Transitional arrangements for the National Disability Insurance Scheme (NDIS):

Submission to the Joint Standing Committee on the National Disability Insurance Scheme

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1) Introduction

I represent people who have Prader-Willi Syndrome (PWS), their parents and supporters. PWS is a rare condition. As such, not many people with this condition have transitioned to the NDIS yet. However, we welcome the opportunity to contribute to this very important consultation[1], at the invitation of the Committee.

I will provide a general explanation about PWS to improve your understanding, and respond, from the PWS perspective, to the specific issues open for inquiry.

Prader-Willi syndrome (PWS) is a life-threatening condition. It is a complex, multistage genetic disorder affecting multiple systems in the body. It significantly impacts on behavior, learning, mental and physical health. People with PWS exhibit high anxiety, complex and, at times challenging behaviours and cognitive dysfunction throughout their lives. They have poor judgement and are socially isolated. Whilst they have variable developmental delay, they all have significant cognitive and functional impairments. Many have psychiatric problems and autistic characteristics as well. A defining feature of PWS is compulsive over-eating. Without adequate support, people with PWS die young.

'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

PWS effects males and females, and social and ethnic groups equally. Difficulties are present from birth, and although the manifestations change as the individual matures, the person is always disabled and needing support. Therefore, at present across Australia, there are people with PWS at all ages and stages of life. Children live at home, and adults typically require supported, group home accommodation. People with PWS need holistic care because of the interdependencies between their poor physical and mental health, cognitive limitations and other disabling attributes.

2) Purpose

The feedback provided in this submission refers to the NDIS transitional arrangements within the scope of the committee. The purpose is to let the committee know how people with PWS, in their various circumstances, are being impacted by the NDIS transition arrangements. Some recommendations are made.

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[1] The Consultation Paper was available from the web page
http://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/Transition

3) Response

Four categories of inquiry have been identified by the Committee.

A. *Boundaries and interface of NDIS service provision, and other non-NDIS service provision, with particular reference to:*

i) Health

PWS is a multi-system disorder, which involves both health and cognitive problems. The different problems of PWS impact each other. Therefore, managing one facet well, brings benefits to other facets of the disability. The opposite is also true; manage a feature poorly, and it will have adverse consequences on other presentations. So, the boundary between mainstream and disability services for people with PWS is very blurry. For example, research found that "…early diagnosis and careful attention to detail regarding all the potential endocrine and behavioral manifestations can lead to a significant improvement in health and developmental outcomes"[2]. As such, the boundaries between disability driven support needs and chronic health needs overlap.

Due to this interplay of symptoms, the PWSA is concerned that the health system needs more direction from the NDIA to properly support people with PWS. PWS is rare. Typically, a parent who accompanies their loved one to hospital has to provide the hospital with resources about PWS, and educate immediate staff about the consequences of having a patient with PWS.

People with PWS suffer from obesity and behavioural complications, amongst other things. Parents gave examples of adverse hospital experiences such as:

- An already overweight patient being discharged from a stay in hospital heavier than when they went in. This is completely counter-productive to the health of the patient and ultimately puts more cost on the public purse
- A PWS patient being given food inappropriately during a stay, thereby negating the test results and having to start the process all over again
- A person with PWS being refused emergency admission to a psychiatric ward on the basis that the challenging behaviour was disability related, rather than mental health related, even though the patient was admitted the next day
- The doctor of an adolescent patient insisting that the information provided by the PWS patient alone was enough to form the correct view; This is contrary to expert advice[3] that people with PWS are known to be poor reporters of their own health, and that anything said which impacts treatment decisions should be corroborated by a parent or carer
- There should be specialist PWS clinics at strategic hospitals across Australia. This would help to build communities of expertise in PWS, offer better service and reduce the risk of the patient being misunderstood, and staying longer than necessary, causing disruptions or returning again too soon. A 'multi-disciplinary clinic' model should be available in children and adult hospital settings.

