

26th June 2008

Antonella

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

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 do not wish any confidential information concerning my identity to be published with any part of this submission.**

As a Carer, I feel that my role is almost beyond human ability at times. I feel like I have to fulfil all of life's normal roles "mother", "wife", "daughter", "homemaker", "worker" etc which are all challenging in themselves but then in addition to (and overlaying and impacting on all of these roles) is that of "carer". At times I feel I am physically, emotionally, financially, spiritually pushed to the very limits. My role as carer is all-consuming sometimes leaving very little of me for myself.

I face the following problems;

- Not being able to do the simple normal everyday things that are taken for granted in today's society. Doing things as a family, shopping, visiting friends and family attending events like weddings and other social occasions as a family, seeing a movie or having dinner together, going on a family holiday. These things are the very glue that hold families and relationships together so they are all affected.
- Doing things as a couple – being carers puts an extreme strain on marital relationships
- The role of carer takes away your ability to earn income in many ways and then adds the financial burden in terms of the costs associated with the person being cared for. For example when my son was diagnosed with autism I had to leave my employment but then had to find the money to fund a \$30,000 a year home-based ABA program in addition to many other costs we now faced and continue to face.

I need help with;

- Respite and Child care – especially suitable after school programs like those that are offered at mainstream schools. This would greatly help with regard to earning income- even when it is in home-based employment- by extending the paid working hours available to carers.

- More respite programs which offer the individual suitable activities and stimulation e.g. Villa Maria Flexi Respite in Melbourne, a fantastic program which should be extended.
- Financial/Medicare support in terms of interventions, which include biomedical, psychology speech therapy etc.
- Suitable regular programs outside of school hours for children with autism and other disabilities. E.g. mainstream children play sport, learn musical instruments etc. There should be programs for children with disabilities to participate in similar programs. This would aid in their growth and development, extend the feeling of "normality" which so many families in this situation crave.

I think the Government can better help Carers by;

- **Providing them with the reassurance that their loved ones will be cared for compassionately and respectfully and be allowed to live happy and fulfilling lives when their parents or other primary carers are no longer able to look after them or are no longer here.** Every parent I know who has a child with a disability has had sleepless nights worrying about what will happen to their child when they are gone. There should be many different options and choices in the type of residences and care available for our children when we are gone.
- Providing more respite options for carers. What exists is good and there are many wonderful and compassionate people working in this field but there are not enough respite facilities or hours.
- Providing assistance with all the above and building some sort of relief into the tax system so parents and others can better support those they are caring for. For example special investments for people with disabilities and tax deductions/exemptions for items which they require. Parents who wish to invest in housing or accommodation for their disabled children should be given special consideration with regard to capital gains taxes etc. By giving us the ability to better support and invest for our children the less they will have to rely on government support in the future.
- I think what carers need most is assistance and support in being able to have a LIFE beyond their role as carer.

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

Antonella