pwsa
prader-willi syndrome australia

National Disability Agreement Review – Issues Paper:

Submission to the Australian Government Productivity Commission

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1) Introduction

I represent people who have Prader-Willi Syndrome (PWS), their parents and supporters. Many people with PWS have a variety of complex disability and health needs. We welcome the opportunity to contribute to this very important consultation[1] at the invitation of the Australian Government Productivity Commission.

I will provide a general explanation about PWS to improve your understanding, and respond to the specific issues and questions raised in the Paper, from the PWS perspective.

Prader-Willi syndrome (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 of children and adults. People with PWS cannot successfully live independently without supports, and may occasionally engage in open employment, but only with considerable support.

People with PWS typically die young, due to complications associated with obesity. *However,* when PWS is managed properly, people with the condition can be expected to lead a more ordinary life and live longer.

> *'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.*

In order to manage the complexity of PWS, it is essential that all the service systems know their support role. It is essential that the mainstream and disability services deliver a cohesive and holistic framework of support where there are no gaps for the disabled person to stumble or fall. Already we are seeing one service system trying to pass off responsibility to another. And whilst the services argue backwards and forwards, the person with PWS gets poor service and lives with added risk. In the case of PWS, a failure in one support service will inevitably exacerbate PWS problems, and the sufferer will begin to make demands on another service (e.g. from hospital to police, or from a Commonwealth service to a State one). So, whilst one sector may think it is efficient and saving money by pushing a PWS client away, they are only escalating the problem and putting a greater drain on the public purse through unnecessary use of another sector.

In short, the changes to the National Disability Agreement (NDA) should recognise that PWS is not like other disabilities. Funding and support models that are regarded as adequate for other types of intellectual disabilities will not be sophisticated enough for supporting people with PWS. Therefore, a contemporary and enduring ND Agreement should contain elements that close gaps in service responsibilities to those with PWS. A new NDA must ensure that there is a clear and speedy resolution pathway for people with complex disabilities who do not have the cognitive

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[1] The Issues Paper was available from the web page http://www.pc.gov.au/inquiries/current/disability-agreement/issues

capacity to negotiate the support system. People with PWS are further disadvantaged when there are unmanaged gaps in holistic service provision.

The heart of this study is the aim to promote the wellbeing of people with disability. Therefore, an improved NDA needs to address any lack of willingness by authorities to work in a collaborative manner devoid of demarcation disputes, and without burdening the disabled person, their families and carers.

2) Purpose

The feedback provided in this submission refers to the review being undertaken of the National Disability Agreement (NDA), and in particular whether any changes are needed to the NDA in the context of contemporary policy settings.

3) Response

What framework and assessment criteria should be used to review the NDA?

> The outcomes and outputs of the NDA are still valid. These should guide the scope of assessment criteria. Members of the PWSA have experienced adverse consequences of the many gaps that exist between the NDIS model and reality. For example, mental health service refusing to admit a participant, deeming the psychotic behaviour to be due to an intellectual disability rather than the mental illness which was subsequently diagnosed a few days later. Or, home modifications not being made for a participant whilst NDIS argues landlord's responsibility (ie public housing) but the state government says it's an NDIS cost.
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> The concept of respite for carers has been left out of the NDIS. Within the disability context, respite is highly valued, as evidenced by its inclusion in the NDA in the first place. PWS is a very complex condition, with many behavioral challenges. As such, families need to be able to access respite services.
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> In short, State governments have stepped back too quickly from disability assistance, leaving vulnerable citizens and families in difficult and risky situations.
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> Any new framework must be able to identify shortfalls. It must make State governments and territories accountable for covering shortfalls, until the NDIS proves itself as a scheme that can take a holistic approach to support and care of disabled citizens.

Considering developments in the disability policy landscape and intergovernmental funding arrangements, is an NDA still required?

