



pwsa

prader-willi syndrome **australia**

**National Disability Insurance Scheme (NDIS) Costs – Position Paper:
Submission to the Australian Government Productivity Commission**

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1) Introduction

I represent people with Prader-Willi Syndrome, their parents and supporters. Prader-Willi Syndrome is a rare, life-threatening condition. I wrote to the Productivity Commission previously to alert the Commission to the likelihood that due to its complexity and volatility, PWS could cost the NDIA more than anticipated. I will provide a general explanation about PWS to refresh your understanding, and respond to some of the specific requests made in the Position Paper.

Prader-Willi syndrome (PWS) is a complex, multistage genetic disorder affecting multiple systems in the body. It significantly impacts on behaviour, learning, mental and physical health, community inclusion and social relationships. People with PWS exhibit high anxiety, complex and, at times, very challenging behaviours, along with social dysfunction throughout their lives. Whilst they have variable learning disability and communication skills, they have substantial cognitive and functional impairments. As children they need early intervention and as adults they need intensive service support from specially trained staff, integrated with supported accommodation. They rarely work in open employment. PWS is not like other intellectual disabilities.

'BEST PRACTICE GUIDELINES FOR STANDARD OF CARE IN PWS' have been published for use internationally. More successful outcomes are achieved when service providers, educators and others adopt the specialist skills and techniques needed to support people with PWS.

2) Purpose

The PWSA welcomes the opportunity to give feedback to the Productivity Commission, particularly as the NDIS goes through its development phase. The feedback in this submission is provided from the perspective of the unique needs of those who have Prader-Willi Syndrome.

The feedback addresses those Information Requests and Recommendations in the Commission's Paper, where the PWSA feels it has knowledge on which to base its comments.

The PWSA has provided this feedback with the intention of helping to shape the emerging NDIS scheme. PWSA is aware that most providers and health professionals know little, if anything about PWS, and how it can impact on service needs. Hence, the PWSA contributes the following to further the understanding of all stakeholders involved with helping people with PWS to have an ordinary life.

3) Responses

Draft Finding 2.4 – "... those who struggle to navigate the scheme, are most at risk of experiencing poor outcomes."

The PWSA strongly agrees with this finding. Even though some people with PWS can read, and speak quite well, their other cognitive limitations means they cannot take up the level of choice and control anticipated by the NDIA. People with PWS struggle with abstract concepts like a service level agreement, and cannot plan to monitor, or comprehend under-performance by providers, never mind dismiss them. They cannot understand invoicing or budgeting on an NDIS

scale, nor the criticality of completing multiple layers of administration to ensure service delivery. People with PWS suffer from high anxiety and being confronted by confusing and relentless administration exacerbates their anxiety and reduces the likelihood of their goals being reached. Even the standard letters issued by the NDIA were found to be incomprehensible by people with PWS.

The PWSA recommends that the NDIA allows for adequate support funding so that when the person with PWS has indicated their choices to their key support (eg Nominee) and Planner, someone else has responsibility for administering and operationalizing the plan, This includes monitoring quality and performance of providers, on behalf of that individual. It is important that no added risk is incurred by this fragmentation of control over spending.

Information Request 3.1 – Maintaining List D

For PWS, List D is very important. All children born with PWS have early intervention and life-long support needs. Early support gives them the best chance of having fewer support needs as adults. Recognition on List D that PWS is a permanent disability is a big help to families. Onerous entry requirements are a valueless burden to both families and the NDIA.

The inclusion of PWS on List D reduces the extent of the burden on families which would otherwise be:

- Stress of going to assessment appointments when they are in the middle of looking after a child that already needs many hours of extra support compared with a neurotypical child (eg naso-gastric feeding, speech therapy, occupational therapy)
- Complications of care arrangements if there are other children who need looking after whilst parents attend appointments with the PWS child to gather proof
- The cost of attending appointments (eg travel/parking), in particular for rural and remote families
- The potential costs of specialists and their reports
- The administration involved in chasing, collating and submitting reports
- Time lost from work of the secondary carer in relation to the extra appointments
- The strain of the NDIA not believing how bad PWS is, in terms its devastating impact on an ordinary life
- The fear that the NDIA will be forever questioning their child's eligibility (eg as happened in some State education systems) and starting the bureaucratic process all over again
- Parents would start out with a very negative impression of the NDIS, if the obvious eligibility of people with PWS for the scheme, was not recognized.