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[2] Endocrine manifestations and management of Prader-Willi syndrome https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3751775/

[3] PWS Awareness for Meetings with Professionals, IPWSO (2016), https://docs.wixstatic.com/ugd/a71d4c_ed96afec72db454bb700f769bbcba01d.pdf

- A PWS inpatient disturbs others with disruptive behaviour driven by anxiety about the hospital environment; This occurs when the hospital is focused on the medical service, with less effort on the specialist 'care experience' needed by those with PWS
- A PWS adult out-patient is given a follow up appointment date. The date is not independently conveyed to a responsible carer. The date 'falls through the cracks' and the follow up appointment is missed. This results in the treatment lasting longer than necessary and in further unnecessary administration for all concerned.

Allied health service providers rarely have knowledge of PWS. A major issue when dealing with people with PWS is the variety of issues they have, and how all these interact. Issues are both behavioural and physical. There is a risk that the efforts of one provider will counteract the efforts of another. Hence, there needs to be a holistic approach to the support and care of someone with PWS. For example, in general conversation a podiatrist agrees with the patient that it should be OK for a person with PWS to have desert for their tea each night, even though the dietician recommended against that.

The PWSA is concerned that someone needs to be educating each service provider, at the point of new contact with the patient, on how PWS will impact that interaction. A big risk with the NDIS, particularly during transition, is that service provision to people with PWS will become more fragmented than holistic. For sufferers living in the family home, this is less of a risk, because there is a consistent carer, who has the participant's whole welfare at heart. But for adults living out of home, there is no case worker to ensure cooperation between *all types* of services, and monitor the response of the participant. It is therefore foreseeable that if fragmentation persists, the vision of the NDIS may not be realized for those with PWS.

PWSA recommends that:

- For residents of SDA, there needs to be an NDIS Key Worker role, as existed in the group homes model[4] in Victoria and elsewhere. This role takes a holistic view of the participant and ensures cohesive mainstream<>disability service delivery, with the desired outcomes. This will be particularly important during transition.
- Clarity should be given by the NDIA about which SDA support worker role is responsible for ensuring *holistic* mainstream<>disability service delivery to the PWS participant. The NDIA must allow provider funding for NDIS SDA Key Worker to educate other service providers (mainstream or not) who interact with their PWS charge. The NDIS Key Worker must also have time to ensure that all health and allied services are delivered as expected. For example, the Key worker would ensure follow up appointments were known, coordinated with other commitments, attended and the results acted upon. This would reduce the risk of 'cracks' appearing in an otherwise fragmented service delivery environment.
- Hospitals across Australia should be given consistent information about how to look after a PWS patient, whether they be in or out patients (in addition to the specific medical alerts that already apply), and made responsible for contributing to holistic care
- Hospital staff must expect to spend some time with the PWS patient's other supports, where applicable, to avoid a conflict of, or misunderstanding about treatment

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[4] Making a good life in the community: Implementing key working in group homes for people with intellectual disabilities http://www.dhs.vic.gov.au/__data/assets/pdf_file/0004/605947/kew_Keyworking.pdf

- Funding should be made available to PWSA to develop and distribute resources to hospitals, GPs and allied health providers that explain the best approach to caring for PWS patients.

ii) Education

Children with PWS need assistance with their schooling. They need educational, social and safety support. The PWSA is yet to learn about the consequences of the NDIS on people with PWS at school. On the face of it, the positives seem to be that the learning assistant can focus on the school curriculum, whilst the NDIS support can focus on any self-care needs. However, there appears to be some 'grey areas'. That is, there are known risks for students with PWS, but a lack of clarity for who will be 'on the spot' to address those risks in real time. Risks for students with PWS that do not seem to be addressed are:

- Poor social skills, which lead to social exclusion if not supported in school
- Food seeking from unsuitable sources and eating non-food substances, causing ill health, if not supervised outside the classroom
- Tripping or falling when on stairs or other uneven surfaces when going between class activities or in the playground (due to low muscle tone and small hands and feet)

PWSA recommends that:

