Inquiry into Disability Care and Support
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

21st July 2010

I would like to put forth a submission to the inquiry regarding disability care and support. My brother has cerebral palsy, epilepsy, osteoporosis, a moderate intellectual disability and he is legally blind. At the moment he is living with my parents but one day, I will be his primary carer as my parents have their own disabilities that they struggle with. My mother has a degenerative muscle condition and my father has a broken back and heart problems. Due to these disabilities they are unable to work and must live on disability pensions. To make life more difficult, they are continually coming up against obstacles put in place by the Australian government due to their lack of funding and services.

My Submission

- A National Disability Insurance Scheme with self-directed funding for those born with a disability or who become disabled due to illness or accident.

- Self-directed funding is a must, as only the person affected and their carers know what they need day to day. It should not be up to a committee, social worker or occupational therapist to decide what a person needs and when.

- Training and resource centres in each state to train Disability Support Workers in all areas of disability care. Our loved ones lives are in the hands of these workers and they should be properly equipped to care for people of all ages with various disabilities and personal needs. They should also be assessed on a regular basis and undergo an accreditation program (like teachers) to ensure they know how to care for people with disabilities adequately.

- Parents and caregivers should only have to outline their child's disability once, through Centrelink. For a parent to have to fill out a form sometimes two or three times a year, to state that their child is still disabled is wrong. Cerebral Palsy, for example, does not go away so a carer should not have to continue to fight for their payment and to 'prove' their child is still disabled.

- Legislation that requires all insurance companies to insure modified vehicles for the cost of the van AND modification. Too many insurance companies refuse to insure the modification meaning if the vehicle is written off or stolen they cannot recoup the cost of the modification.

- A no interest loan scheme for low income families to buy a modified vehicle as needed. A large number of carers have to stop working to stay home and care, full time, for their loved one. Therefore, a large number of families with a member with a disability are on low incomes and are unable to afford a new vehicle, let alone a modified one. The cost of these vehicles is a burden to families all because they have no choice in what they need. Without a vehicle, people with disabilities are often confined to their homes, or must rely on wheelchair taxi's which are unreliable and extremely expensive. Not having a vehicle has a large impact on a person's life from being able to shop when needed, making it to medical appointments and their social life. Every person should have access to a vehicle.

- More funding for organisations that provide equipment and services to those with disabilities. Also, this funding shouldn't be allocated on a "one item per person, over so many years" basis as most currently are, but on personal needs. People's needs and problems are diverse and not everyone can survive with say, just a walking frame or just a manual wheelchair. In an ideal world electric wheelchairs would have access to all buildings and places of public interest but that is not how things are. Often a person in a wheelchair will need both a manual and an electric for different situations and both should be provided. Without both, they are limited in where they can go and what they can do therefore making them 'handicapped'. Instead, we have these organisations telling us that they don't have enough funding and therefore you can only have one piece of equipment. Not good enough.

- Changes to the legislation surrounding group homes. People should have a choice over where they want to live, not just be 'put' wherever there is an open place. Clients should not be able to be moved from one group home to another without parental consent, parents and carers should retain full rights in regards to decision making. The use of any income after expenses are paid, should be left in the hands of the client, their carer, parent or client elected representative. A government agent should not take over a person's finances as it is degrading to have to ask for access to your own money. I for one, would never put my loved ones in a group home under the current system, as it takes away all rights of the clients and their families, treating them like children unable to look after themselves. Sure, to a certain extent, some people cannot (hence, the need for group homes) but all people, regardless of ability, need some sense of control over their own lives and be able to make their own decisions. Group homes do not offer this.

- Although possibly unrelated to this inquiry, an overhaul of legislation surrounding "disabled" rooms in hotels, resorts etc. is needed. Most disabled rooms just have a rail in the bathroom and an open shower. This is not a disabled room. Doors should be widened, the floor should be tiled not carpeted, electronic hoists should be installed in the roof, the bed should be able to be raised and sat up, taps should be sensor taps in the sinks etc. The list goes on. I have not stayed in one "disabled" room which is actually set up correctly for those with disabilities. All hotels should have to have at least one room that is correctly modified (dependant on size, the bigger the hotel the more rooms they should have) and this should be mandatory. People with disabilities are often excluded from travelling or stay in holiday accommodation due to these issues. This is just one more obstacle in the way of a person with a disability living a full life.

- Lastly, a question…. What happens when my parents die? Sure, I will be here for my brother but what happens? I will have to leave my job, my career I have been working at for years. What happens to my children and my husband? My house isn’t modified, does that mean I need to leave my home and go live with my brother? Do I need to get a large loan and modify my house? Do I put him in a group home and constantly worry about if he is being looked after properly? Or, can he stay in his own home, with my support, and the care of service organisations to help care for him? That last option sounds the best. He would have his home where he has lived most of his life and he would have independence. Unfortunately, with the current state of the system and the lack of funding, this does not look possible. Instead, in years to come, we will be faced with a hard decision with no good outcome.

These are some of the issues that I believe need to be looked at in more detail and addressed by the government, as they have a major impact on the everyday lives of Australians living with a disability. As you can see, most of these issues are related to things that you and I take for granted such as being able to leave the house when we want, live where we want, go on holiday when we want, but people with disabilities are unable to do these things due to the inadequacies of the current system and lack of funding. This needs to be changed.

Thank you