Inclusion of PWS on List D would not be having unintended consequences on excessive retention in the scheme or unnecessary delivery of supports. Individuals with PWS predictably need disability support throughout their childhood, school years and into adulthood. The PWSA has previously made applications to have PWS placed on List A as there is no evidence worldwide of anyone with PWS surviving for anything but a few months without support. If PWS was reinstated to List A, then arguably List D could be dropped from the perspective of the PWSA.

Information Request 4.1 – Clarity of 'reasonable and necessary'

Good decisions about what is reasonable and necessary can be made by well trained and experienced Planners. Every participant's needs are different. The scheme must have flexibility to allow a person to have a life that is ordinary *for them*, given their unique and improving capacity. For example, a young man who plays in an all abilities cricket team may sometimes

be able to use public transport, under predictable and routine circumstances. But when the training or match destination is well away from home, with a large amount of gear to transport, no ordinary person would be expected to do that on public transport. An adult without a disability would be able to a) drive and b) afford a car. The person with PWS who is prone to anxiety and needs to get to their destination on time, may miss out on this social community access opportunity all together if the organizing is too difficult and stressful. Planners being decision makers allows for participant flexibility, especially in the early phase of the scheme. After some precedent decisions are made by the AAT, then maybe it is appropriate to provide a more specific definition in legislation.

Information Request 4.2 – Delegate plan approval functions to Local Area Coordinators?

No. Not for PWS – it is too complex. The Planner must be trained directly by the NDIA. The consistency of initial/original plans must be established in the scheme first before devolving, and potentially diluting skill level and risking a reduction in plan quality. Perhaps at plan review a LAC could do it.

Draft recommendation 4.1 – Planning process improvement

Agreed. Plan reviews must be more responsive, to avoid a costly crisis.

Draft recommendation 4.2 – Improve understanding about different types of disability

Agreed. Specialist knowledge is essential for PWS. Experts from the PWSA could be involved. However, they are volunteers, who typically go to work in 'day jobs', and there would be costs involved, particularly for remote locations. The NDIA would need to identify how this could be effectively implemented.

The PWSA has already prepared some advice for Planners and the NDIA Technical Advisory Team. It can be found on the PWS Australia website <http://www.pws.org.au/ndia-worker-lac-advice/>.

Draft recommendation 5.1 – Increase funding for ILC

Agreed. Peek body organisations such as the PWSA are invariably run exclusively by volunteers with very low overheads, however, particularly in the initial rollout stages of the NDIS, these small but important support organisations are experiencing significantly higher costs. For example, the PWSA has chosen to amalgamate their Melbourne, Sydney, Brisbane and Western Australian Association into one National body which will then have State branches. Our reasoning is to enable standardisation of our PWS educational materials and support services across Australia (implement fairness and equity and remove post code restraints for the PWS recipients).

We have previously been unsuccessful in our applied for an ILC grand that would enable us to development a National education and support campaign – 'reaching across Australia'. We believe that organisations such as ours represent good valid-for-money to NDIA, due to our high ratio of volunteer hours. Hopefully we will be successful next time, as reducing isolation for our members with PWS is of vital importance, however, we recognize that the pool of funds available for ILC is currently small.

Draft recommendation 5.2 – Governments to make public their approach to providing continuity of support.

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Agreed. States and territories must say how their SDA residents (current and future) will be assured for accommodation if other providers are unavailable, or refuse to offer service. For example, even emergency SDA should be available from Government, until a plan is renewed and upgraded to more appropriate supports, for which another provider can then offer a service.

Draft recommendation 5.3 – Dealing with boundary issues

Agreed. Also, States have to commit to enabling their mainstream services to act in a holistic manner, for the overall welfare of the participant. There have been instances where the treatment of people with PWS by mainstream services, such as hospitals or police have been *the cause of behaviours of concern*, rather than helping to support the disabled person given their PWS traits.

Draft recommendation 6.1 – Introduce independent price regulation

Agreed.

Draft Finding 6.1 –“... thin markets will persist for some groups...”

Agreed. This is of concern to PWSA, because PWS is a rare, complex and challenging condition. Because of this, there are international guidelines to address the management of PWS. People with PWS often do best when they live in specialist SDA and SIL settings that directly address the traits of the condition. Not many providers have adequate knowledge and capability to deliver an appropriate service for this cohort, although there a few in Australia that have proved successful. People with PWS are at great risk of being under-serviced and not reaching their goals or increasing their capacity.

Information Request 6.1 – How should thin markets be addressed?