> Yes, an NDA is still required. Over and above service delivery, there are commitments in the NDA that need to remain in place to ensure disabled people get the support they need. For example, a gap identified by PWSA is that there is no accommodation provider of last resort. This service is critical to ensure disabled people with challenging behaviours do not end up in the justice system. Also, the Productivity Commission identified gaps in roles and responsibilities for improving the interface between NDIS and mainstream services. As such, all governments must continue working together to ensure relevant services are in place. The NDIS cannot do it alone. Therefore, it is important that:
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> - parties work co-operatively together

- parties be accountable to the community for maximising the contribution from their areas of responsibility
- public leadership actively promotes the rights of individuals with disability
- all governments recognise that achieving improved outcomes for people with disability, their families and their carers, is contingent upon the effective coordination of efforts across government services
- there is provision of disability workforce and sector development relevant to the local context
- there is local investment in initiatives to support nationally agreed policy priorities

Another looming risk is that the NDIS has not adequately recognised that some participants need minimum ‘maintenance’ funding. That is their complex disability is not going to go away. Their capability may increase somewhat, but not enough to change the required maintenance funding.

The States and Territories should therefore be advocating for their citizens to make sure that the NDIS does not cut plan funding based on assumptions that stability of complex behaviours is a newly acquired capability. When stability is achieved, it is because of the scaffolding of supports. The scaffold should not be dismantled and put the participant at risk.

If so, how can the NDA remain policy relevant in an evolving policy environment?
The NDA must cover those aspects of disability support that the NDIS is not, whether through design or incompetence. The NDA can be subject to review more frequently, say every two years and adapt to the changing disability landscape.

What should be the purpose of the NDA?
The NDA should be an accountability mechanism (but not the only one), so that State and Territory governments remain focused on getting an effective, holistic support system in place for the disabled. State governments should be delivering on improving mainstream service acceptance of disabled people. For example, the NDA should provide a foundation for ensuring that States and Territories respond to resourcing needs for ILC activities.

Is it an effective accountability mechanism for government actions relating to disability?
Apparently not. Despite the NDA being in place, there are gaps in the NDIS, for which the States seem not to be proactively seeking solutions. An example is adequate funding for complex participants with cognitive impairments. Such participants need case workers for when a crisis arises. Support co-ordination is not adequate. Complex participants need closer involvement of a consistent worker.

There is a widely held perception across the sector that the NDIS has not adequately allowed for complex participants who require a lot of administrative support, over and above face-to-face support. This view is held by providers and participant’s families alike. Participants with PWS can barely understand or evaluate what appropriate support services are, and cannot exercise enough choice and control over significant expenditures in their life. Therefore, someone else must be paid to hold a duty-of-care role, and exercise judgement in the best interests of that participant. In addition, complex clients often need more skillful staff to assist them with their activities of daily life and community access activities. Furthermore, overseas experience has demonstrated that individuals with complex needs invariably require more highly qualified support staff. And yet the current funding model constrains paying higher wages for higher quality staff, as it would reduce hours of service overall.

What should be the scope of the NDA? Should it continue to cover all people with disability?

Yes. If an NDA is not in place, people with disabilities who are not eligible for the NDIS will be left without any support.

What services should it cover (such as specialist disability services and/or mainstream services, including mental health, healthcare, aged care, education, transport, housing and justice)?

Yes, the NDA should cover all the above services. For aged care, it only needs to cover the transition of disabled people who have not been accepted into the NDIS prior to 65 years old into an appropriate support arrangement.

Are the objectives, outcomes and outputs of the NDA relevant in the context of contemporary policy settings? Are they clear and consistent?

As above.

To what extent should the outcomes be aspirational (worked towards but not necessarily achieved within a specified time period), versus achievable within a defined period?

There should be interim, achievable and measureable outcomes. Otherwise the outcomes are just motherhood statements, for which there is little tangible evidence of any change in practice.

Should there be specific performance measures linked to the outputs and if so, what should they be?

