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prader-willi syndrome **australia**

**National Disability Insurance Scheme
Code of Conduct Discussion Paper:
Submission to the Australian Government Department of Social
Services**

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1. Introduction

I represent people in Australia who have Prader-Willi Syndrome (PWS), their parents and supporters. We welcome the opportunity to contribute to this very important consultation¹ about how to protect NDIS participants from abuse, violence, neglect and exploitation.

I will provide a general explanation about PWS to improve your understanding, and respond to each section of the proposed Code, 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. 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 intellectual disability, they all have significant cognitive impairment, and can be quite gullible. Some defining features of PWS are a lack of insight, confabulation and compulsive over-eating.

Because of its complexity and the need for a multidisciplinary support team, there is an International Standard for the Management of Prader-Willi Syndrome. In Australia, there are only a few service providers that offer a specialized group home environment for adults with PWS (Eg DHHS, Victoria²). The specialized service model has delivered very successful outcomes.

An NDIS Code of Conduct should enhance not hinder the proven PWS management model.

It cannot be presumed that people with PWS have adequate personal capability to safeguard themselves or select quality services, no matter how much information they are given. People with PWS often have good verbal skills, although this is not matched by comprehension. Therefore, they may be able to read, but not understand abstract concepts such as 'monitoring' or 'competition'. Due to limitations in executive brain functioning, they are not good at planning, organizing, following processes or understanding consequences. They are definitely at risk of not being able to recognise and report on poor quality service, or matters of abuse or behaviour which harms them. Additionally, people with PWS may at times require an intimate level of personal contact, such as with showering, to complete the task and ensure their wellbeing.

Therefore, a Code of Conduct is a good foundation for helping to protect vulnerable people with PWS. However, ensuring that the Code is adhered to is highly dependent on the NDIS providing independent supports for the person with PWS. The supports, on their behalf, then have responsibility to assist with monitoring, assessing, reporting and complaining, if and when the Code seems to be breached.

2. Purpose

¹ The Consultation Paper was available on the Internet until 21/6/2017: <https://engage.dss.gov.au/ndis-code-of-conduct-consultation/ndis-code-of-conduct-consultation-discussion-paper/>

² Department of Health and Human Services, Eastern Region
http://www.dhs.vic.gov.au/data/assets/word_doc/0004/729760/RSPM3rdED_Part-5_Feb2014.docx.

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The feedback provided in this submission refers to the needs of NDIS participants , with particular reference to the experiences of Australians who have PWS. The feedback is intended to highlight where the Code of Conduct could be refined or where there are consequences for operationalization, as perceived by the Prader-Willi Syndrome Association members.

The feedback will refer to various sections of the Discussion Paper (DP), by section number as it appears in that Paper.

3. Concerns, and feedback about perceived consequences

3.1. *Compliance and under-performance by providers and workers must be visible to participants, so they can exercise informed choice*

DP 1.3.1 "A compulsory orientation module..."

Will the NDIA be a) keeping a list of all providers and their workers that need to complete the compulsory module and b) auditing, to establish whether those that must complete the module have actually done so?

How will participants know whether their particular support worker has completed the module? The participant should be able to look up their support worker's name on a list The list should be visible to all participants (say in the portal), and show all providers and workers that have successfully passed the screening process and completed the module.

DP 2.3 – Worker qualifications: The screening process could view and record the worker's qualifications for participants to view.

DP 1.4 "...provider facing civil penalties, enforceable undertakings, revocation of registration or ban orders..." A list of providers subject to the above 'breach' action(s) must be available to participants. The list should include the names of providers referred to the police or being investigated for fraud, even prior to conviction. The list should also show any conditions that have been placed on the providers registration, like occurs for the medical profession.³ Otherwise there is a great risk that the provider will persist with representing itself as safe, ethical and honest NDIS provider. The NDIA must provide this level of transparency to enable market forces to play a role in motivating providers to deliver services in accordance with the full intent of the NDIS. The public must be able to make informed decisions about where to spend their money. There have been problems in some sectors because the providers have been able to hide their poor performance from potential customers (eg Finance and further education). We do not want to see such problems confronting the NDIS and our most vulnerable citizens.