- The NDIA monitor the consequences of a lack of support in the risk areas noted above, and assesses outcomes of school incidents, for who should have been responsible for alleviation
- Any additional non-educational supports needed to address the risks above should be provided by the NDIS.
- If further gaps are found, the NDIA should negotiate through COAG as to what additional services are needed in schools to improve outcomes for students with PWS, and who will pay for and enact that additional service scope

iii) Transport services

Of concern to the PWSA, is not enough transport assistance for people with PWS. Some people with PWS cannot use public transport at all. They need support to get to their regular day time activity and anywhere else. They may be too restless to be accompanied on public transport, leading to stress and challenging behaviours. Pension money will not be enough for them to make daily taxi trips alone. NDIS-assisted transport is important because even for those individuals who can apparently use public transport, their capacity to do so varies from day to day. It also depends on their destination. Just because a person with PWS can use public transport to travel a predictable route, say to and from a day program, this does not automatically mean they can negotiate public transport safely anywhere else.

Some will be able to use public transport during the day, but not after dark, when they are more vulnerable and more anxious. At times, when a person with PWS has heightened anxiety for an unknown reason, it reduces their resilience to cope with the stress that comes with using public transport. Hence, even on a predictable route, on random days the PWS person may need assistance to get to, say, supported employment (or back), if they are not to miss out.

Another example is a young adult who plays in an all-abilities sports team. This person can use public transport, under predictable, short, routine circumstances. But the all-abilities club training and match destinations are far from home, with sports gear to transport too. The person also needs support from a worker during these events, because at times there is a medical or behavioural issue to manage. If the transport arrangements are too complicated, unpredictable and prolonged, the person with PWS (who is prone to anxiety and low volition), may miss out on this valuable opportunity all together (social, fitness, community participation).

Not only that, an ordinary person can choose a club where their friends play, and drive themselves. They would not be expected to travel those distances, under those conditions on public transport. An adult without a disability would be able to a) drive and b) afford a car.

Another problem can arise. The example is that a taxi comes *early* to pick up the person with PWS for a medical appointment. This surprise causes the participant so much anxiety they refuse to get in the taxi and the appointment is missed. The appointment process has to be administered all over again.

PWSA recommends that:

- The NDIA recognize the substantial difficulties experienced by those with PWS in using public transport, even though it is feasible for some under limited conditions
- The NDIA ensures that people with PWS can attend skill building or employment related activities using NDIS transport assistance
- The NDIA ensures that people with PWS can attend all their regular social and community access events, by providing transport assistance, otherwise those participants are at high risk of missing out
- The NDIA provide transport assistance for ad hoc occasions of need

B. *Consistency of NDIS plans and delivery of NDIS and other services for people with disabilities across Australia*

Plan consistency is a potential issue with PWS. This is because:

- Prader-Willi Syndrome is complex and changeable, making it hard to quantify its adverse impacts and needs anytime, not just during transition planning
- Parents and informal supports may lack capacity to adequately assist their loved one with NDIS requirements
- PWS is rare, and needs specialist care skills[5]; 'Thin' demand is likely to make service hard to purchase in country and remote areas, leading to inconsistency in service delivery
- NDIS experts may not have had enough training yet to understand PWS

The complex behaviour of people with PWS can lead to difficulties in discerning their true needs. If the Planner is not skillful, and knowledgeable about PWS, in advance of a planning meeting, there is a significant risk of misunderstanding the needs of the participant. There is a real risk of under-servicing, with an adverse impact on the wellbeing of, and outcomes for the PWS participant.

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[5] International Best Practice Guidelines for Standard of Care in PWS http://www.pwsausa.org/product/best-practices-guidelines-for-standard-of-care-in-pws-cd/

An example of complexity is that many people with PWS apparently have good verbal skills. But the adults are also very prone to confabulation. So, they will 'lie' about their abilities, with all sincerity. However, this masks their true, impaired ability. Combine this with high anxiety, an inability to adapt, and functional limitations, means they actually need significant support.