The existing performance measures should continue. But there are some glaring omissions that need to be added. Key subgroup data for the existing measures needs to be collected, and progress reported against:

- People whose disability is primarily a cognitive impairment (in contrast to those who have only a physical or sensory impairment), and
- Each measure for carers needs to *distinguish between* paid and unpaid carers. Their views are likely to be quite different and need to be recognised, and identify any actions arising.

New performance measures need to be:

- proportion of parents/guardians/supportive attorneys/alternative decision makers for people with disability who are satisfied with the range of services available, and with the adequacy and quality of services provided, to the person with disability and to the carer (whether paid or not), and
- proportion of disabled adults living as independently as possible, (key sub group data for those with cognitive impairments) in suitable supported living arrangements outside the parental home

In light of the changing policy landscape (particularly with respect to the NDIS), do the roles and responsibilities of Governments in the NDA need to change?

It seems that the main changes would be a matter of emphasis. That is, State and Territory governments should still be holding the same responsibilities, but the focus would be on mainstream services, NDIS gaps and disabled people who are not eligible for the NDIS (rather than direct disability services to the NDIS funded cohort).

What role should the NDA play in assigning responsibilities for all disability services between governments?

As above.

Should the roles and responsibilities of mainstream services to people with a disability be more clearly outlined in a national agreement?

Yes.

Where are the main gaps in services outside the NDIS? What are the problem areas?

PWSA is not familiar with that situation since the severity of PWS means that in all probability, all sufferers will have a funded NDIS experience.

To what extent does the NDIS (for example, through the provision of ILC activities and Local Area Coordinators) cater to people outside the NDIS?

Disappointingly, PWSA has seen little evidence of ILC activity, or beneficial outcomes in mainstream services that increase the inclusion of people with PWS.

What role could the NDA play in assigning responsibilities for addressing service gaps identified in the current arrangements?

The NDA could play a very significant role in encouraging State and Territory governments to continue to advocate for a more effective NDIS, to fill gaps in NDIS service provision and foster better support in mainstream services for those with cognitive impairments, mental illness and other disabilities.

Should the agreement have regard to the way States and Territories are delivering services to people with a disability outside the NDIS (for example, through mainstream services or through specialist disability services)? If so, why?

Yes. To date PWSA has seen examples of where mainstream services have not changed their attitudes or practices towards disabled people, leaving them at a disadvantage. There has not been enough commitment by funders of mainstream services to make changes.

Does public reporting against the indicators serve to ensure that governments are held accountable for their policies and actions relating to disability? If not, why not, and how could this be improved?

No, public reporting is an inadequate means of holding governments accountable. People with disabilities and their supporters are seen as low risk, in terms of any consequences from an adverse report. There needs to be greater consequences than just a ‘ballot box’ risk.

Are the criteria for good performance indicators listed in box 2 suitable?

Yes.

How should the significance of changes in indicators be judged? For example, what magnitude of change in the indicators should be targeted?

There should be continuous improvement.

What level of disaggregation should the indicators provide?

They should be articulated at the national or jurisdictional level. They should be disaggregated by the nature of the disability, ie cognitive impairment or not, and others as described above.

How relevant is the current performance reporting framework of the NDA in light of the implementation of the NDIS?

The NDIS will have its own reasons for reporting and may not provide enough key sub-group data, as mentioned above. States need additional data to be able to identify where their citizens need additional support, and to identify where they are having success in local initiatives (e.g. ensuring an accommodation provider of last resort is in place).

4) Conclusion

The PWSA is very committed to supporting people with PWS. Their disability is complex. They will need disability, education, health, mental health, accommodation and social supports throughout their lives. This means a lot of service interfaces and provider education. The supports that people with PWS need are scattered across many sectors and facets of their life. The NDIS alone cannot deliver a holistic support model. Therefore, there needs to be a formal commitment by State and Territory governments to continue to contribute to the support of its disabled citizens in ways that the NDIS will not. A National Disability Agreement is one instrument to ensure that this happens.

I am happy to discuss these issues with you in more detail if that would be of assistance.

James O'Brien
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