Submission No. 367
(Inq into better support for carers)

A.O.C. 1/7/08

19 June 2008

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family
Community Housing and Youth
P O Box 621
Parliament House
Canberra Vic 2600

Dear Mr Secretary

Re: Inquiry into Better Support for Carers

I thank you for the opportunity to share my personal experience with you in the hope that it may provide you with relevant insight into the plight of people with disabilities, in particular, the people that care for them.

I understand that Terms of Reference is as follows:

- The role and contribution of carers in society and how this should be recognised.
- The barriers to social and economic participation for carers; with a particular focus on helping carers to find and/or retain employment.
- The practical measures required to better support carers, including key priorities for action; and
- Strategies to assist carers to access the same range of opportunities and choices as the wider community, including 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.

Background

Before I address the Terms of Reference, I believe that it is important for you to see and understand the author and the 'disabled' person.

My name is   and I am 40 years of age, single and primary carer for my mother with Multiple Sclerosis.

I have worked as a consumer relation's coordinator in both the public acute forum of health but also from community. My comments made in this document reflect not only my personal experience but those that I have witnessed during my time in health.

The 'disabled' person is turned 59 this year and has been diagnosed with Multiple Sclerosis for approximately 9 years. worked full time for the State Revenue Office up until 2 ½ years ago when she finally retired due to illness. has just spent 14 months in hospital awaiting a package to come home. I have enclosed a picture so you can see who she is to us.

The family make up is my sister who lives in Cranbourne, my grandmother who lives in Foster and my aunt that lives in Foster.

1 The role and contribution of carers in society and how this should be recognised.

It needs to be stated that I do not wish to be acknowledged as some 'saint' who has taken on a thankless task of caring for her mother. I do not choose this role; it was given to me wrapped in a blanket of guilt and obligation.

To some, I may sound cruel and harsh, considering that my mother selflessly brought me up, provided me with a loving home and supported me throughout my life. The reality is that the day I became my mother's primary carer, I lost my mother.

Instead of a daughter I am now an advocate (my mum calls be bossy and unrelenting), I am a nurse (mum tells me that it is not my problem), I am her mother (mum tells me that I am bossy and disempowering), I am the primary decision maker for both of us (this suits mum on occasion) etc etc etc.

I would like the government to recognise this role by empowering the disabled and streamlining processes. Our role as a carer is often made so difficult because:

- Information and support is difficult to find and access, therefore causing unnecessary time wasting, frustration and financial disadvantage.
- When we try to access support and information from peak bodies such as Centrelink and the Department of Human Services/Health and Ageing, we are often made to feel that we should be grateful for everything that we receive, the information is inconsistent and often incorrect and phone calls for assistance are often not returned. As a carer who works full time, I don't have this much time.
- As a carer, I feel guilty if I attempt to have a social life. Although care is provided, the provision of social stimulation is often lacking and therefore the person afflicted often becomes a prisoner in their own home.
- Have one point of reference for newly diagnosed instead of a million peak bodies who you are meant to ring to get assistance. There should be a simpler way to access timely, accurate information and services.

2 The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment.

Last year, (2007) things did not go well for our family. Mum broke her ankle and that speeded up her MS progression substantially. Being a carer and working full time had finally gotten to me and I had two operations in one year and lost my job. I was made 'redundant'. Around December of 2007 I had used all my savings and was at the point of loosing my house. I approached Centrelink to see if I could go onto a carers pension. I was advised that because mum didn't need care during the day, I did not qualify.

Not one person in Centrelink or in the government bodies that I spoke to understood what it was like for me day in day out as a carer. Yes in a wheelchair, mum was not at risk during the day but it was the 20 hours of care that was provided throughout the day and night that was full on. What Centrelink couldn't understand was that I was often up several times during the night, particularly if she fell out of bed, I had to arrange everything for her day to day needs, organise appointments etc and then go and do a 40 hour working week where my employer expected, and deserved to get his money's worth.

As a result of Centrelink's decision, I finally got a job and am now working back full time.

At every job interview I went to, I advised them that I was a primary carer for my mother and explained what that entailed. I believe that this was to my disadvantage to tell them as I am sure that I was rejected for many roles due to this commitment.

When I finally did get a job, several months down the track a comment was made by my boss that 'when they took me on, they had to **consider** what impact my mother's health would have on my ability to perform'. I was made to feel that I should be so grateful for this position (this is a government funded position I would like to add).

As a carer, I am entitled to 3 days per year out of my sick leave to be used as carers leave. The other times, I have to use my holiday pay, which unfortunately, has to be used in lots of 5 days at a time. My boss, although in the interview advised that they prescribe to a work life balance and flexibility, has not shown this to be the case. I have had to beg for everything and am often rejected when I require flexible working hours.

