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Dear Committee Members,

I present this submission for consideration in respect to the inquiry into Independent Assessments under the NDIS.

I am a father guardian and administrator of my sons affairs. I have been self-managing my sons NDIS Plan for over two years and prior to that was self-managing his Plan under the WA NDIS scheme.

My son has a rare genetic syndrome – Prader Willi Syndrome. The syndrome has a very significant impact on my sons life and results in life long cognitive and emotional development impairment, as well as a range of physical and metabolic difficulties.

In addition the syndrome results in my son feeling constantly starving, with no food satiety, and requires significant food and diet management. Despite this management of diet, due to low metabolism and other syndrome impacts, weight control is very difficult resulting in other health concerns including Type 2 Diabetes.

These and other factors result in difficulties with behaviour management. My sons behaviour is impulsive, obsessive, inflexible, egocentric, and prone to feelings of frustration and anger outbursts. These outbursts have on occasion resulted in physical violence and we have had previous involvement with Police and the Justice system as a result of his actions.

My son lives in an independent low rental accommodation and has a team of 3-4 carers on a rotating roster supporting him on a 24 hour basis. Due to factors such as those referred to previously, group home settings are not suitable for him, and the development of his independent living skills has been ongoing for approximately 3 years.

Whilst he no longer lives directly with me, he remains dependant on me to actively mentor him, and his support workers when required, in respect to communication techniques, emotional control and behaviour management. I live and work within close vicinity and have been required to provide active support on numerous occasions, and mediate as required in order to assist him in controlling his

emotions, and assisting him to not allow his frustrations and anger to escalate.

We have tried various clinical supports including occupational therapist, dietician, psychologist, endocrinologists, and psychiatrists. My son has a regular GP and has regular appointments with his endocrinologist and psychiatrist. (Please also refer to attached recent report from his psychiatrist).

Conditions such as my sons are life long. The best that you can do when caring for those with such conditions is to actively manage his life, be advocates for him when required, and together with him develop goals for his life. Establish opportunities for him to achieve these goals and support him in his daily life and mentor him in developing communication and behaviour strategies that provide optimum health and life enjoyment outcomes. This together with teaching life skills and independent living skills allows him to experience life, develop a level self-awareness and resilience that he will need as he grows older.

There are significant stresses on people such as myself who take on the responsibility of supporting loved ones with such difficulties. Self- management does allow me to select the support workers , establish arrangements that best suit the needs of my son and maximise the funding available that he needs for his supports. However such responsibility impacts heavily on you, your capacity to work, share time with other family members, take a small holiday and simply finding space to be able to think of your own life direction and goals separate to the needs of my son.

The reasons I am submitting this submission are as follows:

- What my son needs, and what people such as myself need, is certainty regarding his funding supports, a system that is easy to negotiate, and not one that creates any feelings of uncertainty, or adds any further stress to our lives.

Regardless of how you develop/ structure it, implementing Independent Assessments of people such as my son who has a syndrome that is life long is not necessary and increases feelings of stress and uncertainty regarding the ongoing funding support he requires.

I have concerns regarding the skills and capacities of those that may undertake such assessments, particularly in respect to complex genetic syndromes such as my sons

Undertaking a snapshot assessment may very well give a completely wrong assessment outcome

My son reacts adversely to anyone that he does not know well, particularly someone reviewing him talking to/ about him and this would stress him out and make any assessment worthless.

No system that seeks to support those with disabilities/ disadvantages in life should create further uncertainty or stress and such implications should be avoided. For reasons as stated above my concerns are that introducing independent assessments into the scheme will do just that..

There is also concerns about individual dignity. Having others that may have technical skills but have no knowledge of the person or his life, reviewing and assessing them is an intrusion into their lives. Combining this with a probable lack of an in depth understanding of complex syndromes would also potentially trigger negative feelings of self- worth and should not in any way be substantiated.

Should it be determined that such assessments be undertaken then it is submitted that those with life long disabilities, that need to be managed for the remainder of their lives should be exempt from such assessments. Prader Willi Syndrome results in such an overarching range of life long difficulties that allocating resources to undertake assessments on those with such disabilities would serve no purpose, and would be a negative experience and intrusion on the person involved, as well as creating undue stress on those that have significant stress in their lives already.

I thank you for the opportunity to present this submission and sincerely hope that consideration is given to the matters raised.

Kind Regards