

A.O.C 14/7/08

30th June 2008

Submission No. 720
(Inq into better support for carers)

Secretary
Inquiry into Better Support for Carers
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 role as a carer is to safeguard my son's lifestyle to live happily, healthily and safely, as a 31 year old adult with Down Syndrome who needs professional supervision in his daily life. I contribute to society by having organized his enrolments at his day respite centers in the local area to enhance and enrich his quality of life. My son's disability pension is mainly used to pay for the day respite expenses, which also gives me the freedom to do some part-time work. I employ a casual carer in the mornings at my own expense to supervise my son's hygiene, breakfast and safety issues before he leaves for his day respite centers.

My caring role affects my life, as I am not free to return to work full time as the cost for me to employ a carer outweighs the benefits and income of full time work. At my age of 60 years I get very frustrated with the ongoing care of an adult who at times has the mentality of 4 year old child. I am unable to take a long break as the most I have had on offer for respite from my son has been 3 nights separation at a time, My son is unable to concentrate more than 15 minutes at most tasks which makes him limited in an employment role. I therefore have difficulty in leaving him alone mornings or afternoons or at weekends as he is capable of going to local shops and stealing coca -cola abundantly unless supervised. On many occasions, my son has been reported to the police who have difficulty and sympathy towards the stealing. Therefore, I find I cannot allow him to go freely anywhere without supervision which nearly always remains by responsibility. I live with padlocks on fridges and the pantry, as he is unable to occupy himself without overeating due to his limited concentration levels, which lead to binge eating and drinking juice, cola or milk. Money can never be left unattended, as this becomes an easy target to meet his obsessive behaviour resulting in some form of isolation as our circle of friends has diminished, as many people cannot tolerate such behaviour. My anxiety is often enhanced and I suffer migraine headaches and have attended an anger management programme to try to overcome some of the frustration.

I think these needs should be recognized by offering immediate assistance with group housing to meet parents' needs. I would love to have my son supported in a home nearby, housing 2 or 3 adults with a carer assisting daily routines. He does not have any funding from the State but with a combined saving on 3 carers' pensions and 3 carers' allowances this funding could surely be transferred to supporting 2 or 3 people with disability in supported accommodation using their combined disability pensions to pay towards the rent and other expenses.

The barriers I experience as a carer in retaining employment are that I find it difficult financially because I am unable to earn enough money to pay for a carer in my own home for when I leave for work or return in the evening or at weekends, without affecting my carers pension. The practical measures that would better support me are that my son has a supported lifestyle in separate accommodation to myself, this support would assist me to contribute to society by paying tax on full employment.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing the recommendations you make in order to improve support for carers.

Yours sincerely,

Barbara Ms (Mother of Stephen)