prader-willi syndrome australia

Submission to the Australian Government Joint Standing Committee on the National Disability Insurance Scheme (Parliament House Canberra ACT 2600):

Market Readiness for the National Disability Insurance Scheme

22 February 2018

1) Introduction

I represent people who have Prader-Willi Syndrome (PWS), their parents and supporters from across Australia. Prader-Willi Syndrome Australia (PWSA) is made up of an amalgamation of State Associations, to become the most expert and representative voice for NDIS participants with PWS.

Many people with PWS have complex needs. They will be heavy and lifelong users of the NDIS. We welcome the opportunity to contribute to this very important consultation[1] at the invitation of Joint Standing Committee on the National Disability Insurance Scheme.

I will provide a general explanation about PWS to improve your understanding. I will then respond to the specific aspects of market readiness identified the scope for the Committee, from the PWS perspective.

PWS is a rare, 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. Adults 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.

> *'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 feedback provided in this submission refers to whether there are enough appropriately trained service providers and appropriate Specialist Disability Accommodation (SDA) housing and short term accommodation options for people with PWS. The feedback also refers to the emerging marketplace and consequences for people with PWS. Additionally, it addresses how participants with PWS are going to be impacted by the market arrangements.

3) Response

a. *The transition to a market based system for service providers*

PWS is a very uncommon condition. It is also a complex, lifelong condition. There are physical needs, which have a degree of predictability. But there are also behavioural needs, which are changeable and volatile. The challenging behaviours require skillful staff who can plan to avoid trigger events and manage behaviours in an agile manner, before they escalate. That is, providers need to have the skills to respond to unanticipated and sudden changes in the level of support required and to deal with what are often volatile and violent situations.

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[1] The Consultation invitation was available from the web page https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MarketReadiness

International Standards of Care & Best Practice Guidelines[2] for PWS exist. However, service providers have rarely heard of PWS. Even those who have, rarely equip their staff to deal with the complexities. PWS is not like other intellectual disabilities[3].
Given that PWS is rare, service providers will find it hard to justify giving extra training to their staff so that they can offer intensive service delivery and appropriate support for participants with PWS.

PWS Australia is concerned that PWS participants will be disadvantaged in the marketplace because providers will:

- be concerned that the participant's funding does not cover the actual cost of the intensive support required to ensure the health and wellbeing of the participant and refuse to offer a service
- be reluctant to house a person with PWS because of the requirement to implement restrictive practices
- be resistant to providing services to such complex participants because of the amount of coordination required amongst all the service providers who address the multiple facets of this disability
- not want to fund the training of primary and back up staff, to the level required for effective PWS support
- find it hard to apply the Best Practice Guidelines and Standards unique to this syndrome
- not offer PWS-appropriate services in 'thin' markets, like the country, resulting in PWS participants having to purchase sub-standard services or suffer with none at all

In addition, the NDIS itself is complex. Providers, especially smaller providers are reported to be experiencing business stress. PWSA is concerned that the complexity and confusion for providers will drive some skilled disability support practitioners out of the marketplace.

PWSA recommends that the NDIA ensures that niche providers are not forced out of the marketplace. Niche providers may be best to support people with behaviours of concern, including PWS. There is a risk that the funding model will disadvantage smaller providers and favour the larger, who only offer generic services to the least complex participants. The NDIA must manage the marketplace so that it is not biased towards large and commercial organisations.

PWSA recommends that block funding be available to enable investment in capacity and innovative approaches, for example in day service skill building options. This is because some participants prefer to attend a familiar location, with their peer friendship group, which also offers social opportunities.

b. Participant readiness to navigate new markets;

People with PWS have very limited ability to be active and effective in their own interests, in the marketplace. Adults with PWS struggle to navigate bureaucracy and are therefore most at risk of experiencing poor outcomes from the NDIS. Parents of offspring with PWS must become very knowledgeable about the NDIS, if they are to successfully advocate for their loved one. Building adequate knowledge is hard for educated people, not to mention those with English as a second language or low education. People with PWS depend 100% on supports to help them participate in the marketplace for NDIS, or any service, and to ensure they are not taken advantage of.

Even though some people with PWS can read, and speak quite well, their cognitive limitations mean they cannot take up the level of choice and control envisaged by the NDIA. People with PWS struggle with abstract concepts like a service level agreement, and cannot plan for, monitor, or comprehend under-performance by providers, never mind hold them accountable or dismiss them. They cannot understand invoicing or budgeting on an NDIS scale, nor the criticality of completing multiple layers of administration to ensure holistic service delivery. People with PWS suffer from high anxiety and being confronted by confusing and relentless administration and assessments exacerbates their anxiety and reduces the likelihood of their goals being

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[2] https://www.ipwso.org/best-practice-guidelines-for-pws-care
[3] http://www.pws.org.au/guide-ndia-technical-advisory-team/

reached. Even the standard letters issued by the NDIA in 2017 were found to be incomprehensible by people with PWS and caused them stress.

