

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth

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.

I am submitting to the Inquiry because...

I am carer to my 17 year old son [redacted] who has Down's Syndrome and Autism as well as a significant developmental delay. He does not possess any "life skills". He requires full assistance with feeding, dressing, showering & toileting (wears nappies full time).

[redacted] has some obsessive behaviours related his Autism spectrum disorder.

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 care for my disabled son as well as my other 2 children. This is a 24 hour 7 day a week Commitment. A typical day entails: waking at 6.30 am, showering, dressing and feeding breakfast to [redacted] preparing his school bag and putting him on the school bus by 7.20am. then I normally wash [redacted] bedding and Pyjamas as they are normally "soiled" during the night. [redacted] arrives home from school at 4pm and expects dinner on the table as soon as he walks through the door (this is one of his obsessive behaviours) otherwise I will have to deal with a tantrum. After dinner I put [redacted] on the toilet (hoping for a success) after which I shower him and dress him. The weekends are particularly difficult as he is home with us during the day and requires a huge amount of attention and care.

I take care of him day in and day out because I love him, however to stay on top of this demanding routine I need a regular break from caring.

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 ...

Finding employment that will fit in with my carer's role has been difficult, even with the most considerate of employers, the biggest issue being that there is no care available during the school holidays, there are no school holiday programs available and the respite facilities offer very little as they are placed under a huge demand. (there are 12 weeks of school holidays and most employers will not give that much time off).

The other huge problem is social aspect of life (virtually non-existent). My son dislikes social situations and hates crowds, therefore any form of outing excludes [REDACTED] this means that my other 2 sons and I usually miss out on attending activities such as school plays, sports days and childrens' birthdays unless we have organised "respite" for those particular days

Please help us to have more access to respite, every time I put in a request, the response is always the same "the demand is so huge that we cannot give everyone the amount of respite they request" more funds need to be put in for the building of more facilities.

More information is attached on a separate sheet

3. The practical measures required to better support carers

As a carer, I need help with ...

Access to facility based respite on a regular basis eg. every weekend and occasional week long respite. More funds need to be put in for the building of more facilities.

Access to funds to help with the cost of continence products.

Access to school holiday programs for children with a disability.

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 access to facility based respite, funds to build more housing facilities (with an adequate amount of respite, carers will be able to look after their family members at home for longer.

. Access to permanent accommodation for people with a disability to assist older carers who no longer are able to look after their family member (the current situation of having to be put on a waiting list, in some cases, for years, is not acceptable)

. continue to pay the carer bonus as this money is normally used assist with the purchase of continence products and pay for respite.

. increase the means test for "Carer Payment" for parents looking after their disabled child.

There are many parents (usually mums) who are forced to give up their employment in order to look after their disabled child. This loss of income has a huge financial impact on many families who in many cases have other children to put through school...many of these families struggle to make ends meet.

. The stay at home carer parent should be entitled to a pension to cover a percentage of their loss of income.

*** Access to regular respite and a better income support structure for parents of a child with a disability to assist families.**

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

Print your name

SOPHIE

Date

12 JUNE 2008
