



pwsa AUSTRALIA

prader-willi syndrome association

The Director
Specialist Disability Accommodation
National Disability Insurance Agency
PO Box 700
Canberra, 2601

14/5/16

Dear Sir/Madam,

Re: Feedback on the Specialist Disability Accommodation Draft Position Paper – Pricing and Payments

I represent the parents and supporters of people who have a rare genetic condition called Prader-Willi Syndrome. Prader-Willi syndrome (PWS) is a complex multistage genetic disorder affecting multiple systems in the body. It significantly impacts on behaviour, mental and physical health. People with PWS exhibit high anxiety, complex and at times destructive behaviours and social and cognitive dysfunction throughout their lives. They cannot live without intensive service support, integrated with appropriately designed accommodation.

We are concerned about a number of operational matters that have not been addressed in the Position Paper. The Paper notes that:

- There is no definition of 'reasonable and necessary' available (Sec 3.1). It is recognized internationally that people with PWS cannot live independently. *The criteria developed must not inadvertently exclude people with this complex condition.*
- There are no rules for the tenant-provider relationship (Sec 4.4.1). There must be a mechanism for removing an unsuitable tenant from a house. The perpetrator of the problems should leave, even if not by choice. Just because the other residents could "choose" to leave to escape an incompatible tenant, they should not be forced into that choice to escape. *There should be a 'model' tenancy agreement available across Australia for optional use by providers. This will allow for choice and control. The intellectually disabled should not have to try to understand a new agreement type every time they are looking for alternative accommodation.*
- There are no 'terms of business' available for NDIS SDA providers (Sec 4.2). Providers self "attesting" that they have met standards is a risk for cognitively impaired residents who cannot comprehend what standards are supposed to be met. *Parents and Guardians need to know the conditions that providers have been registered under, the applicable standards and that providers will be independently monitored for compliance.*

PRADER-WILLI SYNDROME ASSOCIATION OF AUSTRALIA INC
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We wish to alert you to the particular SDA needs of people with PWS. For PWS support there must be overnight care, plus office capacity because the complexity of the condition leads to a multitude of administration and the need for staff security.

There will need to be load-bearing furniture and infrastructure, such as plumbing.

It has been found from experience in Australia and overseas that people with PWS typically need purpose built, robust accommodation design, which may include reinforced walls, doors and windows, removal of tripping hazards, single level construction and access and egress modifications. Other allowances to enable all food sources to be locked away (in a group home, a 'butler's pantry' is least conspicuous and most robust), plus motion sensors. Such participants progress better in a group home of three to five people, preferably with scope for them to have more private space such as ensuite bathrooms or studio style accommodation segments.

If the Pricing and Payments policy does not presently allow for adequate SDA support and choice by people with PWS, then please edit the policy position to ensure their needs can be met by specialist and generalist providers.

I look forward to working with the NDIA to help all people with PWS to get the ongoing supports they need.

Yours sincerely,

James O'Brien

James O'Brien
President
PWSAA