27 June 2008

Committee Secretary Standing Committee on Family, Community, Housing and Youth PO Box 6021 House of Representatives Parliament House CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's enquiry into Better Support for Carers.

My situation as a carer

Financial. I have very much appreciated the annual bonus from the Howard Government and suggest that it be maintained in that form and indexed in some way so that it keeps up with the cost of living.

Social. I feel socially disadvantaged because of the care I have shown over the last 21 years to my sister who requires 24 hour care and is intellectually as well as physically handicapped. People can't help asking probing questions that are none of their business but nevertheless are upsetting.

Proof of condition. I have often been asked to provide evidence of the state of her intellectual disability. She was assessed by a psychiatrist in the psychiatric ward of Wagga base Hospital and more recently underwent an assessment by Department of Ageing, Disability and Home Care (DADHC) for her eligibility for respite care. Both ratings were mild to severe. The problems I come against are in the proof of this, as I have no official form that I can show and the continual doubt whether the condition has changed when I know full well that it won't change as she was brain damaged at birth and she has been no different throughout her life, being aged 55 now.

Legal issues. My sister suffers also from a condition not unlike Bipolar, where she can change moods in an instant through anger, excitement, sadness and being placid. She can become very aggressive very quickly and is capably of "king hitting" someone. If I try to stop her, the law is against me as people and the law are likely to see the situation that I am trying to control as being aggression by me! I am in constant fear of legal outrage against me.

Care. I give my sister the best possible care and attention constantly. She goes out once a week for coffee for an hour with Baptist Community Services and again for three hours twice a month for lunch and bingo, this being funded by Northcott.

Respite care. There is no respite care available in this town for my sister. Northcott Disability Services and DADHC will have a facility available soon in Wagga Wagga for which my sister has been deemed eligible. Local support centres (Nursing Home, Hospital, Health Centre and Day Care) have all rejected her on the grounds of what I see as ridiculous and hypocritical excuses.

Proof of my role. As my sister does not read or write and cannot understand much, I am often queried as to my authority. There should be a simple way around this. My husband of 6 years also plays a role in her care and would also benefit from an authority to act on her behalf without a myriad of questions.

Concessions. It would be of great help for my sister to be given a concession card for free public transport to avoid all the questions that I get asked. She is going in to hospital in November 2008 for a knee replacement operation as her very caring orthopaedic specialist believes she won't be able to walk for too much longer. She will require extensive rehabilitation and I will need to stay near her during her hospitalization. A concession for my accommodation would somewhat alleviate the financial burden of this on me.

Medical travel allowance. I often have to take my sister to Wagga and Canberra for medical appointments and a local hydrotherapist who is out of town and do not get any concession for the cost of travel which is in my own vehicle.

Thank you for taking my views into consideration as part of the committee's inquiry. I look forward to reviewing any recommendations you make to improve the life of carers in Australia.

Yours Sincerely

Jeanette