Market forces alone cannot work for people with cognitive impairments because they do not have the capacity to make competitive judgements. They cannot adequately understand (e.g. contractual obligations), appreciate (whether or not the promised services have been delivered), choose and reason (by comparing the performance of different providers) about the legitimate performance of support workers. Therefore, 'The System' needs to take on the role of navigating the NDIS for participants with PWS. This means by educating advocates and funding monitoring. Quality assurance activities are essential for such vulnerable people.

c. The development of the disability workforce to support the emerging market;

As mentioned above, the workforce needed to support people with PWS must be sophisticated:

- well trained and specialist trained with skills and knowledge specific to PWS; individuals with PWS are unable to accurately monitor their own complex health and well being
- skilled, active listeners alert to any trigger events that may cause behaviours in the participant
- highly motivated to deliver Active Support; by keeping the person with PWS busy, there are less likely to be challenging behaviours
- prepared to collaborate with a multitude of other support workers that help with each facet of this disability, to enable holistic service delivery
- available to support all core and capacity building activities; people with PWS typically like to go out and about often, with support
- able to navigate to the truth, in the face of plausible confabulations from the participant
- well organized, so that the service delivery is consistent with that delivered by the other supports
- aptitude for dealing with anxious participants, and using their nous to allay participants' anxiety in any given situation, to minimize the likelihood of behaviour escalation, and
- engage in the extra administrative tasks needed to support a person with PWS and their multi-faceted condition.

The NDIA funding model must recognise the unique arrangements needed to support a person with PWS. If pricing is not sophisticated enough, there will be no incentive for the market to build a service offering that will be able to support people with PWS. A failure in supports to people with PWS will be a failing of the NDIS principals, and bring an added burden to the public purse when the person with PWS needlessly calls on other service systems such as health, mental health and justice.

It is recommended that the NDIA (a) ensures that it has some technical specialists in its own organisation that can build specialist knowledge about PWS which can then contribute to build market suitability, and (b) ensures adequate funding is available to organisations to provide specialist PWS training to their staff, in advance of that organisation selling services to PWS participants. Otherwise, people with PWS are at high risk of not being able to source appropriate services in a timely manner.

In addition, PWSA recommends that providers working with participants with behaviours of concern can consider the option of salaried, tertiary degree qualified support workers to provide higher quality, and continuity of support.

d. The impact of pricing on the development of the market;

PWSA notes that there are five specialist SDA accommodation homes in Australia for PWS participants and that a sixth (in NSW) closed due to inadequate funding for this complex cohort. The NDIA must make sure that adequate funds are available to pay more skillful and experienced staff appropriately. The amount paid must be enough to offer support workers both a career progression opportunity and incentives for them to stay on looking after people with PWS, that is, service continuity. Overseas experience has shown that tertiary degree trained support staff, such as psychologists or teachers, are more likely to remain in support positions, supporting individuals with complex behaviours-of-concern. Once a staff member is trained as a PWS worker, it is important that they are not lost to the wider sector. As people with PWS find change hard to cope with, it is important that there is continuity of staff. To attract and keep these workers SIL providers are likely to need ‘above benchmark’ funding.

It is important to *PWS Australia* that there be a diversity of service providers in the marketplace. This includes a *choice* of providers with the expertise to support people with PWS. Funding must be adequate for organisations, especially not-for-profit providers who are without big cash reserves, to pay for business on-costs / administrative overheads, as well as staff training and professional development.

People with PWS often exhibit behaviours of concern. These can be managed and reduced with appropriate ongoing supports. However, it would be wrong to assume that once that ‘scaffolding‘ of support is removed that the volatility of a person with PWS will remain low. Nor can it be assumed that a skill learnt in one setting will necessarily be transferred to another setting. The behaviours of concern have a genetic foundation, and the scaffolding of support always needs to be in place. Service providers need to have confidence that once they have invested in providing specialist, intensive services to a person with PWS, that their client will not suddenly be unable to pay the rates because a new planner thinks that the person with PWS can now cope with less supports. There is a significant likelihood that the person with PWS will need intensive support for long periods to maintain an optimum level of functioning, and the subsequent ability to attain some goals.

Also, if pricing is too low, some providers may be tempted to engage in sharp practices. PWSA is already aware of providers taking participants on 1:1 outings, but actually putting two participants in the car once the participants are out of sight of their carers/house staff. The cognitively impaired participants are none the wiser; they can’t report on what has taken place, know what a service level agreement is, whether the service booking is intended as a 1:1, review the associated invoice, or assess whether the SLA has been breached.

