

Commissioner
Review of NDIS Costs
Productivity Commission
GPO Box 1428
CANBERRA CITY, ACT 2600

24/3/2017

Dear Sir/Madam,

Re: Submission on the Productivity Commission Issues Paper - National Disability Insurance Scheme (NDIS) Costs

I represent the parents and supporters of people who have a rare genetic, life-threatening condition called Prader-Willi Syndrome (PWS). I write to inform you that individuals with PWS are likely to require substantial NDIS funding. I will provide a general explanation about PWS to improve your understanding, and respond to some of the specific issues raised in the Paper.

Prader-Willi syndrome is a complex, multistage genetic disorder affecting multiple systems in the body. It significantly impacts on behavior, learning, mental and physical health, community inclusion and social relationships. People with PWS exhibit high anxiety, complex and at times destructive behaviours and social and cognitive dysfunction throughout their lives. Whilst they have variable learning disability, they all have substantial cognitive and functional impairments. They cannot live without intensive service support, integrated with appropriately designed robust accommodation. They rarely work in open employment.

In response to the issues paper about NDIS costs, we will firstly point out that PWS is not like other intellectual disabilities. International research has identified the particularly difficult facets of PWS that require extra support, and the Productivity Commission needs to allow for associated NDIS costs. Evidence for PWS complexity is on this webpage <http://www.pws.org.au/guide-ndia-technical-advisory-team/> (in Appendix 1).

The cost of supporting people with PWS is high. There will be costs incurred that are not face-to-face services with the participant. For example, one role would be the needs for a person to be responsible for the *administration* that accompanies coordination of holistic care. If any aspect of the care and management of a person with PWS is deficient, it will impact on other areas of their life and generate additional costs for the community. For example, if food security is inadequate, the individual will become morbidly obese. Then they typically get diabetes due to predisposition associated with PWS. The additional anxiety cause by poorly managed diabetes is likely to result in more ambulance attendances than for a diabetic who does not have PWS.

Another typical characteristic is anxiety with autistic like features. If the individual has an unpredictable living environment, their anxiety escalates. If the environment in and out of the home is not carefully managed, it is not uncommon for fights to ensue and police to be called. Further administration arises from such crises. It is therefore important that a lot of planning, coordination and training occur in the background, to adequately support people with PWS.

Following are responses to specific issues raised in the Issues Paper:

Are there any cost drivers not identified above that should be considered in this study? If so:

– how do they impact costs in the short and long term?

– how, and to what extent, can government influence them?

For PWS support, there is an International Standard for the Management of PWS. Staff should be trained in accordance with those Standards. Skilled staff, in adequate ratios, will result in lower crisis management and associated administrative costs such as waiting with the participant in hospital emergency, incident reporting, OH&S reactions, insurance claims and legal negotiations. A diagrammatic 'case study' of disability supports, for an adult living in supported disability accommodation, is in Attachment 1, to illustrate the scope of needs. Provision of adequate staffing and service coordination up front, will reduce the escalation of future costs.

Up to this day, people with PWS typically died young, due to complications associated with obesity. When PWS is managed properly, people with the condition can be expected to lead a more ordinary life and live longer. They will need life-long support in purpose built Supported Disability Accommodation designed specifically to accommodate the needs of people with PWS.

What factors are contributing to increasing package costs?

Why is there a mismatch between benchmark package costs and actual package costs?

It is the belief of the Prader-Willi Syndrome Association of Australia (PWSA) that:

- The cost of supporting people with PWS is unlikely to have been adequately estimated by the NDIA, as the condition is rare and complex, not like other intellectual disabilities. Individuals are likely to need 'above benchmark' support funding
- People with PWS in Australia have not been adequately supported in the past, so depending on historical costs as a guide would have been a flawed approach

- The Standards of Care and Best Practice Guidelines for the Management of PWS (<http://www.ipwso.org/best-practice-guidelines-for-pws-care> was released in 2010 and may not have been known to the Commission and NDIA when potential costings were being estimated for the Scheme.

People with PWS are likely to exceed benchmark costs in both service provision and in accommodation. In terms of accommodation, a 'robust' building type is a foreseeable need. In terms of staff, they need to be more highly trained and skillful than the average support worker. They also need to support PWS clients in a higher ratio than for other ambulant participants. For example, where a participant is accessing a sports team, they can be seen to run around on the field or court. However, if the PWS participant has an emotional outburst about something, their support worker needs to assist them to overcome their anxiety, which is not often achievable, or remove the participant from the environment. If this does not happen, it is likely that the relationship with the sports team will be fractured, or someone will be injured. Hence a worker needs to be present throughout the activity.

