerous studies that show the impact on parents and siblings of a child with PWS. Many families experience high levels of stress, depression and anxiety. There are also high rates PTSD amongst siblings.

**Question 4:** What considerations in respect to a carer's situation should be taken into account in order to link them to, or provide, the support needed?

What supports does the family have (from their wider family, the community, from support groups and services)? Are the family feeling isolated? (This is common when a child has a rare disorder because it is unlikely there will be other families living with the same diagnosis in the community. It also means there is often a lack of understanding amongst their community about their child's diagnosis.)

How are family members coping? What help or support do they need to strengthen their resilience or mental health?

In Prader-Willi syndrome, it is usually challenging behaviour which causes the most family stress and referrals are often made to Explore to support families with behaviour management. However, sometimes Explore may not be the most suitable support, or the family may have previously used their services – there needs to be more behavioural support options available to families. For example, would counselling be more beneficial – for the person with PWS and / or the family? Should health advice or mental health advice be sought? Ideally, if mental health services are required for the person with PWS, this support should be knowledgeable and specialised in disabilities like PWS – a targeted service that can be referred to. (Mental health problems often present atypically in PWS and response to medications also differs. People living with PWS often receive inappropriate mental health support or cannot access mental health support at all when it is needed.)

What do family members need to provide the best opportunity for respite – is it practical or possible in the context of having a child with PWS ?

## Make sure the services and support a person receives continues to meet their needs

**Question 5:** How often have your needs and services / supports been reviewed or reassessed?

Families tell us they usually receive yearly reviews. Some families have not been contacted by their NASC for a review and have had their allocation rolled over automatically. Families are aware that this has been due to a backlog of reviews. This means that families are not necessarily having their current needs assessed accurately. This also means that families in desperate need of review have had to wait far too long for a re-assessment.

Families have also mentioned not being sent a copy of their review.

It appears that there is quite a lot of variation between NASCS, with some experiencing short-staffing and back logs. Nationally, this equates to an unfair system.

A few families have told us recently that their funding has been drastically cut, with support hours almost halved. Families have also expressed concerns about either being a) scared to spend funding allocations because they have been warned of sudden cuts at or before expected review and they don't want to be left with insufficient funds, or b) scared to not spend their funding allocation because they have been told they will lose it if they don't spend it. This situation is causing unnecessary anxiety.

**Question 6:** What changes to your circumstances do you think should mean a review or reassessment of your services / supports would be needed?

Changes in status of education, health, employment, available support, behaviour, mental health.

**Question 7:** How often do you think your services / supports need to be reviewed or reassessed? (For instance, every year, every two years, every three years, or every five years.)

Checking in with families annually is a good idea, but a full review may not be needed. There are periods when needs are more likely to remain consistent. Times of transition will almost certainly require a change in support and full review, i.e. finishing school. This can happen suddenly because unfortunately exclusions are common from secondary schooling.

## Helping you access support that isn't available through DSS

We propose that NASCs identify supports that are available through other agencies and provide guidance on how these can be accessed.

This will help ensure that DSS is only used for the supports that are not provided elsewhere.

**Question 8:** What information or support might NASCs provide that will help you access the services, beyond DSS, that you might be eligible for?

The other supports and services that this question refers to are often unavailable because the thresholds are set too high or there are long waitlists. Therefore, many families need to be able to use their funding to access services privately. Until there is systemic change that ensures multi-disciplinary support and the implementation of a rare disorders health strategy that ensures patient pathways for diagnoses such as PWS, families need to be able to use their funding in the way that they know is best for their child. This is often informed by international best practice.

If NASCs are able to identify supports available through other agencies and provide guidance on how these can be accessed, will they also be able to provide some assurance that these supports will be delivered? Will they be able to make referrals? How will some families be able to access these much needed services in a different way than they have already tried to no avail?

We feel it is unlikely that a NASC assessor / navigator would have sufficient awareness of what supports through other agencies would be beneficial to a person with PWS, but if New Zealand had standards of care documents / health pathways for PWS like those available in some other countries, an assessor / navigator would be more easily able to determine and direct to what is needed. A move toward national navigation is a suggestion, as per q.1 response.

NASCS would also need to be aware of the huge variability in what supports are available in different parts of New Zealand. For example, someone who lives in a rural area is less likely to be able to access services that are available in a main centre. Therefore, some families are also likely to need travel assistance to be able to attend and access supports from other agencies. Unfortunately, medical expertise, allied health support, and other therapies are not equitably accessible at present.

## Topic 2: Accessing flexible funding, and how it can be used

There are two options for changing how flexible funding can be used:

**Option 1 – Link flexible funding to the person's plan, with oversight of how it is used**

**Option 2 – Adjust current lists of what can and can't be funded using flexible funding.**

**Question 9:** Do you prefer Option 1 (link flexible funding to the person's plan, with oversight of how it is used) or Option 2 (adjust current lists of what can and can't be funded using flexible funding)? Why?

On the whole, families we have spoken to preferred option 1. Reasons for disliking option 2 were:

- Lists of what funding can and can't be used on were too prescriptive / black and white. They did not suit different needs, i.e. a device might be helpful for one person, but for someone else, something that got them physically active would be more beneficial.
- Families must continually justify why spending is needed. Families feel repeatedly judged.
- Funding hosts sometimes lack awareness or understanding about why something is needed.
- The lists lacked clarity and were open to interpretation by different funding hosts or staff. There was little consistency in what would be approved / declined.

However, families had concerns that within option 1 a person's plan might be goal based with an expectation that targets are met, goals are achieved, or difficulties are overcome. This is concerning when PWS is a lifelong condition in which it is known that support needs become more intense as the child gets older rather than becoming less.

