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Submission No. 1196

(Inq into better support for carers)

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 am submitting to the Inquiry because

As carers we have first hand experience, information and relevant knowledge about the difficulties, the lifestyle, the fears, the anxious times experienced by carers. We are cognisant of the lack of support and appropriate recognition for carers within our community and by our government and its support agencies.

1. The role and contribution of carers in society

As a carer, I feel that my role is

of great importance and is undervalued. (We deserve on Order of Australia Medal !!!!!!!)
Many years ago children with a disability would have been institutionalised with the \$ cost being borne by Governments. As these children/adults are now cared for at home, the \$ cost is now borne by carers. There are also emotional and physical costs on the family as it is a 24/7 (24 hours, 7 days/week) role. Our role necessitates that we provide for him, educate him, socialise him, attempt to enhance his skills and opportunities, so that he can play an inclusive role in his own local community; that he can live with dignity and be treated with respect. To develop and implement a plan which will provide for the care of our son after our death.

2. The barriers to social and economic participation for carers

As a carer, I face the following problems

- Loss of potential earnings, due to being a full time carer, and the long term implications of no subsequent savings or superannuation.
- Dealing with government and other support agencies.
- Difficulties with long waiting lists.
- Lack of response (written & verbal) from support agencies.
- Locating the appropriate personnel.
- Caring is a 24/7 role.
- Agencies telling you that you need counselling, when all we need is appropriate support, which in turn will reduce stress levels, depression and anxiety.
- Repeatedly completing forms and surveys to maintain funding and services, when our son's disability will not change and his needs will only ever increase.

3. The practical measures required to better support carers

As a carer, I need help with

- Accessing someone who has a complete understanding and knowledge of who is responsible for what, what services we can access and who is the appropriate person to contact.
- Increasing the effectiveness and efficiency of service providers.
- Accessing transport; Government and other support agencies should provide funding for programs and activities as a package which includes transport.
- Provision of better support for carers to plan for the future and retirement (Including the preparation of wills).
- Flexibility of employment as a carer.
- Direct increased financial support.

4. Strategies to assist carers to access opportunities and choices

I think the Government can better help carers by

- Increased funding specifically for transport, to provide better accessibility to social programs and activities. Participation in social programs and activities, equates to respite to carers. No participation → no respite.
- Increased funding to reduce waiting lists.
- Cease shared funding for programs and activities by local/state/federal governments. Currently this creates a 'blame' game.
- Providing much greater residential support, so we can access it and integrate those we care for into homes well before we die.
- Don't make everything so hard for us.

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

Yours sincerely,

Stuart and Heather

04 July 2008