It is also important to PWSA that ‘price gouging’ not be allowed to occur. That is, when family members or carers get desperate for service, and no provider will support the participant at the NDIS approved rate, the participant should not have to pay a higher amount for a less suitable, lower quality provider just because they have too few options. Providers must not be allowed to over-charge, and take advantage of service users just because the NDIA has not managed to deliver appropriate market options.

PWSA believes that NDIS pricing must keep up with inflation. This is only fair to service provider staff and will motivate them to stay in the sector. At the same time, it is essential that any CPI or skill based wage increases for providers is reflected in the plans of recipients. This means that plan funding must never lag provider charge increases. Otherwise participants will not get the hours of support they need to reach their goals.

e. The role of the NDIA as a market steward;

PWSA expects the NDIA to be *proactive* in its role as market steward. PWSA expects that the NDIA, as market steward, should continue beyond the transition period if there is evidence that the market is failing the disabled. Disabled people are already at great disadvantage, especially if they have a cognitive impairment like those with PWS.

PWSA expects the NDIA to provide monitoring, facilitating and commissioning stewardship. In addition, the PWSA expects the NDIA to ensure that COAG commitments are enacted. Also, if *service* gaps are found in the Scheme, or a lack of regulation leaves the disabled at risk, then the NDIA will fill that gap by becoming directly involved, and will provide additional, adequate resources to do so, in a timely manner.

Evidence in other sectors has shown that the privatisation of public services often has a negative impact on service users and tax payers, particularly where there is inadequate stewardship. Sharp operators enter the market to miss-appropriate tax payers’ money whether through over charging or underservicing (e.g. VET sector, electricity sector, retirement village sector). Therefore, the steward must act as a diligent regulator and enforcer, and jump quickly to make marketplace improvements and protect some of Australia’s most vulnerable citizens.

PWSA recommends that the market steward make sure that consumers have comprehensive information about service providers on which to assess and make choices. Without comparative information, consumers will find themselves at risk of choosing an unsuitable provider and market forces will not be brought to bear to drive out rogue providers. It is incumbent on the NDIA to provide fulsome information to the public in a timely fashion that is easily accessible and easily understood. The information must be comprehensive since the NDIS is new and consumers are not yet familiar with the different dimensions against which to compare service providers. The NDIA must be more proactive in ensuring that service catalogue, pricing *and* comparative *performance* related information is available about all providers.

f. Market intervention options to address thin markets, including in remote Indigenous communities;

The NDIA must recognise the need for a specialised workforce to support people with PWS anywhere in Australia. A specialised workforce means that the cost per hour to support a person with PWS will be more than average. The NDIA must fund this anywhere in Australia, with incentives. Otherwise the person with PWS will be exposed to unacceptable safety and welfare risks.

Families are not always the ideal support of an adult with PWS. Because of the challenging behaviour, which is often particularly directed at family members, the person with PWS does not want informal support or services from their family members. Therefore, external supports must be made available, in any location.

g. The provision of housing options for people with disability, with particular reference to the impact of Specialist Disability Accommodation (SDA) supports on the disability housing market;

The observation of the PWSA is that housing options are very inadequate. Not only are there a miniscule number of vacancies in general, there are even less that meet the needs of a person with PWS (e.g. a locked kitchen and a Robust design). The PWSA doubts that service providers will offer accommodation to suit people with PWS because it will not appeal to other disabled people, making it more difficult to fill vacancies.

PWSA recommends that, in order to increase market options for people with PWS, the NDIA offer financial incentives to the suppliers of SDA, to offer share houses or cluster units that are suitable for the needs of a person with PWS.

h. The impact of the Quality and Safeguarding Framework on the development of the market;

The PWSA supports rigorous, wide and deep quality and safeguarding arrangements. However, itis concerned that some providers may regard the adoption of comprehensive quality and safeguarding provisions as onerous. They may regard adhering to the Framework as an unacceptable administrative overhead, considering the current funding model. This may drive them out of the market or to resile from the proper application of the Framework. Either of these scenarios is unhelpful for the participant with PWS because they have both a cognitive impairment and challenging behaviours. Those together mean that people with PWS are more likely to need the protections of the Quality and Safeguarding Framework than the average participant.

