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The Committee Secretary
Standing Committee on Family
Community, Housing & Youth,
P.O. Box 6021,
House of Representatives
Parliament House,
Canberra ACT 2600

Dear Secretary,

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

① Because of my son's profound brain damage & physical disabilities I feel that my role is watchdog and protector over him, his guardian in all his affairs, and his personal carer in all his physical needs.

② I contribute to Australian society by voluntarily, and lovingly and continually caring for my son. He is a burden to no one as he lives at home with his parents, (therefore he is not homeless), and all his health needs are attended to, together with first class physical care. If my son were getting this sort of care in a government-run group home he would need 24 hr care by two carers, hoists, special bed, other special equipment at labour costs. What mother/carers do we do for free. (The Carers' pension is appreciated, but it is not wages, and it is means tested.)

3) Support by trained community carers is limited, as these wonderful people are mostly casually employed these days. They are on rostered shifts, so there is no continuity with a particular person; they are paid a pittance for the work they do, some don't get paid travel allowance (in these days of high fuel costs!), so many move on.

Because there is no continuity with a regular carer, as each new carer comes to the home, often untrained, with basic skills in disability, and no knowledge of my son's special disabilities, I have to spend half my time training the latest new carer!

This is very stressful for me, as the respite time is supposed to be rest time for me, and there I am in an unpaid teaching role!

The agencies who employ these people get huge government subsidies to assist carers in the community. They employ nurses to shower people, and other carers for community access programmes for the disabled.

These people should be fully trained, and then appointed to the disabled on a regular basis so that they can form a relationship with people, & there is not so much stress on the client. Rotating different carers from one week to another, is very frustrating for the client.

4) I can't fully participate in social life because my son's profound disabilities mean that he is wheelchair-bound or in his bed. When he attends a Day Centre for 6 hrs three days a week, I use those days to do my shopping, go to the movies with other mother/carers, and have my hair done/go to doctors visits, other business etc.

Because I am an epileptic I don't drive, so I have to rely on my husband to drive me when he is not busy, or use Public transport, which is limited & time consuming.

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These three days are very important to me.

The weekends, I am always at home, unless my son goes to a Respite House for a few days, while we have a break. My time is really not my own.

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The things that stress me about being a carer are:

The isolation. I am home with my son much of the time. He is 40 yrs old, cannot speak, has no real communication. He needs all his physical needs attended to by two people. However when I am by myself I can just manage to change him, although with difficulty. (I am very careful, because I don't want to harm myself). My age is a problem; I am not as strong as I used to be. I have asked for extra help at weekends when I am alone but have been refused.

I am a positive person, I have faith in the Lord, and believe He looks after my son and I.

However, the long times alone at weekends can be most trying.

Why do agencies not employ more carers to assist where the need is greatest? Do you know most agencies close for Christmas, Easter, Public Holidays, as well as weekends? Many carers have to cope on their own during these times! This is an absolute scandal.

If a carer has a partner, they are able to support each other emotionally during these times, even whilst carrying on with the caring role. But what about those carers on their own, left to cope on their own?

I think the Government can better help carers by insisting the agencies that employ the carers will only get their funding if they operate seven days a week, open at holiday times when there is great need, & train the carers in more

than the basics of disability showering!

Careers would also be helped by having regular assistance (not rotated different people from day to day), so that the care of the disabled person is constant, and the carer is not forever training new people.

Regarding Financial Affairs.

The care agencies are being subsidized by the Government both state & commonwealth for the services they provide.

Fees are being requested more & more for the care given.

Showering, which is a basic right, should never be charged for by any agency being subsidized by the government!

However they have been pressuring people for fees for this service, along with all other services.

Agencies having problems with their budgets could cut out some of the massive paperwork which they burden us with. On the "monthly review", which entails one of their co-ordinators coming to our homes, spending an hour of our precious time to assess our situation to see if we have any "problems" (!). These "problems" are always noted, (the co-ordinator is always very nice, but I wish she would go & let me have a rest!)

Nothing ever is done about anything I mention. Ever.

(Unless there is a disaster and I kick & scream, or if one of the two carers is unwell, you may get a bit of attention.)

However, as long as carers continue to go on doing their job lovingly, without complaining, they will be ignored.

(6) Regarding the Carers Pension

I did not receive this until my husband retired, (because of the means test.)

This means that for thirty six years I cared for my

my son with hardly any government monetary assistance.

The paltry carer's allowance was all I received for all my devotion and hard work.

However, I had a loving husband, a beautiful family, and the times were different. Services were provided through The Spastic Centre, The Crippled Children's Society, The Children's Hospital, etc. I was appointed a Care Worker and a Social Worker to help me cope through the years of trauma of looking after a young disabled son & (four other young children.)

We coped & stayed together & we are O.K.

Today's disabled don't get such supports as I did.

The carer's pension should not be means tested, if it must, then it should have a very high level cut off, so only those who are very rich would be unable to qualify.

Information about what is available for carers should be made available. There is so much that people are unaware of, because they are isolated.

Perhaps Carers Australia could put out a monthly or quarterly magazine or newsletter (with government grant) giving information and ideas & stories to encourage carers. I am sure we could contribute to this if we were asked.

I hope I have been able to be of assistance.

Here's hoping something comes from all of our submissions.

Yours sincerely

Anna.

P.S. I look forward to reviewing any recommendations you make to improve life for carers in Australia.