There must be a principle of no person who qualifies for SDA being left homeless. There must be a provider of last resort. If there was a risk of homelessness, or inappropriate accommodation happening in a thin market, then block funding or direct commissioning for PWS participants must occur. This could readily be applicable for people with PWS, who have a commonality of phenotype when it comes to their baseline support needs. Such supports are identified in the international guidelines (and in local models available, but which can't meet demand). So, a portion of the PWS individual's funding could deliver a baseline SDA/SIL service, and the rest of the individual's plan and funding would depend on their unique goals and capacity.

It should be noted that, due to the complexities involved in providing support for people with PWS, numerous individuals may require 'above benchmark funding' for SIL and it is likely that all adults with PWS are likely to qualify for SDA funding.

Information Request 6.2 – Encouraging a greater supply

Providers with integrity may be more willing to participate if there was more confidence in predictability of cash flow, whilst consumers are learning how to purchase services and the pattern of consumer behaviour is more apparent. Not-for-profit providers may offer more services if they have more confidence that any 'rotten apple' competitors would be detected

and weeded out of the market, so that the bad influence did not have an adverse impact on purchasing from honest providers.

Draft recommendation 7.1 – Australian government to retain oversight of workforce development

Agreed. National oversight will foster consistency in things like common skill levels, whether there is actually any need for immigration and ensure regulations dovetail with quality and safeguarding measures.

Information Request 7.1 – Developing a holistic workforce strategy

Some techniques may be to provide minimum indicative pay scales for SDA workers. Such transparency will be good for consumers and workers looking for preferred employers. Pay rates should recognise a capital city loading. A higher rate of pay should be available to workers for higher skills that require specialist training and who manage participants with behaviours of concern. There must be incentives for SDA/SIL staff to become permanent, so that there is better continuity of care for the most vulnerable clients, and who have the least cognitive ability to make any use of the NDIS without comprehensive supports.

We have recently heard 1st hand stories from Victorian SIL support workers operating in 'high support needs' SDA settings, who are considering quitting the industry because their sick leave (stress) days per year are going to be halved. A holistic strategy toward workforce development could, for example, recognise the additional challenges faced by workers in some high support needs settings and enable the development of appropriate award conditions.

Draft recommendation 7.2 – Publish detailed market position statements

Agreed.

Draft recommendation 7.3 – Paying informal carers

This would help in thin markets. But it would have to be structured, along with an appropriate service agreement, and be heavily monitored, including through the use of 'big data'. This would help identify workers who were paying themselves more than the SLA, or who seem to be working elsewhere in the same time period for which they invoiced NDIS services, or were claiming for looking after more than one family member at the same time (group rate). Penalties must be applied and publicized as a deterrent and to contain costs. The rorts like those in the 'family day care' program must be avoided. Complexities regarding determining what level of informal supports should reasonably be provided by the families may be difficult to resolve, however, this restraint should not override fairness in offering financial recompense for family support hours that are above and beyond reasonable levels, particularly in a thin market where alternative supports are not available for purchase.

Information Request 7.2 – Respite services

Respite is critical in PWS families. The behaviours wear down the carers and can have an adverse impact on the family unit and the wellbeing of siblings (up to 95% of siblings of people with PWS require psychological intervention). Respite helps families to have time and fortitude to self-manage their child's NDIS funds and deliver the therapies recommended by specialists.

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Information Request 8.1 – Use of support coordination

The participant should have a holistic NDIS service experience. For anyone with a cognitive/intellectual impairment, they need someone official, who knows them, to 'run' their Plan for them, after implementation. This is more imperative for those not living in the family home.

The Support Coordinator is in place to 'bolster the readiness of participants with complex needs'. But after that 'kick off', someone needs to be with the PWS participant, on a daily basis to see the plan through. This means making sure the participant has compatible co-participants in joint activities, and notice is given if the participant can't attend. Someone has to ensure that each SLA is monitored, and action taken on under-performance. For children, a family member is likely to run the plan in an holistic manner.

For adults, perhaps the SC is the best placed role to ensure the ongoing suitability of services in the plan, as it rolls along. The introduction of yet another role, like an advocate for this task creates a new risk for the person with PWS. That is, more providers create gaps in knowledge, availability and accountability. This opens up cracks, into which the person with PWS can stumble.

Current disability systems have demonstrated that service fragmentation is counter-productive and more expensive. Since the SC is acting as the 'case worker', they know the client best. The SC has the participant's *holistic* needs and plan at heart, and knows all the service agreements entered into.