PWSA recommends that the NDIA make more funding available to providers offering specialist PWS services, to ensure there is adequate market supply of support services. Research by Anglicare about the uncounted costs[4] of complex participants illustrates many examples of the extra overheads that may be incurred by providers in applying the Framework.

i. Provider of last resort arrangements, including for crisis accommodation;

It is *essential* that the NDIA determine and enforce the adequate supply of providers of last resort of permanent SDA, along with appropriate Supported Independent Living (SIL) staff. People with PWS are well known to have challenging behaviours due to their disability. There is evidence that they have been asked to leave some

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[4] https://www.anglicare-tas.org.au/sites/default/files/The%20uncounted%20costs%20-%20choice%20and%20control%20for%20people%20with%20behaviours%20of%20concern.pdf

service providers due to that behaviour and the dysfunctional urge to over eat. Therefore, the NDIA must make sure the market offers people with PWS at least one SDA option. It is preferable that this is a not-for-profit provider. State governments would be appropriate suppliers of a last resort service (SDA and SIL) due to their immediate relationship with COAG commitments and proven experience with complex clients.

Recent evidence in Victoria showed that a disabled young adult was left to languish in a justice remand centre because, despite having an NDIS package, no provider was willing to sell support services to that high-risk individual. People with PWS must not be allowed to become homeless, or reside in unsuitable accommodation that prevents them living an ordinary life and reaching their goals.

Crisis accommodation must also be available to people with PWS, and it must be of a nature that does not cause them health and safety risks. That is, the SDA crisis accommodation must apply the restrictive practices (locked kitchen) that are needed to properly support a person with PWS. In addition, highly skilled staff must be on duty, to deliver an intensive level of service to a person with PWS. They will be anxious about the changes to their familiar arrangements, and as a result can exhibit behaviours of concern.

PWSA recommends that providers have access to a contingency or ‘brokerage’ fund which can be used to contain crisis situations in the shorter term.

j. Any other related matters.

The PWSA is concerned about gaps emerging in proper service provision for people with cognitive disabilities. The market itself is not addressing these gaps, as providers are in a conflict of interest position and many expect the gap to be filled by ‘someone else’. Gaps include:

- for participants living in SDA, there is a lack of clarity about who is responsible for managing interactions (e.g. adjusting, cancelling, rebooking) with a third-party provider who works with the participant. That is, another provider (separate from the Daily Living provider) may take the participant on community access outings. If the participant is sick, someone must tell the third-party provider. And tell that provider *in a timely manner* so that the participant is not charged. There is evidence that the off-site parent has been asked to make the cancellation. But what if the resident does not have a loved one who can perform that function? In other words, house staff must know the cancellation policy in each SLA for their participant and tell the day service, or others, immediately there is a change to arrangements
- Monitoring performance against Service Level Agreements (SLA): The participant can’t do this so the most logical people in the marketplace to do this are SDA house staff. But there is a lack of clarity about funding for that responsibility. Staff should pay attention to what service the third-party provider is supposed to be delivering. Then they monitor performance against that SLA on behalf of their participant. Is the provider running late? Do they return too early? Is the participant dissatisfied? The house staff must then take action. The house staff must notify the third-party provider management (or Support Coordinator) about under-performance issues. Otherwise the participant, and the NDI Scheme may lose money, with unsuitable providers remaining in the market.
- People with PWS have a range of physical, social and emotional dysfunctions. They need a *holistic* approach to support delivery. It is unclear who has responsibility for holistic service coordination after the Support Coordinator funds run out. In any event, the Support Coordinator is not involved in the daily life of a participant where the holistic approach must be applied. PWSA recommends that care coordination should be provided by the primary support provider when supporting participants with behaviours of concern.

PWSA recommends that the NDIA immediately make it clear where the responsibility for proper SLA implementation lies. In logical and practical terms, it is the house staff (in loco parentis) who are in a position to observe and respond to SLA matters. The more third party providers the participant has, the more monitoring is needed. The NDIA must fund the relevant service provider for these administrative tasks accordingly.

4) Conclusion

The PWSA is very committed to supporting people with PWS. It has contact from its members across Australia, as well as from its professional networks. Reports from participants and their families about the NDIS have revealed some concerning trends about the NDIS market place:

- Service providers may be reluctant to offer the intensive service levels needed by people with PWS
- SDA providers have not delivered accommodation options suitable for people with PWS
- People with PWS need 100% support to monitor and manage the SLA's with their service providers. This includes those living in SDA, where it's unclear about the degree of responsibility for SLAs to be taken on by the house staff

PWSA has made a number of recommendations. It has identified how the NDIA can intervene to make sure the marketplace offers appropriate support options for people with Prader-Willi Syndrome.

Also, PWSA has created a variety of resources to educate the NDIA and service providers about the complexity of PWS and how to provide appropriate supports. These can be found on our website at http://www.pws.org.au.

Again, I thank you for this opportunity to provide feedback on the NDIS market place. I look forward to ongoing improvements to the NDIS. I am available to discuss any of the maters raised above, at your convenience.

James O'Brien
President
Prader-Willi Syndrome Australia