

## **Productivity Commission Submission**

### **Our Family Situation**

We are a family of 5 who live in metropolitan Sydney. We have an 8 year old daughter who has multiple severe disabilities. She cannot perform any daily living tasks for herself. We spend hours each and every day feeding, dressing, changing her nappies, coaxing her to drink fluids and doing physiotherapy exercises with her. On top of these daily demands, there are the frequent appointments with medical and allied health professionals. Our daughter is regularly reviewed by a neurosurgeon, neurologist, general paediatrician, rehab paediatrician, orthopaedic surgeon, ophthalmologist, physiotherapist, occupational therapist, speech therapist & dietician. All very time consuming and all very expensive. Our out of pocket expenses for medical, therapy and respite services are several thousand dollars every year.

-Caring for our daughter has to be juggled with the needs of her twin sister and 4 year old brother. We have some help from family who can care for her while we take the other 2 children to their activities or on outings. However, this is increasingly difficult as grandparents age and our girl gets bigger and heavier.

-Each time our daughter needs an item of equipment, there is a significant waiting period, if funding is granted at all.

She requires a standing frame in order to prevent her hips from dislocating. PADP no longer funds them and so we'll have to find that \$5,000 in the next couple of months, unless charity funding can be found. She has outgrown her current walking frame and shower chair. Applications for larger versions of these went in several months ago to PADP but we are still waiting. Our daughter is rapidly outgrowing her current wheelchair. We are very concerned that we will not receive PADP funding before we can no longer squeeze her in to the existing one.

Our daughter weighs 26kg. We can't lift her in and out of the car for much longer and so really need a wheelchair conversion for our car. However, at a cost of \$28,000, it won't be happening any time soon.

-Provision of physiotherapy and other therapy services is woefully inadequate and so we often pay for private therapy sessions to ensure our daughter's outcomes are maximised.

-Availability of respite services and facilities is also hopelessly inadequate; after-school and vacation care for children with high support needs is virtually non-existent. It has not been possible for me to return to the workforce and we have hence absorbed a significant opportunity cost.

-Our family's situation is really difficult. We struggle financially, emotionally and physically to cope with having a family member with significant disability. However, we are far better off than so many others. We are fortunate to have one steady, very good income. English is our first language, we have tertiary levels of education and we can advocate effectively for our daughter when necessary. We have a strong, happy marriage and enjoy the support of a large circle of family and friends. If a NDIS could make such a big difference to us, it could improve the lives of so many others even more!!

Our comfortable lives were turned upside down because of an intracranial bleed at birth. Things can happen to anyone at anytime. As a society, we need to better support and care for those who draw the unlucky cards.

### **How we imagine an NDIS could improve the life of our daughter and reduce the stress on our family:-**

-We could purchase equipment for our daughter as and when required.

- We could make our car wheelchair accessible and save our backs
- We could pay for medical and therapy services and not have these eat in to our family's budget.
- We could possibly employ after school carers and enable me to return to the workforce.
- We could spend less time navigating and negotiating "the system" and more time enjoying time with our children.

Most importantly, we could more adequately plan for our daughter's future and make provision for her care for when we are no longer physically able to provide it. That is the single largest concern for us and it weighs very heavily on our shoulders.