People with PWS will have great difficulty in contributing to the efficient delivery of their plans. They are generally unable to grasp abstract concepts like 'insurance', 'service agreements' or 'monitoring'. They are not able to envisage 'domains' of their lives for which they can articulate their support needs. In fact, a common trait of PWS is for people to over-estimate their own level of ability to manage their daily life as an ordinary person could. They have limitations in executive brain function (like organizing and following through). Therefore, it is typically parents who help people with PWS navigate the NDIS.

During this transition period, members of PWS Australia have noted that the NDIS is a comprehensive, or even difficult program to be involved with. The vision is admirable, but for people with PWS who have multiple, lifetime, physical, health and cognitive impairments, the future under NDIS still looks daunting. Parents have to put in great effort to understand the NDIS and help generate a suitable Plan for their loved one. Operationalising the Plan (training, rostering, monitoring, paying, and replacing workers), and addressing a Plan review, all require relentless administration and attention. This seems to be the case even if there are service providers already in place, prior to transition.

The PWSA is concerned that some families/carers of people with PWS:

- do not know about the NDIS because it is new, or if they do, they will not have enough information to engage with the NDIS process, as intended
- have varied levels of knowledge and skill in dealing with bureaucracy, so there will be inconsistency in pre-planning (and therefore plans)

Also, the person with PWS may have lost touch with their family/informal supports, leaving only paid carers. These PWS people will find it very difficult to get appropriate pre-planning support. Those without family support should be no worse off, under the NDIS. However, the PWS participant may need *more* supports, to realise greater independence and more community involvement.

The PWSA is concerned that during transition, not all NDIA Planners and Support Coordinators will be properly equipped to assess the needs of people with PWS consistently. This can lead to inconsistent plans and service delivery, even where participants have a very similar phenotype and baseline level of support need.

PWSA recommends that:

- The NDIA write to all people with PWS, or their nominee, to alert them to the NDIS.
- The mailing list should be drawn from the DSS/Centrelink records. Most people with PWS, or their family are in receipt of a disability related payment, so this should be the most reliable source of identification.
- The messages to the addressee should include advice about:
    - The NDIS itself and how to apply
    - Who to contact for pre-planning support and advocacy

  - A specialist support group specifically for people with PWS and their supporters. Social activities, news, and self-help resources can be found on www.pws.org.au
- To ensure consistent plans and implementation, Planners, the NDIA Technical Advisory Team and Support Coordinators across Australia need training about Prader-Willi Syndrome
- The NDIA Planner should be able to receive and review documentary evidence from parents in advance of the Planning meeting. If that is not feasible, then the Planner should not write the plan until they have read the support materials from the parent, just after the meeting.

C. Rollout of the Information, Linkages and Capacity Building (ILC) Program

Some parents of people with PWS have attended NDIS training to build their capacity. This took 15 hours and was very well received. It was deemed essential by those who attended, in order to build their confidence in navigating the NDIS with their loved one. The training also highlighted, 'what it takes to get NDIS ready'. It seems likely that a parent or informal support could do better planning and plan implementation, with similar training.

The PWSA is concerned that:

- Capacity building opportunities for navigating the NDIS may not be reaching all those impacted by PWS, throughout Australia
- People with PWS can have challenging behaviours, at home and in public. It is important that schools, kindergartens, child care centres, health services, community organisations, employers and the public know more about PWS, and how to respond
- Community members don't know about the different communication style needed for those with intellectual or cognitive impairments.
- The ILC program may not be effective enough in delivering its aims due to constrained implementation, and low uptake

PWSA recommends that:

- Adequate funding is provided for the ILC program, especially during the transition, to inform and educate various sectors of the community about disabled people with challenging behaviours
- The pace of the delivery of the ILC program be increased, so that the community is better informed; This should mean that, as people with PWS get their Plans approved and move around in the community more, there will be better acceptance, and they can have new community involvements, and a more ordinary life
- The ILC program should put emphasis on providing and promoting NDIS pre-planning skills
- The ILC program should include themes that distinguish between the needs of people with (i) physical or sensory impairments, and (ii) those with intellectual or cognitive impairments. There are some significant differences in communication styles and capabilities of these two broad groups, that community members need to be educated about.

