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## Submission No. 950

(Inq into better support for carers)

**From:** D &  
**Sent:** Tuesday, 1 July 2008 8:00 PM  
**To:** Committee, FCHY (REPS)  
**Subject:** Inquiry into better support for carers

Please find below our submission to this Parliamentary Enquiry.

We are the parents and carers of our son who is 21 years old and moderately/severely intellectually disabled.

Alex attends a Day Programme 4 days a week. They are called "days" but in fact operate from 10am to 3pm each day. It is very difficult to manage employment around these hours and "after hours care" really doesn't apply to 21 year olds! All the "after hours care" facilities are directed to school aged children. Our children don't become independent as soon as school finishes. They are dependent all their lives. Barriers to social and economic equality for carers, especially in regard to employment, will remain until there is support to provide care facilities around more work friendly hours.

So, practical measures to support carers

1. Ideally, I would love an in-home early morning "baby sitter" to stay with our son, get him ready for his day programme, drive him to it (or pick up), and then do the same in reverse. This would allow me to work the hours I would like and not arrive at work totally stressed out having shaved, showered, dressed, fed etc etc our 21 year old, driven 1/2 hour to his service provider and then rushed to work to work the 4 1/2 hours I can manage before dashing back again to pick him up by 3pm and do it all over again. I know plenty of young mums are doing this every day with their school aged children (I did it too) but there is no end in sight for us carers. I am fortunate that I can work the hours that I do. This allow me the social and economic luxury that many other carers just don't get.

2. Respite - to allow that much needed break from that every day 24/7 unrelenting care. We get SO tired!

The Future:

Our son will be 33 years old in 2020. Most parents would anticipate that their 33 year old son might be married, perhaps have started a family, hopefully be employed in a rewarding and well paid job and at the very least be living, happily and independently. We know that Alex won't be and it is difficult sometimes not to feel total and overwhelming despair at what his and our future holds.

Alexander is moderately to severely intellectually disabled and suffers from epilepsy and severe scoliosis. He lives full time with us and attends a community participation day programme which is funded for 20 hour per week (he does attend for an extra day per week which we pay for ourselves). We highly value these programmes which provide Alex with activities and social access and they allow us to maintain (somewhat limited for Lynn) employment.

We are granted respite accommodation through the NSW Department of Ageing, Disability and Home Care. The demand for this respite is so great and the resources so limited that we are given 5 nights per three month period and have been told that this may be reduced.

Our major and overwhelming concern for Alexander (and us) is his future accommodation. Where will Alexander live when we aren't able to care for him? He is fully dependent upon us to provide for his daily needs from showering, shaving, wiping his bottom, dressing, preparing and cutting up food, administering medication etc. etc. Our concern about our future is never far from our minds. It keeps us awake at night.

Our submission is for the provision of short term respite care and for the provision of long term residential community based accommodation for those who need it.

Carers need to be secure in the knowledge that our loved ones will be taken care of when we are not longer able to do so and that they will be able to live in a supportive community environment.

**Our Submission in a nutshell:**

**Our hope is in a future Australia with with an equitable society that will provide Alexander the opportunity to live as independently as possible and to contribute to the society to the fullest of his ability. A society which will allow his caring parents the right to enjoy a retirement (as do their peers) safe in the knowledge that Alex is being provided for by the society to which they have contributed so**

much (what worth is full time 24/7 care??)

Don  
Lynn  
Alex