

22 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 Inquiry into Better Support for Carers.

My husband, 17year old daughter and I are carers of our severely disabled 14year old son. He has quadriplegic cerebral palsy, this being a severe physical disability, he has a moderate intellectual disability and he also suffers from gran mal epileptic seizures. His multiple disabilities require constant supervision, full personal care and he is unable to be left unattended.

We struggled for a few years with my husband working full time, with myself receiving the carers pension (not a full pension as my husbands low income cut the pension down), this made life difficult so at the cost of not looking after our son as well as we would like I returned to full time employment to help meet the costs in running our household and raising our children. A part time job would not have met these needs financially.

The main issues facing our family at the moment are;

- **out of school care, (afternoon's between school finishing and work finishing).**
- **school holiday care.**
- **the stress caused to us by continually having time off work to attend to his medical needs and to care for his needs.**
- **the financial strain for his complex medical needs, specialized appliances and travel to see medical specialists.**
- **the uncertainty of his long term well being and care if we become unable to care for him and ultimately his future after we die.**

There is no out of school hour care available to my son in the area were we live, either after School or during school holidays. I have approached DADAC, Life without Barriers, Local Council (who provides out of school hours care for children to the age of 12 years) and other organisations to find assistance. Respite services will not help us as this service does not cater for 'baby sitting' as we are working and not gaining respite. Neither government funded bodies would take this on as their responsibility and I was even advised by the head of our DADAC to "employ someone to look after him" or leave work.

This leaves my husband and me to care for our son at the risk of loosing our full time work. If this was to happen we would need to return to the Carers Pension at a cost to the government and run the risk of major financial hardship and loosing our home.

I whole heartily feel more assistance should be given to Carers who work to retain their employment and this problem should not be met by the private enterprise employer. For the Carers who cannot work a basic full time wage should be provided. This is not a 9 to 5 job and no holidays or sick days are able to be taken.

The things that stress me the most about being a Carer is loosing the security of our home if my husband and/or I were to loose our paid employment as the Government pension would not come close to paying our mortgage and the cost of living as well as our son's medical and specialist appliance expenses.

Our final concern is the well being of our son when we are unable to care for him, because we are too old, frail or injured, or one or both of us die. The government has started to recognise care for disabled people however the need is a big one and this is of major concern for my husband and myself as his sibling should not be responsible for his care, personally or financially and have to go through the problems of being a carer.

For our son there is no cure, no long term improvement and no hope that he will be able to function in a normal environment in the real world. At best he will need constant personal care, strong supervision and a guiding gentle hand for the rest of his life. He will need to be supported in some form of supported living where these needs can me meet. We can only do this for so long before our age and frailty will force him out of his home.

The needs of these people must be considered, they are unable in most cases to support themselves or advocate on their own behalf, this inquiry needs to put their needs first.

Yours truly,

Glen
Donna