

## Submission to Productivity Commission

The 'system' currently is utterly unfair and this needs to change immediately.

ALL people with permanent severe disability should be able to access Govt. services equally.

by this not happening the experience of families is of severe stress and depression at the feeling of banging their heads against a brick wall achieving nothing for their loved one.

Care packages are administered on an ad-hoc basis. Families stress level is HUGE having to 1, fight for the individual needs of their family member and 2, having to do so whilst at the same time caring in many cases 24x7 for their loved one.

This is exacerbated for older/senior carers of their 'adult 'children.

Lives are ruined, energy levels drained and people become exhausted and disillusioned with Govt. bureaucracy, inefficiencies and outcomes.

Monies should be administered much more equitably and far more of it .

As it is now we have the totally unsatisfactory situation whereby in the case of two people with the same disability and circumstances ,one can receive an accommodation package whilst the other does not.

This random unfair distribution of dollars needs to end and be replaced by a substantially increased amount of funds available to all who needs it.

Thinking and acting outside the limiting square of bureacracys mentality needs to occur.

Two people with the same disability are still two different people with differing emotional, physical and social requirements.

The taxi voucher scheme is an example of limiting a disabled persons rights. There should be no requirement as to why a person with a disability wishes to hire a taxi. whether it is for social, educational, medical reasons etc is discrimination and an infringement on a member of the community's rights. For the non disabled in our community we are not .required to state reason for travel. A voucher user has every right to use that trip for whatever purpose they need it for.it should not have to fit into boxes of education, medical etc.

This is but one frustrating example of making a frustratingly difficult life unnecessarily even more frustrating.

The limit of vouchers in this city of Canberra is another hugely infuriating frustration.

For most severely disabled people getting about on a bus service which has very limited wheelchair access is not an option as much as we would like it to be. Sydney is a good example of where buses try their upmost to cater for wheelchair travellers. However here in Canberra where lack of public

transport options seriously impact on a disabled persons right to participate within their community, we are forced to rely on an unreliable ,expensive and inadequate taxi service. the frustrations for cares and families as well as the disabled person are HUGE. we ourselves after arriving from Qld to Canberra by plane arrived to be told by the taxi company that they in fact did not service the airport with maxi taxis. we were left with the only other choice at 9pm to ring someone we knew in town to pick us up in their truck. An appalling situation. and one we went to the media about.

It's as if certain members of the public service industry do not expect people with severe physical disabilities to have a normal functioning intelligent brain and who have desires like 'normal 'people and in fact, are prepared to go to extraordinary inconvenience to themselves just to be able to partake in normal life activity as far as they are able, this 'able 'is so often restricted by the mentality of others who are the very people supposed to be enabling them to become more able.

In our family's case the expenses(not to mention any of the above emotions and exhaustion) of maintaining a life for our physically disabled son for 40yrs have been, and remain, huge.

The disability pension and other packages we have received (only through fighting and by parliamentarians taking up our fight on our behalf) still come far from what is required to enable our son to live to his full potential. It comes nowhere near covering his daily living expenses. Yet without it obviously we would be like many other Canberran families who are victims of this afore- mentioned ad-hoc arrangement. and we wouldn't survive.

Wheelchair repairs, and replacements, specialized seating re fitted every few years, incontinence aids, taxis and personal clothing requirements are just some of the added costs we find ourselves annually approximately \$10,000.00 out of pocket. we are in our 60' sand do not know when we've gone whether this will be able to be continued .It makes looking ahead hugely scary for us and so many families in similar predicaments.

Specialized wheelchair seating clinics in the past have been a nightmare of frustration for families and therapists alike. It took 4 years at one point for our sons wheelchair to be completed. Suicide was on my mind during those nightmare days. Fortunately therapists became counsellors and advocates on our behalf and our son suffered but made it through the unacceptable wait of sitting 4years in an ill fitting chair. Imagine sitting in an airline seat or similar for 12hrs a day 365 days of the year for 4 years WITHOUT being able to move ones own body to try to alleviate the discomfort OR being able to speak to tell of your frustration. Such was his 4years.

I could go on .However looking back is pointless. We need to look ahead and not continue making the same mistakes through ignorance, indifference and imposed red tape.

PLEASE let's have change.

Disability happens to anyone at anytime .It is indiscriminate. It hits the wealthy as well as the poor .

We MUST have a system that is equitable and tailored to the needs of each individual.