D. Any other related matters

Added stress in families

The PWSA is concerned that informal supports (mainly family) of the person with PWS are not being adequately sustained. This is particularly important with PWS, because it requires a lot of behavioural management. If families are to be encouraged to self-manage their loved one's plan, then they need time to do it, without interruption from the disabled person. This time is in addition to what the parents need for spending quality time with other family members and looking after themselves.

Commentary in the community is that some people are not getting services like they had before, even though the NDIA's policy is that "no one will be worse off" under the NDIS[6]. An example is family carer respite. It is acknowledged that the NDIA guidelines allow for 'respite-like' supports. However, it seems this is not made clear to families during planning; It then gets overlooked in the Plan.

Planning process improvement opportunity

The PWSA is concerned that the main supporter/carer does not have access to a *draft* Plan, before it is finalized. The only recourse for a deficient Plan is the review process, which is reported to be slow, cumbersome and stressful. During the transition to the NDIS, it is important to the PWSA that the main supporter/nominee gets to review the draft of the Plan. Because PWS is so complex, and the planning process so new and lengthy, it is easy to forget to relay some needs. Being able to see a draft Plan, and discuss any edits before finalization would surely be more efficient, and certainly give participants more confidence in the NDIS.

Specialist 'respite' accommodation for PWS

There is a shortage of Specialist Disability Accommodation (SDA) and this is likely to continue for the foreseeable future. During the transition period, and until options become available, some funding should be established in the SDA program to facilitate purpose built 'respite' accommodation for complex participants. For example, the provider of an approved SDA for with permanent residents, could aim to utilise the 5th bedroom for short-term stays. Individuals that may access that facility should have overnight funding attached to their Plan, for short term stays in an appropriate SDA service. This is particularly relevant to syndromes such as PWS where individuals require access to a particular SDA building type and very specialised supports.

Past experience of the PWSA has been that individuals with PWS have been refused access to many independence-building opportunities. The reason given was that most facilities do not offer the additional support requirements and/or necessary restrictive practices specific to the needs of someone with PWS (eg complex behavioural supports and locked kitchen). The alternative of supplying overnight services in the participant's family home is likely to be substantially more expensive than providing SDA funding for an occasional short-stay room in an established SDA with multiple residents. A short stay in a PWS-specific SDA would also be more sustaining for families.

4) Conclusion

The PWSA commends the efforts of the Committee in investigating whether the transition to the NDIS is working satisfactorily. The PWSA has identified some concerns, particularly around:

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[6] https://www.ndis.gov.au/html/sites/default/files/documents/factsheet_no_disadvantage_and_the_NDIS_easy_english_text_only.pdf

- the lack of pre-planning capability for PWS supporters
- the multi-system nature of PWS and the strong interplay between mainstream treatment and disability support decisions, where mainstream services lack an adequate response
- potential adverse impacts of fragmented service delivery if there is no Key Worker in SDA to coordinate the extra administrative tasks needed with PWS
- potential gaps in support within education settings
- the unpredictable, and day to day variability in the presentation of a PWS individual makes it hard for untrained planners and other supports to deliver good service
- draft plans not being available
- some public transport capability must not preclude people with PWS from receiving NDIS transport assistance to realise their goals for an ordinary life
- the availability of respite-like services not being explained to parents who would be sustained by those
- enough short-term, PWS-friendly, overnight accommodation and service is not available
- the ILC program may not deliver benefits to people with PWS unless it is promulgated more widely and vigorously

The PWSA has made some recommendations accordingly.

The PWSA is very committed to supporting people with PWS. To this end, it is keen to contribute to the design of the NDIS. The PWSA is very willing to join in further consultations and meetings, to help the NDIA to become better informed about the unique nature of Prader-Willi Syndrome, and the consequences for NDIS Plans and service provision.