3.2. *Any provider receiving NDIS money should have access to consistent NDIS resources*

DP 1.3.2 "A compulsory orientation module..." Unregistered providers should have access to consistent NDIS training materials too. They should be able to access the same orientation module as registered providers (even if it's not mandatory or recoded), so the participant can be more confident about the provider's baseline level of NDIS knowledge.

3.3. *The regulatory function has not been fully tested. Gaps may emerge. The NDIA must be*

³ <http://www.ahpra.gov.au/Registration/Registers-of-Practitioners.aspx>

prepared to adapt, to protect participant

DP 1.4 "...complaints outside of the scope of the Code of Conduct and Commission will be referred to the relevant agency...". This is a new scheme. The NDIA must acknowledge that matters may arise that 'fall through the cracks' in terms of identifying an agency that will resolve the matter. As such, the NDIA must be prepared to review and amend its Quality and Safeguarding Framework, along with the Code of Conduct and scope of the Commission's responsibilities to ensure no NDIS participant is left without an ultimate avenue of redress.

3.4. Workers must balance a request from a participant against risk, not just "accommodate any request..."

DP 2.1 states "...accommodate any requests relating to individual differences as far as possible..." There are some scenarios where the worker must refuse the participant's request, to ensure the participant's welfare is protected. For example:

- the worker's engagement includes helping to deliver beneficial restrictive practices. A participant may have their financial and legal affairs under formal Administration. The worker is expected to uphold those arrangements, even in the face of requests from the participant to breach the Administrative arrangements
- in the case of PWS, sufferers are often articulate, but also impulsive, have poor judgement and grandiose expectations. These lead to requests that risk the welfare of the person with PWS. A typical request would be "I want to buy more food with this money I have". But the participant has to be prevented from putting on weight, which is part of their disability. It is therefore the duty of the support worker not to accommodate such a request, even when it is possible to do so, because to deliver the request will harm the participant

3.5. Under-staffing has been a cause of problems in the past. Service providers must act fast to facilitate an NDIS Plan review, where more staff hours are needed for the participant's safety.

In the old model of disability group homes, violence, exploitation, neglect and abuse were partly caused by inadequately trained staff, and / or not enough staff on duty at the times needed (as illustrated in the DP scenario 2.2.1). A provider organisation will not be able to sustain an appropriate 'daily life' staffing levels, if the participants in the SDA household do not have enough funds to cover better and more trained staff. The NDIA has to ensure scheme planners are very responsive when a scenario of under-staffing is putting the participants at risk. A similar risk could occur when the person with PWS is out participating in the community. Support workers must be available to ensure the safety of the participant and others.

3.6. The NDIA must get proactive in preventing incidents. The NDIA must play a bigger role in monitoring and oversight to identify risk.

The NDIS should gather 'big data' centrally, and analyse it to gain insights to inform preventative actions. All incidents, major and minor events⁴ should be recorded electronically and submitted

⁴ Category 3 incidents defined by DHHS Victoria "These are events where the normal work and routine is interrupted, but the significance of the incident does not extend beyond the workplace or facility. Category three incidents include those which can be dealt with adequately by the facility or work unit and which have no further

to a central NDIA body, the Commission, for attention. Therefore, providers and workers must participate in collecting consistent data to contribute to risk assessments.

By only paying attention to significant incidents of pre-defined violence, exploitation, abuse and neglect, risks will go undetected. This is clearly too late once a participant has been harmed. Centralized data will be most effective in pointing to trends. Providers and workers who are 'outliers', featuring too often. It is the small, disturbing events that, when taken together, point to a trend. Even though the response procedures for minor incidents are different, that is more localised, all providers should still submit those incidents to the NDIA. Only then will patterns of dubious workers moving between employers, or a provider across geographic regions having small but persistent issues come to light. Then the NDIA can hold them accountable, when they thought they would not be noticed within a fragmented system that also has inconsistent data collections.

The Victorian Royal Commission into Family Violence made findings that could equally apply to disabled people, especially who become victims in group homes. It found "...the safety of victims is undermined by inadequate methods for sharing information between agencies about perpetrator risk. This is exacerbated by outdated information technology systems."⁵ That Commission also noted, "While we have tended to focus on how best to respond to family violence once it occurs, prevention deserves an equal degree of attention." The Commission noted that there was a need for "...information technology to underpin and enable the collection of data that can be used to assess and improve risk management and system performance." This type of systemic support from the NDIA would engender more confidence amongst participants and the reputable, honest providers.