Parents felt that plans need to be benefit based and have a long-term outlook.

Plans also need to be easily changeable when circumstances change. It is not always possible to predict sudden changes that occur, such as exclusion from school, onset of mental health problems, or rapid deterioration in food seeking behaviours. There needs to be an allowance for quickly actioning more flexibility within any plan, alongside responsive reviews.

**Question 10:** Do you have any suggestions on how flexible funding can be used to allow disabled people and carers as much choice, control and flexibility as possible, while still providing transparency and assurance the funding is being used effectively, and is supporting outcomes?

Some of the main issues and suggestions with funding control and flexibility are:

- There are no suitable respite facilities in many areas for people living with PWS. Challenging behaviour and the requirement for skilled staff supporting someone with PWS also makes it difficult for families to find appropriate support workers. More respite services are needed and an ability to cater for the safety needs of people living with PWS, but families also need to be able to find creative, reasonable solutions to their respite needs.
- Sometimes the most practical respite break is leaving the family home. It is often much easier for one parent to leave for a respite break than to find a suitable placement for the child outside the family home.

- Sleep disorders in Prader-Willi syndrome are very common and include hypothalamic disruption of sleep / wake cycles. The severity of sleep disorders in PWS varies but some children can be awake for significant time during typical sleep periods and therefore parents also receive disturbed or little sleep. Some parents previously used their funding to have the occasional good night's sleep in local motel accommodation whilst another parent stays at home.
- Many support activities that parents register their children for require advance bookings and payments. Currently, families are unable to claim payments for future services.
- The ability to use funding to address service gaps is essential.
- The ability to use funding for out of region travel is essential because there are often no accessible or suitable activities in the area in which a family lives. Some children also need to attend out-of-zone schools due to their learning support needs or school exclusion.
- Being able to use funding to address and support the stress levels and mental health of the whole family is important. This benefits everyone and builds capability.
- Some families mentioned that they have taken a necessary support person away with them on family holidays and would previously have been able to claim the extra costs of the support person. Some families tell us they are unable to enjoy typical family holidays which are important for siblings and general family wellbeing. (Note: the examples given were local breaks and not expensive overseas holidays.)
- Families need to be able to make a judgement on "what is the best use of my funding right now?" It is not always possible to look too far ahead. People living with PWS have fluctuating behavioural needs and therefore there may be times when more funding needs to be spent, and other times when less is needed. This will look different for each family. It needs to be understood that spending may be sporadic and not evenly spread out. There may be times when set-up costs are involved. Currently, families have worries such as their funding being cut if they don't spend enough, or their funding being suddenly cut after spending a large proportion of it and then having very little left. It is not possible to make long term plans at present with so much uncertainty around funding. Families need the confidence to be able to use their funding in a flexible way as needed.



## Introduce criteria to access flexible funding

**Question 11:** Do you support the introduction of criteria for receiving flexible funding? Please let us know why, or why not?

All funding needs to have a certain amount of flexibility because needs change, circumstances change, ideas change, and strategies change. This is inevitable with a diagnosis such as PWS which is an evolving and fluctuating complex disorder.

**Question 12:** Which of the following criteria for receiving flexible funding do you agree or disagree should be included and why? (Choose all that you think should apply.)

**12a.** Use of flexible funding is part of an agreed plan and linked to a specific need.

Agree/Disagree

Why/Why not?

Agree – if the plan is easily changeable. As mentioned previously, an agreed plan will need to be easily adaptable in the event of sudden change.

Prader-Willi syndrome is associated with specific support needs which means that all people living with PWS will need a certain level of similar flexible supports. However, at the same time they are also individuals with different needs, ideas, and values, different families, different support networks, and living in different areas. Flexible funding linked to an agreed plan and specific needs will need to be individualised and able to accommodate potential future change. Some future changes might be foreseeable to some extent (and could be listed as change activators in the plan) whilst others may come as a surprise.

**12b.** Disabled people and/or their family / whānau / carers are able to manage the responsibilities of flexible funding.

Agree/Disagree

Why/Why not?

Agree.



**12c.** Flexible funding will be used to purchase a service or support that DSS provides through its contracted services/supports, that will address a person's disability-related support, and there is an advantage to using flexible funding to purchase it (such as greater flexibility for scheduling, it is closer to where the person lives etc).

Agree/Disagree

Why/Why not?

Agree that this should be an option.

**12d.** Flexible funding will address a service gap, where the service is not otherwise available, or suitable for the individual.

Agree/Disagree

Why/Why not?

Agree, this is absolutely necessary whilst service gaps exist.

**12e.** The cost of the support or service that will be funded is not more expensive than other ways to get that support.

Agree/Disagree

Why/Why not?

Disagree – The service chosen depends on many factors, including where the support service is located, how accessible the service is for someone living with PWS, and how suitable the service is for someone with PWS and their individual needs. A family would not intentionally choose a support or service that is more expensive without a good reason for doing so.

**12f.** The flexible funding will enable the person to purchase or access a service that is expected to reduce a person's future support needs.

Agree/Disagree

Why/Why not?

Disagree - This should not be an expectation. Some supports may reduce future support needs which is an ideal achievement, but other services may support needs which are ongoing and will not change. Another example are supports or services that provide family respite because this need generally increases as a person with Prader-Willi syndrome becomes older. Several studies have shown that parenting children with PWS during adolescence and early adulthood are the most challenging and stressful for families.

**Question 13:** Can you suggest other criteria for accessing flexible funding in addition to, or instead of, those above? If you have suggestions, please explain why you think they will be helpful for those who are accessing flexible funding.

Diagnosis of Prader-Willi syndrome.