

SUBMISSION FROM MADELEINE

10 July 2008

My daughter is 13 years of age and was diagnosed at 9 months of age with a rare syndrome which includes moderate intellectual disability with medical complications. I have another daughter who is 15 years of age who doesn't have a disability. I welcome this inquiry to help the government determine how to better meet the needs of carers who look after those with chronic illness, disability or frailty. There is no question there are enormous gulfs in our society regarding people with disabilities in many areas, and the regular population. Because my experience is one of a mother of a special needs child, then obviously my submission will reflect my own situation and that of my daughter.

I will present my comments in point form but before I do let me state firstly that we love our daughter dearly, we would not have her any other way and cannot imagine our lives without her. She is very much wanted and recognised as a valued and cherished human being by us, her family. However it is obvious that in many ways society does not feel the same way. This is reflected in many ways by the Government's approach to the care of people under their umbrella of responsibility (as member's of our society) who have disabilities (I am referring mostly to people with intellectual disabilities) reflected by the Government's attitudes to funding and care for these most precious and vulnerable in our society.

A measure of any society is how they care for people like my daughter and how they value every individual no matter what their IQ. There is no point pretending otherwise that many of the prevailing values our society holds dear are based on wealth, beauty, celebrity and what an individual can gain as far as material goods. My daughter is not even at the starting gate of this race and never will be, but society is not seeing the value that her life does hold because they mostly never care to find out. She will also never have her own voice in this society, and will probably never vote. This is a problem for her because a politician will not gain a vote by looking after her, or fighting for her basic rights. There will never be a huge push for disability rights because the people involved are either voiceless (like my daughter) and their carers are often so overwhelmed with their responsibilities they have no energy to take on anything extra.

There seems to be a great amount of support available in our society for people who have made bad choices in life. If you are a drug addict, an alcoholic, a gambler, a smoker; then there are places set up to help you, give you treatment (often paid for by the public purse), there are huge Government sponsored advertising campaigns and counsellors available for assistance. My daughter did not make a choice to have a disability and therefore the prevailing attitude seems to be just "too bad". Obviously the larger percentage of a population involved in a disease or situation then the greater amount of funding goes towards research and assistance. There are great supports for people with depression, diabetes, cancer, blindness etc but if your child has a rare syndrome there is absolutely no support apart from what other parents have managed to grow themselves with no Government funding (in the case of my daughter's syndrome) to assist. To watch the federal, state and territory governments bicker over providing funds to the CSTDA reinforces the attitudes to those with a disability (and the rest of society) that the money is better spent elsewhere, and as far as getting votes then they are probably right. It is gut-wrenchingly sad to watch politicians bickering over a few measly dollars which clearly points to the value they place on a child like mine.

1. The emotional stress on a family who have within it a child with a disability cannot be understated. This stress cannot be measured in terms of a death in a family, moving house, changing jobs etc because it is an ongoing stress which can change rapidly from day to day, but is always present in different levels. My daughter has undergone 15 operations in 13 years, some of these simple procedures and others more major. She also has an intellectual disability which makes many situations in life far more frightening for her, and any medical procedure or appointment takes a huge toll on her and on us because of her past experiences. A simple trip to the dentist becomes another huge mountain to climb. There are also challenges with behaviour and all areas of development that are continual and a moveable feast of difficulties and situations to be faced. This cannot be explained easily to one who does not live it. One of the most difficult aspects of this stress for me is that there is no end point to work towards; it is just a matter of enduring it day after day. I do not have the comfort of thinking that once she grows up then she will be responsible for herself, she will never be. My husband and I will always be responsible for her, and due to the current level of funding the government gives to group homes and other options for adults with intellectually disabilities, then we have accepted that as long as we are alive then she will be with us. What happens when we die does not bear thinking about.
2. The financial stress is another huge aspect of having a child with a disability that includes juggling specialist after specialist and attending one appointment after another. The cost of time, petrol and parking alone to cover all these aspects of care is a huge burden and then there is the cost of each appointment. Ophthalmologist, orthodontist, gastroenterologist, Ear, Nose and Throat, orthopaedic, plastic surgeon, dentist, paediatrician, and the list continues to grow as the year's

progress. This does not include the countless trips to the GP and the continual cost of prescription medication that my daughter is on permanently. The weekly payment of \$50 that I receive from the government just doesn't come anywhere near the extra costs that this disability entails. Then of course is the extra cost of speech therapy, physiotherapy and occupational therapy that my daughter should be receiving but isn't, because it is just too costly. So she doesn't reach her full potential, only the potential we can afford to pay for her.

3. From the day my daughter was born she needed special care and a child care centre would never be able to provide the care she needed, for example feeding her for hours and hours out of a special squeeze bottle because she was born with a cleft palate and then having her reflux the contents and starting all over again. I was never able to go back to work fulltime and put her in childcare like other families and there was no other option available. I worked for a couple of days but had to employ a nanny at home to be with her which cost more than I earned in the day. She has been in a special school environment almost all her school life which doesn't offer after school care (and for which I also have to pay private school fees) so I always have to be at home in the afternoon. Even if there was after school care she could not have coped with an even longer day. She is now in high school and I still have to be home at 3.30pm every day to care for her, which limits my own options to work in a job with normal work hours that other regular families take for granted. I have not been able to pursue my career because of this situation, but also because I had to spend so many days home with a sick child and so many days waiting in doctor's waiting rooms. I don't resent this because I love my daughter, but it has had a huge impact on my career and our family's financial situation over many years and many more to come.
4. It is with a growing sense of frustration that I read articles in the paper regarding increasing places for students to attend selective schools and the money poured into educating the brightest students where the students at the other end of the scale are just neglected, functioning with services that are hugely under-resourced with many committed staff overworked and underpaid. It all comes back to value. Students with disabilities should get the services and education they require to reach their full potential, as is the right of other students in mainstream education. They are not labels, they are human beings. If Government's put in the money to early education and followed through the whole education system then children with disabilities would be far better equipped to function in society with the skills they need to cope as adults.
5. As a "carer" it is difficult to fit into any one definition of the role. Yes I did choose to have a child, and yes I am responsible for her as is any parent. If I decided I could no longer care for my daughter then a foster carer would be paid in excess of \$500 per week to care for her, they would be offered training and assistance and respite. I get \$50 a week and am lucky enough to get 3 hours respite per week with no training or other assistance. It seems the responsibilities of caring are recognised when the Government has to pay someone else to do it. My

wish is that they would recognise these responsibilities before a parent is in the devastating position of having to relinquish the care of their treasured child.

6. One of the most frightening aspects of having a child with a disability is how vulnerable they are all throughout their lives. Often the people that are employed to deliver respite or other services to children and adults like mine are not paid well for their care and most are not trained professionals.

Here again is a reflection of the status that people like my precious daughter carry as members of a wealthy, prosperous but often laissez-faire nation. A nation that needs to take a long hard look at itself and the sort of society and values that it reflects. How wonderful it would be for Australia to turn these ideologies on their heads and be a leader in the world with regard to the care and regard they have for the most precious of all people.

Yours sincerely,

Madeleine