



28 July 2017

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

By email: community.affairs.sen@aph.gov.au

Dear Secretary,

Re: National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017

I represent people with Prader-Willi Syndrome (PWS), their parents and supporters. We are looking forward to the opportunities that the NDIS will bring, to assist people with the syndrome to lead a better, more ordinary life.

The following comments are provided in the context of the features of PWS, pertinent to the protective role that the new Commission will play. The Prader-Willi Syndrome Association of Australia (PWSA) acknowledges that the Commission's work will complement the quality and safeguarding measures operating at State and local levels.

Prader-Willi syndrome is a complex, multistage genetic disorder affecting multiple systems in the body. It significantly impacts behaviour, learning, mental and physical health. People with PWS exhibit high anxiety, complex and, at times, very challenging behaviours. Whilst they have variable intellectual disability and communication skills, they have substantial cognitive impairments. The PWS profile means that they need support across all mainstream and disability services. They are not able to monitor, assess or decide on the quality of their providers, nor adequately safeguard themselves from harm. Therefore, in addition to informal supports, people with PWS are heavily dependent on the formal, regulatory mechanisms put in place by legislation.

PWSA welcomes the introduction of the Commission as a single, independent body to address quality and safeguards. PWSA believes this model will serve disabled people better by avoiding fragmentation, facilitating the sharing of critical information, and harnessing the power of 'big data' to identify and act on unsuitable providers and workers. A single Commission will also make it easier to interface more seamlessly with mainstream services (eg health, education, justice) and regulatory bodies, to better look after the interests of disabled people across Australia.



However, PWSA has some ongoing concerns. Broadly these fall into two groups.

- a) Firstly, there have been significant failures in the regulatory frameworks of several industries recently. The failures have resulted in adverse consequences for consumers and taxpayers alike (eg. VET sector, banking, building). It is critical that the NDIS Commission detect problems effectively, and deliver thorough and timely enforcement. The Commission must be adequately funded to ensure that disabled Australians with cognitive impairments are not 'stung' by providers, through an ineffective Commission.
- b) Secondly, where the legislation does not address certain aspects of quality assurance, monitoring and safe guarding measures needed by people with PWS, then the Rules will need to provide those protections. In particular:
 - Minor incidents involving providers and participants: these need to be recorded consistently so that results can be collated into 'big data' and anomalous patterns identified for analysis, and potential actioned by the Commission.
 - Any provider interactions with the Commission and findings by the Commission must be visible to consumers. For example the 'eMarket' could display for each provider, amongst other things, the number of complaints (substantiated or not), compliance notices issued, investigations initiated, etc.
 - The NDIA and Commission need to confer about providers who are appearing 'on the radar' of both organisations; This shared information will give a clearer picture of that provider's behaviour, which may reveal unscrupulousness.
 - A facility needs to exist where registered workers can later be reported as unsuitable to work with the disabled, even without a police conviction. Their name is retained on a list which is then used in future recruitment activity. The Victorian Government recognised that clients in disability residential care services were not properly protected. Victoria introduced the Disability Worker Exclusion Scheme¹ to address this risk. Such a scheme must operate for the whole of Australia.
 - Penalties need to exist for providers when there is a pattern of persistent minor contraventions (of Legislation, the Code, Rules, over charging, refund delays, etc).
 - Adults with PWS typically need to live in a Specialist Disability Accommodation (SDA) group home. The SDA is ideally of the design category 'Robust', and modified to deliver a life-saving restrictive practice (ie a locked kitchen). PWS is a complex and life threatening condition and sufferers cannot survive without 'intensive' support. As such, the Commission will need to be prepared to interact with State authorities that regulate housing, to ensure that SDA providers, or providers of daily life services in that accommodation, do not take advantage of people with PWS. The Commission will need to present a seamless service to the person with PWS who may be experiencing

¹ <http://www.dhs.vic.gov.au/for-service-providers/disability/accommodation/supported-accommodation/disability-workers-exclusion-scheme-information-for-service-providers>



housing stress. The disabled person should not be expected to patch over any cracks that appear between regulatory systems, given they have limited cognitive capacity. The Commission should identify and close any gaps.

- The monitoring of, and responses to questionable housing service providers is more critical than the treatment of community access, skills building and employment type providers. Accommodation and household services cannot be 'put on pause' whilst investigations take place. SDA arrangements for PWS people are not easily repeatable, nor easily found. So the participant cannot choose to suddenly move away from their home, and nor should they have to. There has to be swift and decisive action by the Commission towards questionable providers, so that PWS housing arrangements are not jeopardized.
- For people with PWS, the restrictive practice of a locked kitchen and supervised access to money is life-saving. The Commission's Senior Practitioner needs to be well informed about these predictable practices, and remain abreast of current international practice and standards² for the care of people with Prader-Willi Syndrome.

PWSA looks forward to ongoing involvement with the development of the NDIS, and its Rules, as it gets implemented across Australia.

Yours sincerely,

James O'Brien

President

Prader-Willi Syndrome Australia

² <http://www.pwsausa.org/product/best-practices-guidelines-for-standard-of-care-in-pws/>