

Submission No. 428  
(Inq into better support for carers)

A.O.C. 2/7/08

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Secretary  
Inquiry into better support for carers  
Standing committee on family, community, housing and youth  
P.O.Box 6021  
House of Representatives  
Parliament House  
Canberra ACT 2600

Dear Secretary,

I would like to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers. Taking into consideration your terms of reference I would like to provide the following information.

**The role and contribution of carers in society and how this should be recognised;**

- I provide care for our nearly 18 year old son Ryan who has multiple disabilities and is legally blind and for my husband Garth who is also on a Disability Pension and suffers from severe depression.
- For Ryan to attend school I have had to organise many supports that other parents don't have to such as the Transport department and the Education Department to support Ryan to travel to and from school by Taxi. Ryan travels for approx one hour each way every day. During his school years this has been reviewed at least four or five times and nothing has changed for Ryan the only thing that has changed is Government policy and this has impacted on our family in a negative way, as we also have three other children who are all younger than Ryan, and for many years we had four children at three different schools. As Ryan travels to and from school in a taxi we have had different taxi drivers morning and night and they all get lost or don't arrive to pick him up, and this causes Ryan to become extremely frustrated as he cannot communicate. When he gets out of the taxi he bites, kicks and punches me. I also have to worry about Ryan's safety with the drivers as I don't know them, and

how they drive, if they have been convicted of any crimes. Ryan also has to travel with other students who also have high needs and attend the Special School. Garth and I also have a daughter Cody who is gifted and talented and has been grade skipped so this has caused many frustrations in her education.

- I look after all Ryan's financial, medical appointments, dietary requirements, provide a safe, secure and loving environment for him to grow and develop in, act on his behalf and correspond to all his mail as well as look after all my affairs and Garth's, our teenage children, take them to and from sport, plus all the other demands of life and raising children.
- Ryan requires specialised equipment to be able to maintain some independence such as a special spoon, fork, bowl, shower chair and many other items that are extremely over priced. Ryan's spoon is \$40.00 and how much are normal spoons? These are items of need not WANT. There is a subsidy called the Medical Aides Subsidy Scheme (MASS) but there are many items that are not covered by it and the gap is too large. There are many issues in the caring role such as the Patient Travel Scheme and the cost of travelling to obtain Specialists care.

Summing up Most Carers don't want recognition just our bills paid, not to be treated like dole bludgers and second rate citizens, and to be paid a decent wage.

**The Barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;**

- Carers are looked at as second or third class people due to low income.
- Many carers don't have any social life or contact with people of similar age.
- We cannot participate in any work as what employer is going to let us commence work when we can and finish when we have to. ( sometimes we have to leave early to pick kids up due to illness or behaviour problems) I was a qualified nurse before I had Ryan and have not been able to work since and when I did go back to work Garth looked after Ryan and in the middle of my shift Garth was admitted to hospital with anxiety and chest pain.
- If we do work we are penalised so much so that it isn't worth us going to work. Centre link takes a percentage of our wage so we are never able to get on top of our bills. We have had to sell many of our possessions in the past just to pay large unforeseen bills these are needs not wants.
- Carers need part time work for maintaining social skills, and adult conversations to remain sane.

- You talk about skills shortage maybe if you raise the amount that is earned from part-time work that doesn't affect the pension/dole this would help alleviate some of the financial burden on carers.
- Carers come from all walks of life and from different education levels and they have skills that could be utilised in the work force and in the community even if its one day a week.
- Carers don't have the resources or funds to set up superannuation so therefore the government will always be supporting us.

**The practical measures required to better support carers, including key priorities for action;**

- I guess that the easy answer is more funds but who has the bucket of money to do it?
- Carers need either a wage that they can use so that they can plan for their retirement
- Carer respite and outings for the family
- Knowledge that when the carer dies that the person in care will be looked after Not in a nursing home.
- Social outings for younger carers with other younger carers of the same age
- Younger carers are often teased about their caring role so they may need access to a councillor
- Recognition in the community of younger carers ( maybe a special day)

In an overview of our situation I would like to ask why we have to advocate for all our son's needs. I have to beg and plead for things such as his education, medical needs, specialist care, funding to support him, and all I get is a headache and a higher dose of anti depressants. I don't have to advocate for my other children to attend school. It appears to me that if you are Different (have different needs such as gifted or require special schooling) you have to continually fight for your rights for your children. My husband is also on a disability pension and I am his carer and my second oldest son who is still at school and currently in year 11 is a younger carer for our son Ryan. It is perceived in the community that to be a carer is an easy job and anyone can do it. I wish that the community would take more of a caring role and help the true carers to care for there loved one, whether it is a friend or family member. We are not DOLE BLUDGERS as we work 24 hrs a day 7 days a week and don't complain. When do we, the carers, get a chance to do anything for ourselves such as go to the doctors, shopping for clothes, or buying medication for ourselves. Most of the time we carers go without many basic items, and even put other peoples needs before ours so that they can have there necessities of life.

I would like to congratulate the government for considering the rights and needs of carers but I worry about what is going to be done with the submissions that we have supplied to you. Is anything going to change?

Another point is how much time do you think that carers have to submit submissions like this, you haven't really given us much time as our caring role is full on. Most of us are extremely tired and don't have the mental capacity to sit and think about something like this, (the submission), in future you need to give us more time being at least 3 or 4 months.

Kind regards

Michelle