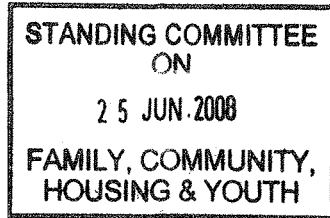


A.O.C. 1/7/08

19<sup>th</sup> June 2008



Submission No. 353  
(Inq into better support for carers)

Secretary  
Inquiry into Better Support for Carers  
Standing Committee on Family, Community, Housing and Youth  
PO Box 6021  
House of Representatives  
Parliament House  
CANBERRA  
ACT 2600

Dear Secretary,

I am writing to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

My son is a wonderful human being. He is handsome, creative, and extremely social and caring. I hate having to go into the negative aspects of our situation. I have worked extremely hard to build us a decent life and support networks which are positive. However I do need to let you know that it has been and continues to be very very difficult journey these past 16 years. When people speak of 'having to fight for everything' that is so true, but it does not convey how hard that is on a family. It is especially difficult when you have no relatives in this country.

My role as a carer is caring for my son who has multiple physical disabilities. My son is very intelligent however he has some learning difficulties associated with Ataxia. My son has to dictate most of his work at school and I act as his teacher aid at home, sometimes using the respite workers to assist me as it is extremely demanding to keep on top of all the work requirements as my son moves into senior schooling. I am a sole parent and have been since my son was 2 years old. The demands for specialist appointments and therapy are a constant factor and expense.

He is now turning sixteen and this has been a particularly stressful time. Despite all my advanced lodging of the incredibly onerous amount of paperwork and assessments we will still be left on Monday without my Carers pension and my son's Pension and this will be the case for several more stressful weeks, thanks to the requirements of the current Centrelink system.

One of the most difficult things is getting people to understand the ramifications of having to be here every day to place my son on the taxi to go to school and to be here at 3 pm daily to meet the taxi, which can be up to two hours late. My son also has many days off school due to fatigue and when he has a cold he cannot go to school as walking around all day is too much for him.

This makes my employment situation very difficult. I can only work a few hours per week and need to do contracts so that I can set my own schedule.

My financial situation is precarious. I am currently having to go the bank to yet again 'restructure' my finances. All this means is borrowing yet more money and extending my mortgage as much as they will allow. I will not ever be able to 'retire'. I have not been able to save for my superannuation. Attempts by Centrelink to send me to job networks have proved fruitless as they do not listen to my needs and come up with jobs which <sup>are</sup> totally outside the hours I can work, or are too many hours. My health has suffered due to all the stress and demands on me.

I am a very well qualified person with an MA. I find it very frustrating not to be able to do the work I would love to do, but I have done a huge amount of volunteer work and a few hours paid work over the past 14 years. My paid work is supporting people with disabilities ( People who have mental health disabilities and Acquired Brain Injury) in their employment. My volunteer work has consisted of Advocacy to improve the Education system for students with Disabilities. To this end I have served on many committees for the Education Dept and on a Ministerial Advisory Committee, to name just a couple. I have also assisted many parents individually and given my time to assist the policy development and staff training and parents of the Cerebral Palsy League of Qld.

I have had to work extremely hard at both obtaining services and making official complaints due to very poor service from time to time. The various requirements of many respite services mean we have to fit their requirements rather than they fit our needs. Services we have found very supportive and accommodating have given away over the past 5 years to ones which don't serve our needs well at all and this is extremely tiring and frustrating, and actually adds to the stress if things are not going well. I can give very extensive views on this and I have written a paper for an International Social Work Conference 9 years ago on how services affect the mental health of families caring for a disabled member.

I have applied for a family support package to DSQ for the past 5 years. The non recurrent support has been useful in obtaining items needed for my son, eg his wheelchair, laptop etc, however it is so discouraging to know that we will never 'qualify' for a package as we are not seen as in crisis.

The education system has probably been one of the largest sources of stress for us. I cannot spend the time to go into this, but just to say we have faced discrimination and very poor treatment on many occasions. We have had some fantastic support and we have had some ghastly experiences, which have been nightmares really.

**What would help?**

Paying respite carers decent wages, to avoid constant turnover and provide high quality of care.

Paying NGO's decent wages so they do not leave all the time and put funding back into therapy services into schools. We depend on those services and they have disappeared!!!

We need individual advocacy on occasion and we need an independent complaints procedure in place for the education system.

Providing working carer funding for my age group (I am in my 50's) I get this once per week but need it every day after school!

A carer pension that also recognises the need for superannuation!

Supporting me to go back to Uni, I would like to do my PHD! Or at least update my learning.

Support for job share, I could do one of these jobs if one was available!

I need a health care fund, but I cannot afford it.

I need funding to go on Holiday occasionally, both with and without my son.

Thankyou for taking my views in consideration as pare of the Inquiry. I look forward to reading the recommendations you make to improve support to carers.