From a social perspective, what can I say? I don't go on dates, who wants to bring a new partner home to a house where my mother would be there. I can't sleep out overnight anywhere because she can't be alone at night and I can't be out till all hours because to be honest, I am too tired.

I have been advised that we will receive carers to come and help put mum to bed, however, there will not be enough funding for the required two assist that she is so I have to be home every night at 9.00pm to help put her to bed. When was the last time that anyone got home from dinner at 9.00pm or went out to dinner at 10.00pm?

Things that the government could do to assist this situation would be:

- If you are going to provide care, provide what is needed, not only half of it.
- Ask the carer (not in front of the disabled person) what the realistic care needs are for the person.
- Centrelink needs to start assessing cases on a case by case basis, rather than just going on black and white rules. Disability is never black and white.
- Educate employers to the value and commitment and how this could be of benefit to their workforce. Being a carer is not an obstacle to an employer if they are give the support and flexibility that they need.
- Increase or supplement carers leave so that the disabled person's needs can be met.
- Provide appropriate and realistic support or programs for the disabled so that they are not socially isolated while the carer 'guiltily' goes to work or out.
- When a disabled person is case managed, the carer is often forgotten. It should be part of the case managers role to assess the needs of the carer and put them in touch with practical initiatives that would enrich their life.

3 The practical measures required to better support carers, including key priorities for action;

I was at a meeting the other day and a member of Centrelink was discussing aged care bonds and assets testing. I was interested from a carer's point of view and from my employer's point of view.

The Centrelink speaker advised that when placing someone in a nursing home, you have two years before the family home was considered an asset. Once it became an asset, it could affect the person who had been placed into care, financially. They may be required to pay a bond or may loose part of the pension. What this may mean for the carer is that they could be forced out of the home, to fund the new requirements. According to Centrelink, I am not even recognised under this criteria because I only receive a carers allowance and not a pension.

A practical measure in this instance is to stop punishing the carer once the disabled person goes into care. It is a hard enough decision to place someone into care without then probably loosing their house in the throws of this. Is there no recognition of the life that the 'carer' deserves to have?

Priorities for action are:

- Stop accepting that carers and disabled people **deserve** to live a life with limited opportunity and financial abundance.
- Streamline access into services, instead of creating minefields for access?
- Recognise that these disabled people often once were strong contributors to this economy and paid tax for many years. Empower them to have a life that is full and engaging and not hidden and sad. This can be achieved by age related day programs, asking the disabled person what they would like and reminding them of their value in the community.
- Stop making caring a death sentence. There needs to be financial acknowledgement of the service that carers provide to the community. The support needs to be person cantered and realistic, not we will give you some help and you figure out the rest.
- Carers would be happy to work if they knew with confidence that the person they care for will be managed well with community supports and that there life will be enriched as much as what the carers is.

4 Strategies to assist carers to access the same range of opportunities and choices as the wider community, including 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.

It has been interesting lately to hear the new government's platform and all I hear is that I am no longer valuable to this community and neither is my mum because we are not having children and we are not a fully productive family.

The unfortunate reality is that disabled people are a drain economically on society – no one disputes that. The difference is that carers will step up to the plate and take on the role without burdening the government too much. The government still has to acknowledge that whether they like it or not, they also have a level of responsibility to these people.

I have stated many observations thus far in my journey that represent a middle aged carer and her mother. You will receive other journeys from younger people, from mothers, father, brothers, sister's, daughters, sons husbands and wives. All of them will highlight that although the burden is infinite, love continues to provide the strength to maintain momentum.

The biggest message from me would be to say that if you are going to help, help realistically and not partially. Understand that if my mother still feels that she adds value to this world and is happy and medically stable then my world is happy to.

To help the carers, help the disabled and provide relevant, timely services and information. Increase the pension so that a day at the movies is not a special treat but something that a disabled person can enjoy weekly without worry that they wont be able to afford their medications.

Include care that is holistic and takes into account social and allied health needs rather than the bare minimum. By providing this type of care you prevent frequent use of public hospitals and early entry into retirement facilities.

Educate employers to the value that carers provide in this community. Equate a carer's dedication to their loved one to that commitment to work – they will never get a better employee.

Provide provisions in the workplace where carer's leave is more abundant (within reason) and that the saying work/life balance actually does exist.

I think that I have probably said enough and I hope that my journey has provided you with some insight. I am grateful for this opportunity and hope that it will assist you in your enquiry.