

Submission No. 445  
(Inq into better support for carers)

A.O.C. 2/7/08

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 Standing Committee's Inquiry into Better Support for Carers.

I am in a situation where I care for my younger brother who has Down Syndrome. I am 59 and he is 47 years of age. My brother shares a rural property with my husband and I, and has his own home on the property. He is mildly intellectually disabled and independent to large degree, but still requires a substantial amount of our time and resources.

I am aware there is assistance offered for carers of people who are more disabled (most deservedly) but I believe the mildly disabled group should not be ignored. At this stage the system does not recognise me as a carer.

**Financial issues:**

My brother struggles financially on the disability pension, even though he sticks to a budget and is careful with his spending. There are certainly no extravagances in his life, like eating out or having a coffee at a cafe. Items that others buy spasmodically like clothing, manchester, replacement of electrical appliances etc are a real hardship. My husband and I help him out with such items. For him to go on a holiday also requires some subsidy from us, and even then it is a camping holiday. He is grateful for such help, but I know he wishes he wasn't in the position of needing extra financial help. We contribute to give him a better quality of life (ie, still not close to what would be considered 'normal') but it is also a financial stretch for us.

I believe some consideration should be given to financially assisting either the cared-for or the carers for the bigger financial outlays in the lives of people with disabilities. The pension is not enough, putting the burden to carers.

**Prop-up assistance:**

My husband and I are happy to give my brother any time he needs to sort out his money, make holiday plans, try to find suitable social activities, find second-hand items that he can afford, cook him meals, help in his home, explain issues, leisure activities, plan shopping lists, correspond and make phone calls on his behalf, teach him independent living skills, sort out messes he gets

himself into (socially and financially) etc etc. The list goes on. As you can imagine this is a drain on us, it affects our relationship husband/wife relationship at times, and means we can't leave for extended periods to holiday.

I believe some recognition of time spent and the need for break should be forthcoming. After all, keeping people with disabilities in their homes is of huge benefit to Governments. This has been recognised with aged people through the HACC Scheme. My brother's needs are quite comparable to those of our elderly mother in terms of support. Perhaps a similar scheme could be implemented where disabled people can be eligible, or even purchase, services which can enhance their lifestyle and level of independence.

**Aging:**

Down Syndrome people have a life expectancy of about 20 years less than for other white Australians. At 47 he is starting to show signs of aging and we anticipate this may accelerate over the coming years. This is of concern as we age, too. Will we still have the energy to support him, what sort of additional support will he need, will he become sick (with heart and lung weaknesses), what will happen if we are not able or here to support him? Does the aged care system cater for this 20 year difference?

I have been disappointed in not being able to find information about the aging process with Down Syndrome people. Such information would be useful, along with some reassurance that my role as a carer will be recognised at some stage. Information about what services are available should the cared-for require more assistance, would also be of comfort.

Many people in this country are interested in this Inquiry, and await the outcomes with anticipation. I hope we are not disappointed. I hope the outcomes can improve the lives of people with disabilities through giving carers more support and recognition.

Yours sincerely

Jenny  
29 June 2008