Are there other early intervention programs that could reduce long-term scheme costs while still meeting the needs of participants?

Children with PWS need many types of early intervention to reach their individual potential, due to their multiple disabilities (<https://www.nichd.nih.gov/health/topics/prader-willi/conditioninfo/Pages/treatments.aspx>). However, this does not mean they will exit the NDIS later. It will allow them to lead a fuller life and participate in more activities. So far, it has been shown that ongoing support is needed to maintain that participation in a range of activities, to maintain a resemble or ordinary life.

How has the interface between the NDIS and mainstream services been working? Can the way the NDIS interacts with mainstream services be improved?

People with PWS have had countless negative experiences in mainstream health and other community services when the provider is unaware of PWS. To achieve the best outcome, education, plus a holistic approach, is needed to manage the variety of health and behavioral conditions they have. As health status impacts the capacity to lead an ordinary life, the holistic approach needs rigorous coordination in PWS. Coordination may be done by a Guardian or Nominee but if there isn't one, a paid disability support coordination worker is needed, not a health provider who may only considers *health* needs. The International PWS Organisation has published advice about care (<http://www.ipwso.org/famcare>) and for raising the awareness of

professionals working with PWS

(http://media.wix.com/ugd/a71d4c_ed96afec72db454bb700f769bbcba01d.pdf).

Health providers, and other service settings, need to be informed about the complexity of PWS otherwise inappropriate service may be delivered, with no improvement in outcomes. Also, the participant may display challenging behaviors at the service, causing time delays, security alerts and associated costs. PWS is rare and providers often know little about it, or the idiosyncrasies of the individual. Therefore, the PWSA recommends that NDIS plans fund support staff to have administrative time to educate health providers that look after PWS participant. This will improve the interaction of mainstream services with NDIS participants who have PWS. If angry outbursts are not mitigated in advance, at times people with PWS have been excluded from social and economic activities. Advance preparation by the PWS participant's key disability support worker, gives the best chance of a successful outcome in the use of mainstream services. A research study has reported on uncounted costs in NDIS for participants with behaviours of concern. Such behaviours are a feature of PWS. <https://www.anglicare-tas.org.au/sites/default/files/The%20uncounted%20costs%20-%20choice%20and%20control%20for%20people%20with%20behaviours%20of%20concern.pdf>

Is the planning process valid, cost effective, reliable, clear and accessible? If not, how could it be improved?

PWSA believes that the planning process is better when the Planner is educated about PWS. Anyone acting as a Planner for a person with PWS should be properly informed about the complexity of the condition, *plus the types of risks likely to arise within the planning process*. Information about PWS specifically for Planners is available in Australia here <http://www.pws.org.au/guide-for-planners/>. There is also information for NDIA Plan Reviewers here <http://www.pws.org.au/guide-ndia-technical-advisory-team/>.

To what extent does the NDIA's budget-based approach to planning create clear and effective criteria for determining participant supports? To what extent does it lead to equitable outcomes for participants? What improvements could be made?

The budget-based approach has been difficult for people with PWS. They often have needs for support quality and quantity above benchmark allowances to allow them to lead an ordinary life and at the same time remove the risks associated with their life-threatening condition. Without adequate funding, people with PWS do not have the promised choice and control of the NDIS.

Are the avenues for resolving disagreements about participant supports appropriate? How could they be improved?

The PWSA recommends that the participant and their Guardian or nominee be given a draft of the first and other plans before finalization. This will avoid misunderstandings and oversights.

How might assistance for informal carers affect the need for formal carers supplied by the NDIS and affect scheme costs?

PWSA draws your attention to a situation with PWS participants that is not uncommon. They have a strained, and potentially volatile and violent, relationship with family. As such, more formal supports may be needed than anticipated.

What scope is there to expand the disability care and support workforce by transitioning part-time or casual workers to full-time positions? What scope is there to improve the flexibility of working hours and payments to better provide services when participants may desire them?

People with PWS need highly trained support staff, and a consistency of staff so that there is minimum disruption to service quality. PWSA recommends that full time, permanent staff support people with PWS for better outcomes. After a training investment, it is important to have low staff turn-over. As such staff need incentives to work with this group and their complex behaviours.