3.7. The concept of worker 'duty of care' needs to be explicit in the Code of Conduct.

DP 2.4 "Provide supports in a manner..." Every support worker has a duty of care to their customer (participant), especially the intellectually disabled. As such, it is the responsibility of the support worker to gain some understanding about the disability so that appropriate care can be taken. Then, the rights of the participants can be better balanced with actions by the worker, in the best interest of the participant.

- the participant has suffered mental illness in the past; the support worker needs to be alert to, and report on any warning signs in the participant that may indicate another mental health decline, even though the participant may not prefer this
- the participant's Nominee or Guardian may have agreed a course of action with the participant, based on their deep knowledge of, and enduring relationship with the participant; It is expected that the worker would take those arrangements into account when helping the participant.

The duty of care is even greater towards adults who have moved out of the parental home into Specialist Disability Accommodation, because of the level of risk associated with the type of support provided. It is important for the Code to reference this 'duty of care', because some

implications for the community, region or the department."

http://www.dhs.vic.gov.au/__data/assets/word_doc/0006/984471/Information-sheet-NDIS-psychosocial-support-providers-March2017.docx

⁵ <http://www.rcfv.com.au/MediaLibraries/RCFamilyViolence/Reports/Final/RCFV-Summary.pdf>

www.pwsa.org.au

support workers may not be employed by an organisation, or be registered with the NDIS.

3.8. The concept of a holistic approach to service provision needs to be in the Code.

Fragmented service delivery reduces the likelihood of better outcomes; Care includes providing support that complements other supports used by the participant

A participant with PWS has multiple and complex needs. The Code must be explicit about service providers delivering their services within the context of **holistic** care of the participant. This will reduce the likelihood that quality and safety become matters for concern (DP 2.5). Holistic service might mean a provider needs to attend group case meetings, answer phone calls from another provider, seek advice from a co-provider about service so there is no duplication or counter-productive intervention. Providers may need to participate in consultation, cooperation and collaboration, to deliver the best service to the person with PWS. Where a person exhibits challenging behaviours, multidisciplinary positive behaviour supports have to be in place; a holistic approach is expected of providers and workers.

In its paper 'The Case for Change' (2012), the Victorian department of Human Services noted that "By aligning and integrating the human services system [of which disability is part], we can reduce duplication and focus on shared outcomes for our clients."⁶ This recommendation applies where services delivered, in the silo of a particular support, fail to look ahead and flexibly offer a suite of collaborative supports to deliver a better overall outcome for the participant.

In PWS, there needs to be conscious oversight of the wellbeing of whole person. This is usually a parent, where the person lives at home, or another person responsible for daily care, like a Key Worker; all other providers then contribute to holistic support. All service providers need to be giving the person with PWS consistent messages so the participant does not get confused, anxious and disappointed by missing out on things that cannot be achieved. The Support Coordinator is another pivotal role in facilitation of information sharing. For example, the school or workplace support needs to liaise with the dietitian support and the household meal preparer. This coordination ensures that food access in the school or workplace is managed effectively for the person with PWS and balances the diet carefully with calorie intake at home.

3.9. The NDIS is new. Regulation, collecting information and investigating in these early stages should be energetic, to help better understand and improve the scheme.

DP 2.3 "...Providers and workers must not ask for, accept or provide any inducement, gift or hospitality..." The Code needs to provide guidance to workers and providers about their obligations if they observe any of the incentives mentioned above. They must know how to report instances to the NDIA Commissioner/Registrar, so that big data can be collected and culprits identified and actioned.

The NDIA/Commissioner/Registrar should regularly publish the conclusions from the reporting, to give participants and honest workers and providers confidence that their voices are being heard and there is an outcome. Everyone in the NDIS can learn from those results and they can act as a deterrent to other inappropriate conduct.

