Submission No. 331
(Inq into better support for carers)
A.O.C. 1/7/08

**From:** Graham & May
**Sent:** Tuesday, 24 June 2008
**To:** Committee, FCHY (REPS)
**Subject:** Submission for the Inquiry into Better Support for Carers

***Tuesday, June 24, 2008***

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

I am a mother of four children aged approximately 12 to 6 years old, the youngest child with severe disability exhibiting most of the characteristic symptoms of Rett Syndrome.

Over the last 5 years I have struggled with what seemed at times an insurmountable battle to be taken seriously as a Carer of a disabled child, instead of being viewed as a sleep-deprived mother of a difficult baby whilst trying to manage a large family.

*I have been utterly discouraged by…*

- The lack of support for disabled children under 6 years of age in areas of early intervention and respite.
- Being informed of many recreation opportunities but then deemed ineligible because of the severity of my child's disability, or the activity is not age-appropriate.
- Receiving no practical guide through the early stages of diagnosis.
- Being offered antidepressant medication instead of practical help or support (e.g. Someone to clean my home so I can catch up on lost sleep).
- A bitter and prolonged fight for case management.
- The utter change of life with loss of all familiar support & friendship.

*I can't fully participate in social life because …*

- I am exhausted by the sheer amount of time consumed by disability and the need to balance the needs of all members of the family.
- Most people have no appreciation of what it means to have a disabled child and misunderstand inability to participate in activities *they* take for granted as lack of interest or lack of friendship in us. Our disabled child is then viewed as an inconvenience, or the parents as being overprotective and child-consumed, or simply we are not worth the bother.

*I face the following problems …*

- The need for case management so I can be acknowledged when I require funding and support, and paying for the privilege of having a case manager but enjoying little benefit. The time and work involved in research of services, follow-up and management of my child I have to do myself.

- The time spent in caring for the needs of my disabled child and 'case management' applications, follow-up, etc. is not counterbalanced by funding for housekeeping, or adequate respite so as to be able to spend time with my spouse and children.

*The things that stress me the most about being a Carer are …*

- The fear of encouraging resentment in natural sibling rivalry from the unbalanced percentage of time I spend on my youngest child.
- Feeling helpless to be as active a participant or advocate in my other children's lives.
- Being humiliated by the requirement to be unnaturally aggressive, rude and demanding before attracting any attention or support.

*I think the Government can better help Carers by …*

- Sorting out the ridiculous maze of service and funding providers.
- Providing a uniform approach of cooperation and communication between service providers and the medical field.
- Providing dedicated disability social workers or the like from day one to hand-hold or guide shell-shocked parents/carers, organising practical tasks for them that their traumatised reasoning cannot manage instead of referring them to 'empowering groups' to take on information they cannot assimilate. A reasonable program of weaning these parents to stand on their own strength and knowledge can be introduced once the shock of the early YEARS (not weeks or months) of accepting diagnosis/prognosis begins to loose its paralysis.

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
***May***