

A.O.C. 17/7/08

Submission No. 757
(Inq into better support for carers)

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 Sir/Madam,

How does one begin to describe my role as a carer and my views on the current level of support?

There are not enough words or enough time to adequately voice my views so I will try to concentrate on the main points relevant to me.

I feel that my role of the carer for my nineteen year old daughter is a never ending nightmare. I love my daughter dearly and gain much joy from her life. However, each day is a constant struggle as my husband and I try to combine our full time careers with our daughter's needs and also our other daughter's needs. Why do we have full time careers? We both feel that it is important that we contribute to society. In addition, due to our daughter's physical needs we built a house that would accommodate her and best meet her needs. Needless to say, a hefty mortgage went with that building. Like all Australians with a mortgage, the constant rising of interest rates has made this more difficult. However, to the best of our knowledge there was no financial support available to us to help us build this house although we understand that if we had renovated there would have been. Where is the equality in that?

How do we feel we contribute to society? Each and every day we provide a level of care to Rebecca that would cost the Australian taxpayer a large amount to provide yet we provide that care for love and the princely sum of \$50.30 a week. For that amount we provide her with transport everywhere as she has to use a wheelchair for mobility and does not have the intellectual capacity to use taxis on her own. We look after her personal care although we do get help four mornings a week. However, as Rebecca can't toilet herself or bathe herself there are a lot of hours spent outside those four mornings assistance that need to be dealt with. Rebecca goes to a Community Participation Program five days a week. However, in order to do that and work we have to transport her one way which means my husband starts work at four a.m. then comes home and takes Rebecca to her program and returns to work to finish his day at three p.m. My work hours do not allow me to be at home in time to receive Rebecca most days (she is transported home but Hey! there goes half of her mobility allowance.) This means that Rebecca's younger sister needs to be home to receive Rebecca and care

for her until we arrive home. As she is studying for her HSC this is a huge commitment from her but hey! we receive \$50.30 a week between us for this care and what choice do we have? Rebecca also has epilepsy so needs to be constantly monitored as she often fits silently. So our lives are a constant round of one of us being responsible for her while the other completes whatever tasks are needed to be done. Therefore we have little or no social life. One of us goes out while the other cares for Rebecca. Or if we take Rebecca, we need to be sure that where we take her is wheelchair accessible and has facilities for her to be toileted. Obviously the standards are very suspect for wheelchair accessibility as there have been times when I have had to stand on a toilet to be able to get Rebecca's wheelchair in and close the door of a "wheelchair accessible" toilet. Not every person in a wheelchair can use the facilities on their own.

What recognition do we get for this work? Basically none! As long as we keep doing it- it doesn't matter to society. We don't want a pat on the back for loving our daughter/sister. We want a better system of support for carers.

We want a system where if we apply for support such as respite we don't have to apply to several different agencies and fill out the same information for each of them. Sometimes the paperwork makes us wonder if it is worthwhile. Why isn't there a central agency that we provide information to and it is passed on to others? so we don't have to keep repeating ourselves. Why is DADHC set up in such a way that to obtain any help is once again a nightmare of repeating the same information that you have given them every other time you have needed help. Why is DADHC set up in such a way that they don't tell you what help you are entitled to unless you already know and ask for it. Every carer should be advised of what they are entitled to in the way of assistance. It seems to me that we reach crisis point before they step in with information and if we had been aware of what help we could receive we might have avoided reaching that point. Our daughter has a genetic disorder that she was born with and is not going to get any better. Yet in order for her to maintain her Centrelink entitlements we have to regularly provide evidence that she is disabled. Why doesn't the Centrelink system have some method of noting people with PERMANENT disabilities and not requiring us to go through the heartbreaking task of reliving all our daughter's problems.

What else do we want? We want a standards system set up that requires all public places (including shopping centres etc) to have wheelchair accessible facilities that really are wheelchair friendly. We want a system that acknowledges that varying degrees of disability need different levels of financial support. We want a Centrelink system that acknowledges and provides an adequate level of financial support for persons who need frequent medical appointments. I know that public hospitals have clinics etc but when you work you need to access private appointments to fit in with your work needs. We want a system that provides financial support in providing a home for a person with disabilities whether that is by renovation or building. We want a system whereby support groups and departments acknowledge that some carers do work and provide the same opportunities out of hours as they do for those who are home. We want a medical system that provides not only means for the disabled person to have a full medical checkup but also for their carers to have that same opportunity. We want provision for us to have that medical care with adequate care for our caree while we access this. After all who will provide the care if we can't?

We want a system where we as carers don't have to go to work when we are sick because we need to keep our sick leave in case we have to use it to look after our child. We want a system that provides a wide range of out of home care for our child so that we can choose what we know will meet her needs best so that if anything happens to us we know that Rebecca's sister is not going to spend the rest of her life caring for her sibling. We want that care to be available when we need it. Not have to ask for it now so we won't miss out. Most of all we want every member of this Committee to spend a week on their own caring for Rebecca or someone else with multiple disabilities and then tell me that the system we have is meeting our needs.

Karen