⁶ Stored by http://www.thelookout.org.au/sites/default/files/1_iwas_human_services_case_for_change_0412.pdf
www.pws.org.au

3.10. *In addition to Privacy, the Code should be explicit about the circumstance of sharing participant information, if it would deliver better quality and safer supports, with improved outcomes*

Sometimes a participant's outcomes and wellbeing are better when information is shared between *specific support workers*, rather than being kept totally private. However it is important that *only relevant* information is shared. Shared information must not be available to all staff in a provider organisation, because they do not need to know it. Sharing of relevant information is essential for participants with intellectual disabilities and cognitive impairments who might not absorb, remember, or pass on information that is needed for the purposes of smooth support delivery and participant welfare. In fact, workers have a duty of care to pass on some information to other supports, to ensure the safety and wellbeing of the participant. NDIS workers and providers have to be given education about when it acceptable to share information, and appropriate mechanisms for doing so. The NDIA should provide baseline awareness raising about this topic, with State and Territory variations promoted locally. The Victorian Commissioner for Privacy and Data Protection has seen fit to publish Guidelines for Sharing Personal Information⁷, because there is widespread misunderstanding about this topic.

4. Feedback about the scenarios

It is noted that the scenarios stopped short of illustrating how the participant could exercise choice and change their service provider organisation after a breach. It would have been helpful to carry through at least one of the scenarios to its full conclusion. It would be preferable to expand on 2.7.1, where the SIL provider had to leave the SDA. Presumably this would trigger a significant series of NDIS events. The Support Coordinator would have to find another provider urgently. (If the effected individuals did not have Support Coordination in their Plan, then an event such as this should trigger a Plan Review.) Presumably any other participant using that de-registered SIL provider would have to be notified and supported to promptly find another SIL provider. A full illustration will give the community greater confidence that participants are being safeguarded at a systemic level, as well as local.

5. Conclusion

Members of Prader-Willi Syndrome Australia make the following recommendations for the NDIS Code of Conduct:

- The same NDIS education materials should be available to all providers and workers that get money through the NDIS, for consistency and a common baseline of awareness
- Participants must be able to look at a single list of NDIS registered provider and worker, to learn about their profiles and performance. This will give the participant control and enable them to make informed choices about which providers to use, if any
- If it emerges that the Code of Conduct leaves loop holes for providers and workers to under-perform, or some complaints have not found an authority to action them, the

⁷ https://www.cpdp.vic.gov.au/images/content/pdf/privacy_guidelines/CPDP_Information_sharing_guidelines.pdf
www.pwsa.org.au

NDIA must be willing to review and update its own instruments to ensure participants are properly safeguarded.


- Workers must not just “accommodate any request...”, but balance a request from a participant against any adverse impacts on the outcomes being delivered by other supports
- The NDIA has to ensure scheme Planners are very responsive when a scenario of under-staffing is putting the participants at risk, so that adequate funding is always available
- The NDIS Code needs to support the collection of consistent data from provider and worker incidents, for the purpose of prevention. Centralised ‘big data’ about minor and major incident events, can be used for monitoring and oversight, to identify risk and enable the NDIA to initiate early action on adverse patterns.
- The concept of provider and worker ‘duty of care’ needs to be explicit
- The expectation the workers will contribute to a *holistic approach* to service provision through cooperation and regulated information sharing needs to be explicit
- Actions taken by the NDIA, the Commissioner or other regulatory body against a provider or worker needs to be transparent to participants, and persist over time
- The NDIA needs to provide adequate resources within its own organisation (and the Commission) to ensure that rigorous regulation and enforcement of the Code is seen to be happening. The person with a disability needs to be safeguarded and have enough information to be able to easily find quality services. The community at large, whether participants, families, workers, employers or taxpayers, need to have confidence in the NDIS.

We believe the NDIS Code of Conduct will help in guard against the NDIS becoming another of those programs where

“... in Australia competition policy has been a miserable failure”...“governments have failed to deliver on [adequate regulation, monitoring and enforcement]”... instead, “letting market forces run on, to the benefit of certain elites”; and, “...markets are only as good as the legislative/regulatory framework (set, monitored and enforced by government) within which market forces are free to operate” *Professor John Hewson, SMH, 29/12/2016.*⁸

PWS Australia is fully supportive of a strong and robust National Disability Insurance Scheme. We look forward to our members moving forward in their life’s journey and experiencing improved life outcomes.

I am happy to discuss any of the above with you, and provide examples of cases that reflect the short-comings listed above, if that would be fruitful.


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⁸ <http://www.smh.com.au/comment/governments-need-to-throw-out-the-status-quo-and-start-again-20161229-gtj7di.html>