

A.O.C. 8/9/08

**From:** Malcolm  
**Sent:** Monday, 30 June 2008 11:43 AM  
**To:** Committee, FCHY (REPS)

**Subject:** fchy - Inquiry Into Better Support For Carers

The Secretary,  
House of Representatives  
Standing Committee on Family, Community, Housing and Youth

### **Inquiry Into Better Support For Carers**

We are the parents of a 29 year old young lady with Cerebral Palsy and uncontrollable epilepsy from birth, whose health has deteriorated over the years. She is non-verbal and has an intellectual disability, and is totally dependent on us both for all her care needs (which are classified as "high support" or total care).

Her father is her "official" carer with centrelink, being in receipt of both Carers Payment and Carers Allowance, however it takes both of us to attend to her personal care needs (toileting, bathing, dressing etc). It would be helpful if Centrelink recognised both of us when dealing with Centrelink and not her father alone. We also receive a rebate on the cost of electricity as she requires the use of an oxygen concentrator each night. The extension of the utilities allowance will be welcome, although we heard on the radio recently that electricity suppliers are seeking to impose a 10% increase in this region as well as imposing an additional charge for Service Availability. Although these rebates are very welcome, they don't keep up with the real cost to the consumer and as prices go up the rebate gets smaller.

The new government initiative of \$100million for additional supported accommodation to help ageing carers is also welcome news, but we will be unable to access it as we do not fit it's criteria of 65 years of age. We know that the burden of caring for many families does not necessarily relate to the amount of time spent in that role but we do feel that some concession should be made for people in our situation where the caring has been at such a high level and has gone on for such a long period of time. It is essential for us to have access to age-appropriate respite in our area (Batemans Bay NSW), where our daughter has contact with her peers and the community and can attend her regular day program, if we are to continue in our caring role.

### **Barriers to social and economic participation for carers.**

Like many carers, we both juggled work and family commitments with our caring role for many years. If our daughter was sick and couldn't attend her day programs one of us was required to stay home with her. On many occasions other family members helped us out where possible. Due to her deteriorating health and increased caring requirements her father had to leave paid employment (31 years service at the age of 50), and is consequently on a severely reduced state superannuation benefit. Her mother ceased working 4 years ago and has no superannuation or income.

We are fortunate that our daughter attends a day program Monday-Friday, so we are able to participate socially during those hours, and providing she is not home due to illness or seizures. Social commitments beyond these hours depend on carer assistance through Flexible Respite

Programs. Living in a regional area, we are required to provide our own transport for her day program and travel to and from her day program twice a day averages 96km travel per day. The spiraling cost of fuel (usually higher in the South Coast of NSW) cuts deeply into our weekly budget. Our daughter does receive the Mobility Allowance which provides financial assistance for transport costs, but in regional areas with long distance to travel, the mobility allowance is not sufficient to meet our daughters transport costs.

### **Practical measures required to better support carers and key priorities for action.**

- RESPITE! Provision of age appropriate residential respite places in regional areas is essential for planned respite as well as emergency/crisis respite placements.
- Choice as to placement, if possible. Respite that is in the local area, so that the disabled person can access their day programs or school.
- Age appropriate respite - no nursing homes for young adults with high support needs

Most parents want respite to be age appropriate, in an appropriate setting. In-home respite does not provide a total break for parents. Major cities provide respite in a house and transport to day programs. (In Sydney we accessed this each month for 3-4 days and were also able to have a few week's break each year; now we live in a regional area that has no centre-based respite). Due to our daughter's high support needs, we required an Aged Care Assessment 2 years ago for respite placement in a nursing home, as we were desperate for a break. This resulted in hospitalisation, and it took us 2 months to get her better. Consequently, the 63 days/year to which we are entitled is not being accessed as we refuse to send her to nursing homes again. We are fortunate that her day program offered us 2 nights every 2 months respite. Recently, this respite bed has received funding through Commonwealth Carer Respite Centre Southern Highlands, but only for emergency or crisis accommodation.

Why can't we use some of the allocated 63 days for a planned respite there, since the staff already know her and provide respite for her and she is able to attend her day program where she interacts with her peers and within the local community? We, as carer parents, need a total break to enable us to actually have uninterrupted sleep and do all the things that everyone else takes for granted. Our life revolves around our daughter's physical and medical needs - we are on call 24/7. When she is unwell or fitting, she stays at home, so it is difficult to plan ahead with any certainty. Usually when we have our 2 days respite each 2 months, we rush up to Sydney to see our adult sons and their families, so not much rest time.

### **Strategies to assist carers to access the same range of opportunities and choices as the wider community**

- Flexible funding agreements between government, service providers and families. Funding should be allocated to the individual (case based funding) rather than the organisation.
- Case-based funding from time of birth, diagnosis or injury, based on assessed need and responding to individual need, but also ensuring that families are linked in to support services.

### **Strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future**

- Adequate provision of residential respite places (whether in a house, cluster housing, or a

shared complex with on-call or live-in support as required, based on individual need) within the disability accommodation sector and in regional areas as well as in suburban areas.

- This would ease emergency/crisis placements and provide families with an opportunity to establish relationships and experience supported accommodation prior to permanent placement.
- Supported accommodation options (as for respite places above), with transitional respite to ease the person with the disability and the family into the new living arrangements.
- This would also mean that "ageing in place" can occur in response to an individual's changing accommodation needs within a community setting, so that they can move between in-home care, respite and residential care with specialised disability services.

Our caring role will always restrict our access to the range of opportunities and choices that the wider community enjoys, but adequate respite will enable us to continue in this role for as long as we can. We would hope that suitable supported accommodation features in our daughter's future.

REFERENCES : Eurobodalla Shire Council's Eurocare Services Submission Providing Input to the Design and Development of the Australian Government Disability Supported Accommodation Program October 2007

30th June 2008

Malcolm and Jill