

**Submission to the National Disability Insurance Scheme (NDIS) Costs study  
Productivity Commission  
GPO Box 1428  
BARTON ACT 2600**

Dear Commissioners,

I am writing this submission on behalf of my 30yrs+ disabled son "A". He was diagnosed with Infantile Autism when he was 3years old . He is non verbal, has epilepsy , highly mobile with no understanding of dangers. Due to his level of disability he has acute behaviour management issues which meant that he required one on one care since he started receiving government services some 20+ years ago.

**Cost points for consideration.**

My son has been receiving funding from NDIS for nearly 2 years . Initially we were very pleased with the NDIS, the days of stress in having to "beg steal and borrow" for services had disappeared. But it wasn't long before we realised at the annual review process those days were returning and once again we had to start all over again and to justify our sons reasonable and necessary support needs.

**We have been told care needs will be benched marked ,which doesn't take into account a individual persons specific critical care needs.**

**The ongoing need for reasonable and necessary support for people with profound disabilities needs to be considered by the Commission to ensure their safety and wellbeing.**

I fully understand the potential for cost blow outs in the NDIS current scheme, but **my concern is that everyone with a disability are not all lumped together for bench marking purposes.**

*For example if someone with a heart condition required plaque removal from an artery, the costs would not be as great as for someone with a heart condition requiring a heart valve replacement .*

The level of my sons disability requires him to have one on one care at all times and 6 hours a week he goes into the community for bush walking and catching buses where he requires 2 staff. ("A" doesn't fit into main stream disability care day programmes) If the funding for accommodation support was capped across the board it would mean people like my son would be at risk of danger and of containment, which itself escalates behaviour management issues.

NDIS will be providing services to tens of thousands of people with disabilities. **In fairness to all participants NDIS should be providing their own team of government appointed medical professionals who have expertises in their field to assess what is reasonable and necessary supports.** In the case of condition such as Infantile Autism there is no cure and the participant will always require specialised care.

At the moment NDIS review support funding is for every 12 months, although some with lesser packages than my son have been extended longer than this period. For most people diagnosed with a severe profound disability, their disability is permanent. Once the level of essential care has been established by the NDIS professional medical team, the review then should be say every 5 years for these participants. Then if the participants level of funding is cut by NDIS and the participant wishes to have this reviewed for the sake of their wellbeing, funding should remain intake until the review process is complete.

Thank you for the opportunity to make this submission on behalf of my son "A"

Yours Sincerely

Mother and Legal Guardian of Participant ("A")

8 March 2017