What are the advantages and disadvantages of making greater use of skilled migration to meet workforce targets?

People with PWS enjoy and build capability from their support staff. Staff must be able to communicate with these participants with consistent messages. As such, staff must be able to speak English very well (for English speaking participants). People with PWS often have auditory processing difficulties. Even a strong accent can preclude the participant from understanding and cause frustration. The nationality of the support worker is immaterial.

Are prices set by the NDIA at an efficient level? How ready is the disability sector for market prices?

Market prices may only be acceptable if there are enough support hours built into an NDIS Plan. For people with PWS, there must be adequate administration hours included. In relation to shared supported accommodation we believe that 'above benchmark' funding will be required.

How ready are providers for the shift from block-funding to fee-for-service?

PWSA sees a risk in the fee-for-service model around staff retention. There will be times when the participant is ill, at an appointment or on holidays and staff ratios at the SDA or in a community service need to be maintained, but not all the usual participants are present.

PWSA is concerned that for-profit providers will take advantage of a poorly regulated NDIS – as occurred with the VET education sector. People with PWS cannot exercise monitoring, judgement and decision making skills that are the skills needed to get proper service in a competitive environment. Therefore, PWSA believes that supports for those functions need to be built into the participant’s Plan. For example, the core service provider (in a group home) ensures the reliability and suitability of the capacity building service providers for their mutual participant.

How well-equipped are NDIS-eligible individuals (and their families and carers) to understand and interact with the scheme, negotiate plans, and find and negotiate supports with providers?

PWSA commends the NDIA for the training resources that have been made available to PWS families and participants to date. A variety of opportunities have occurred with face-to-face briefings and online materials and webinars. This should continue, and provide more detail. More information must be provided about how group homes will take up core and other service provision in a manner that makes it easy for all household members.

To what extent do the existing regulations provide the appropriate safeguards and quality controls? Can these arrangements be improved?

The PWSA is awaiting detail of the appropriate safeguards and quality controls. There needs to be a *centralized* incident management recording system. It needs to include *all* types of incidents, minor and major. The data must be regularly analyzed. Patterns and trends must be analyzed, so that any risk within provider services are identified and remediated early. There needs to be a way of identifying workers who are not suitable for the industry like <http://www.dhs.vic.gov.au/for-service-providers/disability/accommodation/supported-accommodation/disability-workers-exclusion-scheme-information-for-service-providers>, available across Australia. NDIS participants must have access to information about the performance of providers (e.g. number of complaints against them, participant’s budgets running out too early, etc.)

Thank you for the opportunity to respond to these issues.

Yours sincerely,

James O’Brien
President
Prader-Willi Syndrome Association of Australia.

Case study: Disability supports for a PWS adult living in a group home

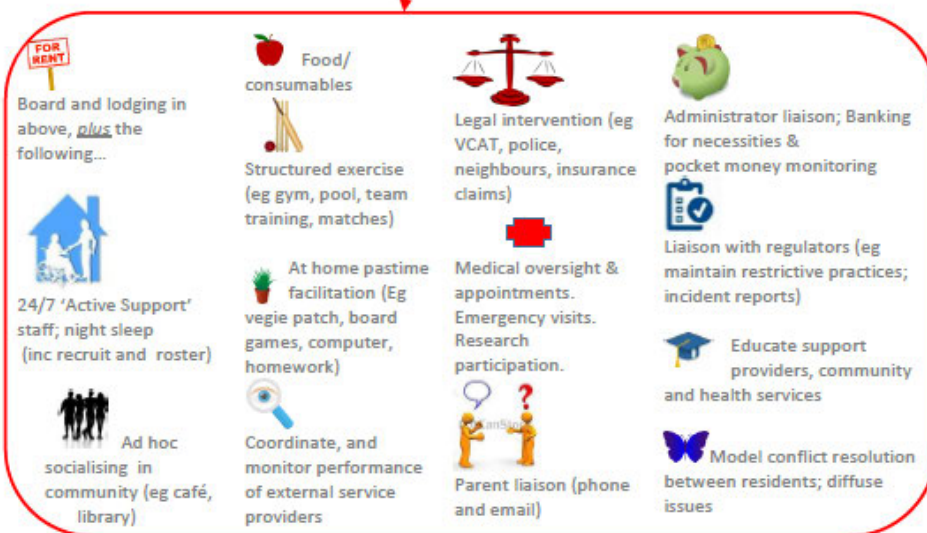
DRAFT



A red-bordered box containing five categories of support for a disability group home. Each category includes an icon and a text description.

