

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600

Submission No. 765

(Inq into better support for carers)

Dear Secretary

AOC 15/7/08

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.

I am submitting to the Inquiry because...

I believe that family carers have had far too much pressure placed upon them to provide the bulk of the care required for the person they care for. Care in the community should not just mean care within the family, which is what it is in so many situations. The government would not be spending a lot more money if it could provide more permanent accommodation for people with a disability. It is obscene that there are so many ageing family carers in the community who do not know what will happen to their child if their carer is no longer able to take responsibility for their care. There needs to be some positive response to the many desperate situations which are constantly being portrayed in the media. It is insulting for family carers to be given token payments each year which are seen by society to be valuable. It is the carers who have value and in particular, the mothers who are often left by their husbands/partners to care for their disabled child/ren alone. I am the mother of a child with severe multiple disabilities and I have a voice, as I am educated and work in the field of disability. I wish to speak on behalf of the multiple carers in our community who are too exhausted/have a disability themselves/ill/unable to speak English/angry to speak for themselves.

More information is attached on a separate sheet

1. The role and contribution of carers in society

As a carer, I feel that my role is...

To create the very best opportunities possible for my daughter, who will never walk, talk or interact with people in any way without 24 hour support. Carers should have a stronger voice to let society know how it is. The majority of people have absolutely no concept of what it's like caring for a child who has never developed beyond the 'baby' stage in so many ways.

More information is attached on a separate sheet

2. The barriers to social and economic participation for carers

As a carer, I face the following problems ...

I will never be able to go to work or go anywhere at all, without arranging for someone to be responsible for my daughter's care. She will never be able to left alone, work, catch public transport, feed, dress or toilet herself. This means that my husband and I have to organize care for her even if we wanted to go for a walk around the block together and leave her at home for 5 minutes. We can never go out at night after 6.30pm, even if we wanted to take her out, without organizing care, as she is so exhausted by the end of the day (due to her condition and medication required for epilepsy) that she needs to be in bed by 6.30pm. Her care needs have meant that my husband has had to forego possible promotions at work so

he can be at home to care for her if I cannot be at home due to other commitments. Friends have stopped asking us out as it all seems to difficult, in terms of physical ccess for where they might be going, or if it's too late notice to organize a care worker. We are unable to take our daughter anywhere for the weekend unless it is wheelchair accessible. It seems like it's easier just for people not to ask rather than make special arrangements.

More information is attached on a separate sheet

3. The practical measures required to better support carers

As a carer, I need help with ...

The whole of society needs to better support people with disabilities and their carers. What's required is more community support through volunteers as well as paid workers taking part in more creative, innovative programs which truly include people with a disability into the community. Exposure to the community is not the same as inclusion. It would also help our situation if we had some idea of what the future holds. Our daughter is 13 now and we would like to know that there would be an appropriate permanent placement for her once she (and we) were ready for her to live independently with support. The current situation is so depressing, making us feel she will be with us until we are physically and emotionally past the point of wanting her with us.

More information is attached on a separate sheet

4. Strategies to assist carers to access opportunities and choices

I think the Government can better help carers by ...

Providing more family-friendly work policies – eg. More paid carer's leave, especially if the person you care for requires hospitalization. Increasing the Carer Allowance & Bonus to help cover the additional expenses of caring for someone who will never be able to earn a living, let alone take up a part-time job while at school. The cost of fuel to take your child to the many medical and therapy appointments, the cost of medications, additional utilities costs from constant washing of clothes due to incontinence. This all adds up to enormous additional financial stress.

More information is attached on a separate sheet

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

Yours sincerely

Julie

Print your name

28/6/08

Date