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Submission No. 856  
(Inq into better support for carers)

4 July 2008

Committee Secretary  
Standing Committee on Family, Community,  
Housing and Youth  
House of Representatives  
Parliament House  
CANBERRA ACT 2600

Dear Secretary

I would like to make a submission to the Inquiry into Better Support for Carers.

My husband and I are carers for our 16 year old son who has severe multiple disabilities. He has spastic quadriplegia, is legally blind, has no speech, is incontinent and has epilepsy. He needs twenty four hour care and we are unable to leave him alone. Unfortunately we have no family support.

My husband has given up trying to work and is a full-time carer while I work 4 days a week in an administrative position which isn't at a high salary level. After a day's work I come home to more work and after eating dinner and getting our son fed, showered and into bed, I have about another hour to catch up on domestic jobs before crashing out exhausted into bed. I am blessed with a husband who loves to cook and he produces some great meals every evening for us. This isn't something we can maintain for ever

We are both getting on in years, I'm 53 and my husband 61 and am finding our bodies are showing the physical toll of 16 years of intense manual handling. Shoulders, backs, necks, and arms get strained, hurt and damaged. We become exhausted, depressed and anxious. We cannot maintain the level of care we provide forever.

We need help to plan for the future and this can be hard to initiate and get your head around when you are busy and exhausted every day. We try not to worry about our son's future but it's hard not to feel depressed when you don't see many options for a happy future for him and us as a family. All we see ahead is lifelong caring job until we drop dead. I worry that he will not be looked after with love, care and dignity when we are no longer around. He will probably become a ward of the State (as we have no relatives to take over the caring role), which makes me feel even more depressed about his future. The recent findings regarding the neglect and abuse of children under State care makes me sometimes wonder if it would be better for our

son to die happy and loved while we are still around, rather than a future that would appear bleak, lonely and neglected.

What we see as our highest need and priority in the next 5 years is to establish our son in good supported accommodation, say initially on a part-time basis so as to allow a smooth and stress free transition for all of us. We would like our son to leave home, like normal children eventually do. We know the likelihood of obtaining a new home for our son is zero! There is an extremely long waiting list in our State for supported accommodation and I know that parents in their 70s and 80s are still caring for their disabled children at home. My husband and I won't be able to physically and mentally last the distance if we are still in our current situation by the time we are that old!

I know of only one group house that accommodates 4-5 residents being built in our city, in one year!! At this rate it's going to take centuries to reduce the current waiting list. We think the Government can better help carers by initiating an accommodation building program that can provide for more disabled people living in supported cluster housing. Our son needs 24 hour care and our needs are not going to be met by small individual houses scattered through the community. Why not look at the option of larger groups of residents or cluster housing, which may give some economy of scale? Our needs are not likely to be met by the current resistance to anything resembling cluster housing as it conjures up the ghost of "institutionalisation".

**I strongly request that the State and Federal Governments pool resources and fund supported accommodation options for disabled people as an urgency.**

Thank you for taking my views into consideration as part of the Committee's inquiry. All the very best in your deliberations.

Yours sincerely

**Sabine**