

Submission No. 1111

(Inq into better support for carers)

AOC 29/7/08

2nd July, 2008

Committee Secretary,
Inquiry into Better Support for Carers,
House of Representatives Standing Committee on Family,
Community, Housing and Youth,
P.O. Box 6021,
Parliament House,
CANBERRA ACT 2600

Dear Secretary,

We are submitting to the Carers Inquiry because we feel that the role of Carers has been undervalued for far too long. As parents of an 18 year old Autistic son who is totally non-verbal and not toilet trained, and with a very poor intellect although he is very mobile, we felt it important to put our case forward. He has no safety skills and is unable to dress or bath himself. He also has no ability to manage his own finances or able to make his own decisions.

As Carers, we feel that our role is to care for the physical wellbeing of our son, as well as our own and our family's wellbeing – often a huge challenge with restricted access to regular respite facilities. We run a 1,100 acre working farm which is 25 kms from our nearest town. We run 2,500 sheep and have a mixed cropping component as well, which means there are more busy times during the year than quiet. We provide meals for the shearers and do all our own harvesting, which means there are tractors, implements, large harvesting machinery and many large trucks on and around our farm at these times. We have had to take our son out on the farm in summer to move machinery, and sometimes can be away for several hours, which is very challenging in the summer heat.

We have a 21 year old daughter who is in her 2nd year of Uni. She used to be a very good back up for us when she was home, leaving her to supervise while we did jobs around the farm, but now it not that easy. We also have a 15 year old daughter who, despite wanting to help, is overpowered by our son's strength. These 2 daughters have often missed out on 'normal' family holidays or toys, because it's just not possible.

While respite is available in town, there is such a huge waiting list and demand for the service that it is not on a regular basis, which poses huge challenges. Often our day working on the farm, only starts after the school bus run and the taxi collects our son, or alternatively we drive him into the day centre (to save on the cost of taxis), which could be between 9am and 10 am. This is very restrictive because at the end of the day we have to be ready either to meet the taxi at home or be ready to pick him up from the centre by 4pm.

Our day is very much run like clockwork, always watching the time. Completing the mundane jobs of cooking, washing and cleaning also takes a lot of time. Sometimes we have to do a complete change of the bedroom and scrub the carpets due to smearing faeces everywhere except the ceiling! This brings another issue to the fore: Continence products. While there are funds available to assist in the costs of product, needing these day and night puts us way out of pocket and this area needs to be addressed. It's not as if these clients are just lazy, they don't have the intellect to know any different. It's not the 'norm' for parents of adult children having to wipe their bottoms for them and remind them when to toilet. That's what it is for us.

Due to the circumstances listed above, it would be almost impossible to fit in paid employment, even if I would like to. Our mental and physical wellbeing has been stretched to the limit many times, and suffering from depression doesn't make it easy to cope with the everyday challenges as well as paid employment.

Our social network of friends consists of a very small group of people who have been able to cope with the challenges of an Autistic child in their midst. We have had many old friends who have moved on with their lives, finding our situation too hard. There are only a few friends that are comfortable to invite us into their homes. It is often hard to find someone to even ring and talk to or socialise with because everyone else is out working. It can be a very lonely place out there for carers when this happens, only adding to the depression factor.

As Carers, we would love to have more access to regular facility based respite where we know our son was being cared for. We don't expect a lot of money, rather the bricks and mortar in more buildings that could accommodate these clients, to give the parents and families a break from the constancy of the situation. We are sure, that if we did get regular breaks from the demands of caring, the time we spend with our son would be much more valuable for us all. We don't even get to sit down and watch much on T.V. in the evenings because we are always attending to our son and his needs. We have been so sleep deprived over the years, we could sleep for years! Our son was 15 years old before he slept through the night on a regular basis.

The Government could help carers by offering full funding for continence products. We would also like to see the number of days increased from the current 63 days away from the family home, before the carers' payment is affected. There are times when, due to health issues of the carers, these clients need to be placed in care. It would also be good, if the carers' payment reflected the hard work that all carers do. The \$100 per fortnight is an insult. The Government should look at the number of clients with disabilities and provide accommodation facilities accordingly. We shouldn't have to fight for every little thing that we need, but unfortunately that's the truth! The other thing I would like to see happen, is that the equipment to help families cope better, would be provided free or at a greatly reduced cost, rather than what appears to be extra cost when it is to help the disabled.

Thank you for giving us the opportunity as part of the Carers Inquiry. We hope this gives you a clearer idea of what life is like for us as carers, and I look forward to the carers in Australia receiving much needed help.

Yours sincerely,

Mark and Robyn