In SDA, after the plan commences, the resident with PWS is better off with a Key work who knows the participant best. A worker in the householder will undoubtedly be coordinating services anyway, with health appointments, days off sick from other activities, the participant's preference to rearrange the destination of an outing. The SC can put the program of activities into place, but a Key Worker needs to be there, on the ground, operationalising the plan, so that the services occur effectively, and are performed in accordance with the SLA (The SC would not be privy to that, for example whether the provider was running late, charging accordingly or whatever). Additional funds should be channelled to the Key Worker to enable non-contact hours for high support needs Plan implementation.

Information Request 8.2 – Disability Support Organisations and private intermediaries to play a greater role in supporting participants?

As mentioned above, adults with PWS need support after plan 'kick off'. Someone needs to be with the PWS participant, on a daily basis to see the plan through. This means, for example, making sure the participant has compatible co-participants in joint activities, and notice is given if the participant can't attend. Someone has to ensure that each SLA is monitored, and action taken on under-performance. This should not be the plan manager who would be in a conflict of interest situation were they to be monitoring their own performance. Any paid intermediary will have to be empowered to know the participant well, take a holistic view of plan delivery, and be readily available to assist, particularly if things are not going well. A risky situation must not be allowed to escalate because the accountable person was not responsive. In SDA, a Key Worker role would be best placed to support the participant with the smooth delivery of services.

Because adults with PWS have poor self-management ability, they need a 'parallel' service from a Key Worker who knows them, to ensure integrated, holistic care on a daily basis. Such a service is needed for responsible administration, when the worker is not delivering service face-to-face. A Support Coordinator is too distant, both in knowing the participant thoroughly and availability. For example, while the participant is busy outside the home (eg supported employment), the Key Worker needs to be following up on medical results, picking up a prescription, making a new appointment, arranging transport for next week's social activity and keeping the parents informed of progress, etc).

There should be more *diagrams* (flow charts) available, to show the different combination of NDIS administrative supports for adults who have high support needs and don't have the cognitive capacity to administer their Plan. Participants may well be able to express preferences in terms of supports but not manage SLAs, book-keeping, etc. It must be clear who has accountability for what, during the ongoing life of service delivery, especially SLA monitoring and service satisfaction of the participant. Roles are: planner, SC, NDIA as payer, financial intermediary and Nominee. Then there's Correspondence Nominee, Guardian, formal Administrator, Supportive Attorney and informal support, including parent. Parents could in some instances help more, if there was less confusion, and more clarity about how the parent/carer would interact with the others involved in monitoring.

Draft recommendation 8.1 – eMarketPlace

The PWSA supports the concept of an eMarketPlace. But consumers and their supporters must be involved in co-design of the market place. This would include setting the Key Performance Indicators that they want to know about providers, as well as the usability of the site. There would need to be monitoring of entries and any misleading behaviour or sharp practices by providers identified and penalized.

Draft recommendation 9.3 – Public report on plans

Agreed.

Draft recommendation 9.4 – NDIA performance reporting

Agreed.

Draft recommendation 9.5 – A better balance

Agreed. The PWSA supports the role of the NDIS Intellectual Disability Reference Group (IDRG). It has faded from view in recent times, but it is a valuable vehicle for bringing to the table, those issues that confront people who will never understand insurance, SLAs, or administrative processes well enough to navigate the NDIS by themselves. The IDRG Terms of Reference, members, agendas and meeting outcomes should be transparent to the public.

Information Request 9.1 – If rollout slows, what should be prioritized?

The PWSA recognizes hardship resulting from rollout slowing for potential participants with more urgent and complex needs, and people in current state and territory services with complex and urgent needs that are not properly met. Designing processes that sufficiently safeguard these vulnerable participants could prove complex, however, we are not apposed to further privatization developments.

Information Request 10.2 – Better manage cost overruns and liabilities

The PWSA does not support giving the Australian Government greater authority. This is a national scheme, and there needs to be collaboration with States and Territories to get a fair balance of Australian views, and to maintain local integrity of the system.

Draft recommendation 10.2 – Reconsider the NDIA staffing cap

Agreed.

4) Conclusion

It can be seen from the above that PWS is a complex disability. For children, there is an expectation that, where possible, their parents will navigate the NDIS for them.

For adults, whilst a person with PWS can express their simple preferences, likes and dislikes, they will not be able to engage with the NDIS without lifelong help. The supports they will need are varied. And not to be under-estimated is the amount of administration that is needed for a person with PWS to approach having 'an ordinary life'.

The PWSA looks forward to the NDIA's greater focus on face-to-face communications, and improved interaction with disability organisations. This will help to move us all towards better outcomes for people with Prader-Willi Syndrome and others with significant additional needs.