# SUBMISSION

Productivity Commission - Disability Care and Support

This is our submission regarding our daughter Georgia

Background:

Georgia at 4 months of age had her first seizure after her second triple antigen injection that lasted 45 minutes resulting in her first of many hospital stays. For the following years of her life we have spent waiting for the next seizure she had several seizure types the most noticeable were Myoclonic seizures which we termed the “nod and blinks” At around 4 years Georgia developed drop seizures resulting in her having to wear a protective helmet, we have lost count of the number of stitches to the head and damaged teeth Georgia has had over the years. Georgia at first could communicate in the first two years of life verbally then this just disappeared over time. What Georgia learnt in the first two years of life is basically what she will know for the rest of her life. All this time we did not have a definite diagnosis of Georgia’s condition. Georgia is incontinent and requires hand feeding just like a baby she has the intellect of a one year old. Physically she can walk but she prefers to run but she is unsteady and we generally use a wheel chair when going anywhere. As Georgia cannot communicate verbally it has just taken us a week to realise that she has a broken collarbone, and she participated in all her normal activities like school and horse riding. Georgia has been diagnosed with Dravet’s syndrome (Severe Myoclonic Epilepsy of Infancy) two years ago with DNA testing she will soon be 18 years old and leaving school at the end of the year. The syndrome is degenerative and she has a normal life expectancy. I have left Georgia’s name in this submission to give some reality to the text.

Our experience of disabled support in Queensland:

One of the experiences we needed was for someone out there to tell us early what support was available, we really only stumbled on resources when we started talking to other parents at school, and when it came to respite we were all in competition for the same scarce resources. Disability Services in Queensland has been severely underfunded for many years resulting in a system that is not pro active but will give support when families are really in crisis. We are constantly informed of families that either split up or surrender their child.

Our experience of the education system:

Our support from her special school has been outstanding, the staff at the school are so supportive and positive they are an inspiration.

The effects on the life of our family:

I am 62 years old and my wife is 57 years old. We have no close extended family so we are on our own. We really have been house bound for many years. The limited amount of respite has occasionally allowed us to do “normal things”. We have only in the last couple of years started to have holidays when we have gone to enormous lengths to get respite for our daughter. We have taken our daughter to restaurants but it is a struggle, so we generally don't go anywhere because we know we won't enjoy the outing. Both parents are depressed, I am attending counselling for my depression. Just writing this submission is a struggle and I am sure that there will be many submissions not written due to mental and physical fatigue that carers have to endure.

The future:

Georgia will finish school at the end of the year and we have learnt that she will be eligible for a couple of days at a day centre from 10:00 am to 3:00pm and we will have to drive her there and back. This has been the final straw as all I could see for the rest of my life was one big black hole; we have contacted Disability Services and told them to look for accommodation at the end of the year as we are tired of fighting with the system. We have tried our best for our daughter but we realise that we need to let go of our daughter as the family was about to split up and her best interests could be best served if we gave up day to day control and we can the support her from a distance.

The prospect of a properly funded disability insurance scheme:

When we first heard of this all we could think of is not "if there should be a scheme" but "when will it be implemented".

A properly funded scheme would:

Drastically reduce the divorce rate among families with a disability, in Denmark the divorce rate is 20% in families with a disability compared with the overall rate of approximately 40%.

Provide employment opportunities in related fields e.g. Disability Registered Nurses which we do not have in Australia.

Provide appropriate accommodation for the disabled.

Stop the practice of placing the disabled into aged care facilities thus freeing up places for the elderly in an ageing population this is an important issue.

Parents of disabled children could live a more normal life and the pressure to relinquish their child will be much reduced.

Provide school accommodation for students with a disability as another form of respite.

Provide real equality and dignity for the disabled.

Conclusion:

A Disability Insurance Scheme is a great idea and it would only work if the funding was at the appropriate level and the amount of money sifted away for the bureaucracy can be minimised. In Australia currently disabled people have to beg to get help, this in degrading and more in keeping with countries with lower living standards. The important thing is a disability can happen to anyone at anytime and it is only prudent to have insurance against this likely hood just as we have compulsory third party insurance for motorists.

Arthur Powell

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