

15th February 2021

Consultation Manager

National Disability Insurance Agency

Geelong, Victoria, 3220

<https://myform.apps.ndia.gov.au/?src=https://forms.apps.ndia.gov.au/jpgbthlbzknpuvv/ndisconsultation&org=ndis&theme=ndis>

Dear Sir/Madam,

**Re:** **Consultation on Access and Eligibility Policy with Independent Assessments**

As Training Coordinator on behalf of Prader-Willi Syndrome Association of Victoria, I would like to provide additional comment and feedback voicing my concerns that the Individual assessment (IA) Toolkit, as proposed by NDIA, will not accurately give a fair and equitable evaluation of the functional capacity and adaptive behaviours of people with PWS, who are wanting to access NDIS or who are already participating in the NDIS.

I have held the position of Training Coordinator for the Prader-Willi Syndrome Association of Victoria for over ten years. This role has given me broad and unprecedented access to people with PWS of all ages and stages of life. I have worked with disability providers and allied health professionals who support people with PWS. I have completed training across many sites, including residential disability houses, nursing homes, childcare centres, kindergartens, schools, day training centres and workplaces. Most importantly, I have worked with those people who have PWS and their families. I have completed over 100 site visits across metropolitan and regional areas, mostly in Victoria and interstate. I have spent many hours working with people who have PWS and their support staff who know firsthand the impact this disabling genetic disability has on their lives.

Also, I am a trained teacher with over 30 years of experience with special education qualifications working mostly in special needs /integration programs. I have become very familiar with many of the assessment toolkits selected by NDIA in my professional career. I have a good understanding of the strengths and limitations of such assessment tools. I have never seen them used in isolation as proposed by the NDIA. In the education setting, we recognise that to achieve the most holistic picture of an individual’s functioning is to combine the knowledge obtained by assessments with reports from a specialist who know the child and their functional capacity over time in various settings.

On behalf of PWSA Vic, I strongly support the comments and recommendations put forward in the submission forwarded by PWSA concerning the design of the Access and Eligibility Policy as suggested by NDIA.

Background Information

* 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 require cognitive, social, and learning support throughout their lives. A person with PWS can live a healthy, fulfilling life when they have ongoing, consistent support from people who understand the intricacies of PWS.     [www.ipwso.org](http://www.ipwso.org/)
* PWS presents as “a typical neurobehavioral profile that includes altered intellectual functioning and centrally driven maladaptive behaviours.” Individuals with PWS have a flaw in the brain’s hypothalamus, the brain’s regulatory mechanism.
* Due to the fact, their body’s fundamental regulatory mechanisms are dysfunctional, a person with PWS is unable to independently regulate their body’s mechanism that registers and regulates satiety, pain, emotions, circadian rhythms, behaviours and many other regulatory functions that allows a person to participate to their full potential in a safe and healthy environment. For a person with PWS, that goal is only achieved if supported in a PWS friendly environment.

I believe the Individual Assessment (IA) Toolkit as proposed by NDIA cannot accurately provide a fair and equitable assessment of the functional capacity and adaptive behaviours for people with PWS when considered in isolation from other more informed assessments and reports completed by those who have expert knowledge and understanding of PWS.

* Due to the complexities of PWS and the person’s reliance on the support of others to manage their environment, the variance in their functional capacity from setting to setting is significant.

The assessment of capacity/functionality results as proposed are relevant only to the setting the assessment takes place in – in real life the variance in the levels of functionality to complete a range of activities and routines, from situation to situation depending on the quality and level of support provided, is considerable.

* The IA assessment results will only ever provide a snapshot of a particular day, in a specific situation, when the person with PWS may or may not be adequately supported.

I am not aware of any research that demonstrates how this suite of assessment tools mentioned in the NDIS toolkit can accurately capture a person’s functionality in a range of activities and routines when competency is so dependent on the quality of the support the person with PWS receives in any one setting.

The person with PWS often has no real control over the quality and quantity of support received daily.

Therefore, the predictability of capacity, functionality, and adaptive behaviours based on assessments one day is unlikely to provide a fair and equitable evaluation of the person’s functionality in a range of activities and routines, completed in many settings with varying support levels, over some time.

PWS is too complicated a disability and too dependent on the variability of external environmental factors to gauge a measure of a person’s functionality and adaptability with a simple set of assessment tools in three hours.

It is a blunt measure than can never accurately assess the depth and breadth of this complex disability.

 The information collected from the IA can only ever be one amongst many sources of information, collected over some time, in many different settings to inform the NDIS planner as to what is reasonable and necessary to achieve the person’s goals.

Yours sincerely,

Kate de Josselin

Training Coordinator

PWSA Vic