

Submission No. 650

(Inq into better support for carers)

A.O.C. 8/7/08

30 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

The following is my submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's inquiry into Better Support for Carers.

The role and contribution that carers make to society is hidden from the eyes of most people. The role I play within the framework of life is that of a care giver to my disabled son who has Cerebral Palsy and mild autism. It is the only role that I have been able to play for fourteen and a half years due to being a sole parent to him and my other son and my own failing physical health. The contribution made by myself to our society is beyond compensation. I have saved our economy thousands of dollars and sacrificed my own dreams for my children. I also feel that I don't really contribute to society other than being a carer and mother, but the skills I have learnt from caring and my own life experiences can be reinvested back into society through helping other people when my son is put into full time supported accommodation.

The problems I face day to day are physical health issues cast upon me due to caring. I have developed a stomach ulcer due to stress, fibromyalgia; muscle inflammation that prevents me from doing anything outside my caring role, a degenerative spine condition and depression which are all exacerbated because of caring. I also have to fight and constantly push for equipment, much of my equipment has been outgrown by several years and by the time you receive new equipment it is already half outgrown again or my son's current wheelchair is literally falling apart.

Caring is such a full on job that when you do receive some respite you are too exhausted to do anything social or you have to do the things pertaining to running a household. I struggle every week to pay utility bills, buy groceries, pay for medications and incontinence pads and pay respite bills. After taking all these issues into consideration it doesn't leave any time or money to have a social life.

I feel I am unable to hold a job due to the commitment that caring takes. Caring is a very complex role and the intricacies involved include attending appointments and physical and emotional exhaustion. I need to look after myself first so I can keep caring and do not need the extra stress that having a job could initiate. If I was to work I would like to have a job where I can use my intelligence and life skills not a mundane job like working on a checkout, but as a carer I would not be able to do this sort of job to the best of my ability. Employees are blind to the commitments of caring and need to understand that caring is your priority not loyalty to them or their company.

Unless I receive an individual support package for my son allowing him to be placed into full time care my future holds a grave outcome. The nature of my son's disability and my own health problems mean that one day I may also require a carer and be a burden on the welfare system. My other son deserves

to follow his dreams and work in the IT industry; he has worked hard at school and shouldn't have his future taken away from him.

I find that the following situations surrounding my caring role cause me the most stress. I have to continue to be a carer regardless of how sick I get. I have to battle over receiving the basic equipment that I need; it makes a huge impact on your life if you have the appropriate equipment. I worry about having enough money to buy groceries or pay other bills. I don't have the privacy that others take for granted I currently have two people each morning, two people each afternoon and another person each evening, Monday to Friday come into my home. You feel you live under a microscope and don't have much privacy, I also feel judged by new people who may not agree with your lifestyle or who walk into a stress offload. I also reach stress offload if I have had a busy week and have to do several things at once like changing a soiled pad when you are in the middle of cooking dinner.

I need to receive an individual support package and feel that putting my son into full time supported accommodation at Hartley Lifecare when he reaches sixteen would help me the most. In the next eighteen months I need to be able to access more supported respite out of home because my body is becoming more of a curse to me, I am unable to continue down the road I am travelling. I have been able to access emergency respite at Hartley Lifecare which has helped me to keep my head above water. I require a van fitted with a hoist and anchors to transport my son while in his wheelchair, he is fourteen and a half and I am currently lifting him in and out of a car. This lifting in particular causes my back and neck aggravation and in turn induces much pain. A van would make a huge impact on my caring role making it easier to take my son out, not just to appointments but also to social outings.

More support from the government is needed in the form of increased funding for respite and individual support packages. Increased Centrelink payments because what we receive now doesn't pay for all our expenses and an increased earnings threshold for carers before it affects our payments. The community needs to become more aware that carers are people too and we have a place in society. The last suggestion that I will touch on involves carers who are no longer able to care for their child under eighteen due to ill health. I would like to see some funding provided for these children and places made available for them other than carers having to relinquish their parental rights over to family services. Carers should not be placed into the same basket as parents who neglect and abuse their children; we really do deserve to be treated as valued citizens not criminals.

I would like to thank you for taking the time to consider my points as part of your inquiry. I wait in expectation for the Committee's positive response to improve mine and fellow carer's lives.