Input to the Productivity Commission's Review into Disability Care and Support

PERSONAL RESPONSE

We are the parents of a seven year old boy with moderate intellectual disability, epilepsy, low muscle tone and autistic tendencies. Whilst we love our boy dearly the last seven years have been a real struggle. Our son is a terrible sleeper and we can count the number of nights we have had a full night's sleep since he was born. Our son needs full support for toileting, dressing and assistance with eating. He gets exhausted and frustrated very easily leading him to regularly having tantrums, throwing things and hitting. His anti-social behaviour, particularly with other children, makes it difficult for us to socialise as a family. Getting the services we need has been a struggle although with the help of good social workers we now have some respite, intermittent therapy and have been able to access some equipment, ie. for toileting through a flexible family support program.

I think that a NDIS makes a lot of sense for the following reasons:

Philosophically: Disability can affect any one at any time and when it does it so drastically affects your life. A national insurance scheme recognizes this and would potentially share the financial burden more equitably than is currently the case with families currently bearing the majority of costs associated with disability.

To provide incentives to reduce preventable disabilities: We believe, and a number of experts concur, that our son's disability was preventable. Our son had extremely high jaundice after birth which was not treated quickly enough and potentially caused his brain damage. Despite being the most likely cause of our child's disability taking legal action has not been possible and we are left to bear the costs of his disability. We would hope that a NDIS might have an interest in reducing disability and take on an advocacy role, in working with the health and other systems to achieve this. The work of the TAC in reducing deaths and disability from car accidents is an example of this.

To bring more consistency in services around Australia: We live in the ACT and after spending time on waiting lists and almost having a nervous breakdown we have now have access to reasonable services. My family is in Melbourne and at some point we would be interested in moving closer to them. It is almost impossible to find out what sort of services we would be able to access if we moved to Victoria: from schooling to respite the answer is "wait until you are here and you will be assessed". I am terrified of moving to potentially less services and the impact this would have on my mental health yet I can also see the benefits of moving to be closer to family. In no other area: health, education etc. is there such a lack of information on services available or such inconsistency between States, different regions or suburbs within a State. A national approach to disability, and a greater rights based approach, is desperately needed.

What kind of scheme is needed:

Flexibility: My most positive experience has been with organizations that provide funding through “flexible family support”. They generally consider applications on a weekly basis and are very quick to provide funding. Grant schemes that are once a year can be very debilitating: certain criteria have to be met and the application needs to be written in a certain way. Grants generally decide what they think is important rather than letting families decide what their priorities are. Ideally a case manager working for such an organization can explore with the family what their greatest needs for support are and how that can be met.

Focus on the support required and not just on the severity of disability: I think it is very difficult to classify the difficulty and impact of a disability according to use of words such as severe or moderate. For example because of our lack of family support in Camberra and our son’s specific need for constant supervision the demands of his disability on us are extremely high. I think it is much better to focus on the need – respite needs, equipment needs, accommodation needs. My family has similar respite needs to many families of children with severe disabilities because of the high level of supervision our son requires due to behavioural issues. We do not have the same equipment needs. A national scheme should decide what equipment is eligible for funding and why and then people who need that equipment would benefit: similar to the PBS, rather than talking about people being “in or out” of the scheme.

Wide coverage

I believe that a scheme should provide wide coverage with tapered benefits depending on the level of need. Having hard cut offs for services creates all sorts of incentives to exaggerate a disability or bring oneself within the scheme. For many families of children with more mild disabilities could benefit greatly from low cost and well targeted interventions.