- Robust house, with sleep over & break-out rooms, land with garden** (Icon: House)
- Utilities, phone (land & mobile), rates, etc.** (Icon: Power outlet)
- Insurance** (Icon: Car)
- House/yard maintenance and repairs (mowing, leaky tap, deliberate damage, etc.)** (Icon: House with hammer)
- Curtains, washing machine, fridge, lounge, utensils, etc.** (Icon: Washing machine)

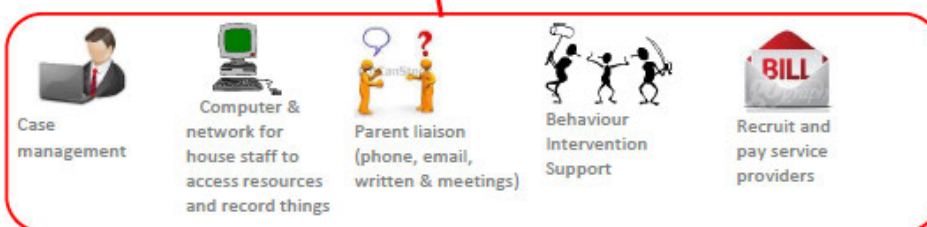
Disability group home



A red-bordered box containing various support services. It includes a 'FOR RENT' sign icon and several categories of services.

- Board and lodging in above, plus the following...** (Icon: FOR RENT sign)
- 24/7 'Active Support' staff; night sleep (inc recruit and roster)** (Icon: People in a house)
- Ad hoc socialising in community (eg café, library)** (Icon: People walking)
- Food/ consumables** (Icon: Apple)
- Structured exercise (eg gym, pool, team training, matches)** (Icon: Tennis racket)
- At home pastime facilitation (Eg vegie patch, board games, computer, homework)** (Icon: Vegie patch)
- Coordinate, and monitor performance of external service providers** (Icon: Magnifying glass)
- Legal intervention (eg VCAT, police, neighbours, insurance claims)** (Icon: Scales)
- Medical oversight & appointments. Emergency visits. Research participation.** (Icon: Medical cross)
- Parent liaison (phone and email)** (Icon: People talking)
- Administrator liaison; Banking for necessities & pocket money monitoring** (Icon: Piggy bank)
- Liaison with regulators (eg maintain restrictive practices; incident reports)** (Icon: Clipboard)
- Educate support providers, community and health services** (Icon: Graduation cap)
- Model conflict resolution between residents; diffuse issues** (Icon: Butterfly)

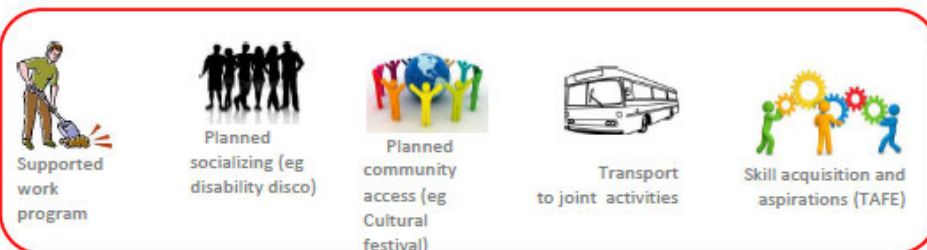
Support services within that home for daily living and accessing the community



A red-bordered box containing five categories of regional office supplies and services.

- Case management** (Icon: Person at laptop)
- Computer & network for house staff to access resources and record things** (Icon: Computer monitor)
- Parent liaison (phone, email, written & meetings)** (Icon: People talking)
- Behaviour Intervention Support** (Icon: People with speech bubbles)
- Recruit and pay service providers** (Icon: Envelope with 'BILL')

Regional office supplies...



A red-bordered box containing five categories of further funding for capacity building and participation.

- Supported work program** (Icon: Person with broom)
- Planned socializing (eg disability disco)** (Icon: Group of people)
- Planned community access (eg Cultural festival)** (Icon: People holding hands)
- Transport to joint activities** (Icon: Bus)
- Skill acquisition and aspirations (TAFE)** (Icon: Gears)

Further funding for capacity building, social and economic participation