

## **Introducing Competition and Informed User Choice into Human Services: Identifying Sectors for Reform**

*Submission in relation to the Productivity Commission Preliminary Findings Report (Sept 2016)*

The Prader-Willi Syndrome Association of Australia (PWSAA) represents people who are disabled by this syndrome and need lifelong human services support.

PWS is a rare and very complex, non-inherited genetic disorder. The syndrome includes intellectual, psychiatric, emotional, social and physical problems. People with PWS are often easily frustrated, impulsive, quick to anger, rigid and concrete thinkers, and highly anxious. Throughout childhood and into adulthood, people with PWS will require the support of a multitude of professionals. People with PWS are typically on a low income (Disability Pension income support) and cannot live independently. People with Prader-Willi Syndrome invariably, to some degree, need their choices to be assisted or facilitated through an agent or intermediary who is tasked with implementing their preferences.

As such, the PWSAA is making this submission in relation to the Social Housing, Public Hospital Services and Dental Services sectors only, of the Commission's Report.

### *Social Housing*

People with PWS are not in a position to compete for affordable accommodation. The PWSAA acknowledges that the National Disability Insurance Scheme (NDIS) will provide services to people with PWS. However, people with PWS need access to affordable (built) accommodation, with specific characteristics relevant to their disability. Since, they cannot live by themselves, the accommodation they rent needs to house a number of residents, plus sleepover care staff. The PWSAA calls on the government to make appropriate housing stock available for people with PWS, along with a building maintenance program.

### *Public Hospital Services*

People with PWS have many medical problems. These are compounded by having atypical symptoms and reactions to treatment. Apart from medical assistance in hospital, people with PWS have a commonality of challenging behaviours that need management in the hospital setting. Non-medical care needs to address their acute anxiety, food seeking and potentially anti-social behaviours. International evidence has shown that people with PWS do not have the capacity to make informed choices, particularly about medical matters.

Patients with PWS are expensive, due to their complex needs. A potential risk is foreseen in a competitive environment, in relation to the non-medical care. That is, some hospitals may not be interested in offering PWS-appropriate ancillary care, communication, waiting times, etc, as it could attract a higher proportion of costly PWS patients from out of the area. A 'clinic' model may help mitigate such a risk.

Therefore, the PWSAA is calling on all public hospitals in Australia to:

- offer *consistent* PWS-appropriate patient care (non-medical) *and* medical treatment to people with PWS. (For example, to prevent stealing other patients' food; providing detailed reassurance about unfounded fears such as 'poor' washing facilities; avoiding the pitfalls of confabulation; managing disputes over diagnosis), and
- offer PWS-specific outpatient clinics at strategic hospital locations, with the purpose of multi-disciplinary, holistic and preventive care

Ensuring that all hospitals have the same protocols for managing PWS patients (in or out), will reduce demand from individuals with PWS on future service provision.

### *Dental Services*

People with PWS have specific dental problems with a higher than normal risk of tooth decay caused by sticky saliva. They also have limited financial resources. Therefore, they need access to timely and PWS-appropriate dental services. This will avoid potential future costs resulting from poor infection and cavity detection and dietary problems.

The PWSAA proposes a 'bulk billing' dental model for PWS patients. They would be able to go to a private dentist, but would incur no out of pocket expenses. The government would pay for the service, as if the patient had attended a public dental service.

### *Conclusion*

The PWSAA believes that there is a *very high* risk of poor health and housing (welfare) outcomes, by expecting people with PWS to access human services in a competitive environment. This group does not have the capacity to make informed choice, or the kinds of judgements required to ensure the delivery of honest, quality services. They cannot discern who has given them better service or who has cheated them, nor plan and take steps to move to an alternative service.

People with PWS cannot think clearly enough to make effective use of any benefits that may be present in a competitive human services environment. Consumer protection, that is, additional support, should be provided from within the human services sector, at a systemic level. Therefore, the position of the PWSAA is that government regulation, through defining and enforcing quality standards, safeguards, monitoring and enforcement is essential for people with PWS. The government of a civilised society has a responsibility to adequately fund health and accommodation for people who have limited cognitive skills and financial resources to make independent choices.

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