



Submission No. 321
(Inq into better support for carers)
A.O.C. 30/6/08

20 June 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 and Youth's Inquiry into Better Support for Carers.

Presently I care for 2 family members that have disabilities: a teenage daughter with multiple disabilities, and an adult son with a mental illness. As such I deal with a variety of government and non government agencies and charities, at both State and Federal level.

My first comments are about the differences between states and the way services vary so hugely. I believe this issue has not been tackled by any previous Federal government and needs to be addressed. All states receive funding on a per capita basis so why are the services so very different?

Presently I am on a waiting list for a consultation with the Autism team in Canberra for my daughter and have been told we may be on the list for anything up to a year or longer. Earlier in the year when we had a crisis with my daughter's behavior, we waited 5 weeks for an appointment with a social worker. The wait for a position in School Holiday Care is over a year. And so the list goes on. All services in Canberra, including accommodation for disabled people seem to be in a constant state of crisis. No help seems to be available when needed. And when we are able to access services we have found them so inadequate as to be almost useless. These things impact on our family hugely. Both my husband and I now suffer constant chronic illnesses. We are chronically sleep deprived.

I actually believe that my daughter is more disabled than she should be because services in the ACT have always failed to deliver therapy when needed. When she was a very young child for instance there were no speech therapists available for over a year to visit her special school. Funding constantly ran out for the services of psychologists. Indeed things were so bad that in 1993 therapy services for young disabled children in the ACT were described as the worst in Australia.

I am unable to work because of my daughter's illnesses and school absences and my own health. And even if I did work would be unable to work during school

holidays because of the lack of funding available for care. Like many families in Canberra, our extended families live in other capital cities and would not be able to help with the particular behavior problems we experience with our daughter.

Like many in the community, my husband and I both have aged mothers that are presently needing aged care and nursing home placement, together with our siblings we are finding it extremely difficult to find appropriate nursing home places.

I also have siblings who have mental health illnesses and I have great concerns about their care as they age and need accommodation, the waiting lists for public housing in NSW are very long.

There needs to be a whole of government approach to Aged and Disability and mental health care which includes the needs of

Carers. Neither of my children would have the same quality of life they now have without me caring for them. But the quality of my life is constantly degraded by having to deal with government departments that are badly resourced, and stretched to such an extent that the services that they do offer are of little use to us. I have in the past and will continue to step outside the government system to get services that I think will benefit my daughter in particular, but the financial and emotional costs to my husband and I are huge.

To this I must add the frustration and fear we feel as we approach 60 years of age. We do not begrudge missing out on many benefits we could have had during our working years, such as holidays. We may regret, but do not begrudge the fact that we will never take the gray nomad 'road trip' in our retirement – because we will not have a retirement. But we suffer great pain in the knowledge that in 15 years time, we will be in our 70s with limited capacity to care for our children, who will then be in their 30s, and the realisation that there will be no secure future for them at a standard of living other Australians take for granted.

Yours sincerely

Katrina