

Disability Care and Support Public inquiry

Submission to Productivity Commission.

11 August 2010

REQUEST NAME BE WITHHELD

My daughter, aged 31, is a highly intelligent, compassionate and public spirited mother of two young children. She has an Honours degree in Anthropology and for several years worked as a policy officer for a State government in the areas of health and Aboriginal affairs. She was making a significant contribution to society through her work and her support to the community.

She continued to work following the arrival of her healthy daughter, now five. However when her son, now two, was about 16 weeks old he suffered the first of many seizures and nearly died. He has been diagnosed with a fairly severe form of epilepsy and although now nearly two and a half, cannot yet crawl, sit up unaided, walk or talk. While he is cheerful and sunny, he is more like a six month old than his chronological age. Physically however, he is still growing and putting on weight and the time is coming when his mother will no longer be able to lift him unaided. Drugs and a special ketogenic diet have reduced the frequency of his seizures but it is now clear that he has incurred neurological damage so that he is unlikely to be able to develop the normal motor skills which we all take for granted. He requires special equipment for bathing, travelling and the like.

Because of this our daughter has no choice but to stay at home and be a full time carer for her son, and there is no end to this prospect in view. She and her husband and her healthy daughter have incurred very significant financial and other penalties to their way of life and their aspirations due to these circumstances.

While I am not qualified to quantify it, it is obvious that society too has incurred a price because of this young boy's disability because his mother is no longer able to carry on her worthwhile profession. His father, too, has to take considerable time off from his work (it is fortunate that he has an understanding employer) and his career options are curtailed to some extent because of the difficulties they face.

If there were a National Disability Insurance Scheme in place our daughter could get the carer assistance she needs, pay for needed specialised equipment, and she could return to a worthwhile and fulfilling career which would benefit society. It is entirely possible that there would be a net economic benefit to society if she were to be able to access such a National Disability Insurance Scheme.