

A.O.C. 12/6/08

5th June 2008

Inquiry Into Better Support for Carers

The Secretary of the Committee
FACSHIA

Dear Sir/Madam

I write to you as the mother and primary carer of a man with a severe intellectual disability. My son is now thirty-one years old. I would like to express my appreciation for this opportunity to voice my opinion, which has the weight of some decades of lived experience behind it. This is the way in which you can recognise the role and contribution of carers in our society: you can give us a voice. For too long I have read comments from disability activists and academics purporting to represent the wishes and needs of persons with a disability and their carers and yet they do not speak for me or for any carer that I know. We, the workers at the coalface, must have an equal voice with service providers and peak bodies and we must have our own funded advocacy. We do, after all, provide the vast majority of the care and accommodation in this nation and we have been unheard and unacknowledged for generations.

The one practical measure that would have given me the support I needed when my son was growing up was respite. This was not a word I knew until he was ten years old and when I discovered its meaning, I also discovered that there wasn't any of it in my locality. However, after much lobbying, we were able to secure a local respite cottage and we found that we could look forward to a few days break and some time to spend with our other children. Over the years, needs change as does demand for scant services. Our respite cottage now services double the number of families it did in those early days, respite clients travel across the city to use it and it constantly has those ubiquitous "blocked beds". As a consequence of this, respite is increasingly difficult to access. While I and my peer group age and tire, the respite becomes less and less.

Respite comes in many guises, so it is important to understand what form of respite I am discussing. The carers of an ageing parent or an ailing family member and possibly those of a disabled child may be content to receive a few hours of in home or out of home respite. We who are lifelong carers have different needs. We are at the stage in life where our other children are grown and we are at or approaching retirement age. It is holiday length respite of medium to long term duration that we need and it must be centre-based. Centre-based respite gives the disabled person, who is often lonely and isolated living with parents at an age where it is no longer appropriate to do so, the opportunity for social interaction with their peer group. Centre-based respite is seen by us as training for the long-awaited and inevitable move into supported accommodation. And centre-based respite gives us, the carers, the chance to lock our doors and go away for a time as the wider community does. In the absence of supported accommodation for our disabled person, respite is the means by which we get to sample the quality of life, opportunities and choices that other Australians take for granted.

However, there are many instances in which the provision of centre-based respite on its own does not ensure that the long-term carers receive a holiday. This is because carers must still be on hand to transport the person with a disability from respite to work or day placement. Often the respite service does not provide care between 9am and 3pm and the distance involved may be too far and therefore too expensive for the use of a taxi. Carers find themselves transporting their son or daughter even though they are supposedly on holidays! I would suggest that a practical measure to assist carers to have the break they need and deserve would be to provide funding for transport between the respite location and the day/work program.

The one measure that must be put in place with urgency is the measure that will eventually see us relieved of our caring role. The best support that a carer can have is to know that theirs is a finite tour of duty and that one day in the future they will no longer be required to care. This is because a strategy has been mapped and is being implemented to ensure that adults with a dependent disability, who are citizens with equal rights in this great and wealthy nation of ours, will be taken care of by the community. They will be taken care of, not when their parents have died or are about to do so, but when their parents have reached retirement age. It seems to me to be totally inequitable that those parents who have had the most difficult experience of parenthood are the same ones who may never have a retirement. Lifelong carers such as myself are desperate to see progress in the provision of supported accommodation, but we see only rhetoric, debate and promises. We wish to see our people settled in appropriate out of home settings while we are still well and active enough to assist with their transition. In many cases, our sons and daughters are asking to be allowed to leave home as their non-disabled peers have done at their age, or often a much earlier age. It is only the provision of well-managed supported accommodation that will give carers the confidence, certainty and hope to maintain a sense of well-being and resilience in their caring role as they see others settled out of home and wait for their person's turn to come.

Estelle