

Submission No. 1022

(Inq into better support for carers)

Dear Secretary,

AOC 28/7/02

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.

My husband and I have four children. One aged 27, one aged 18 as well as caring for two high support needs 30 year old daughters. As a carer, I am too busy and tired, both emotionally and physically and do not have the energy nor the time to put together, yet again, to let you know our plight. I am indeed battle weary and often wonder WHAT IT WOULD COST THE GOVERNMENT FOR MY REPLACEMENT--- As I receive no work cover, no super, no sick days or pay, no holidays, no long service leave, no health and occupational guidelines to protect me, no study leave, no training days to keep me updated on protocols, no 30 hour week work only, no public holidays off. Yet I work 7 days a week, 24 hours, 365 days a year. I WILL NOT GO TO MY GRAVE AS A CARER OR AS AN UNPAID CARER.

I am a trained Div 1 nurse who chose to have a family when I was 28- twins wow. I was then welcomed to the world of disability. The girls have various complex and continuous needs both day and night. Being who I am we manage with no help until our fourth child was born and we had a milk bar to run also. Help was required. Now I receive Carer's Payment and Carer's Allowance but my terms of employment are under demeaning conditions and under paid.

Number One- The Carer's Allowance should be immediately doubled.

Number Two- Carers payment should not be means tested as to what your husband earns; you are the one who can't enjoy employment of your job choice because of your caring role. When you are sick and unwell you still have to continue with your job role and be tax exempt.

Number Three- Foster Care families choose their job role and are paid accordingly up to \$30,000 per year. The A.T.O does not recognize this as income. Discrimination amongst us carers here somewhere, this is not indeed fair.

Number Four- Looking back now, we were on our own; a family government funded advocacy such as Gippsland Carers would have saved me much heartache over the gone years. I did not know where to ask for help, I was too busy, too overworked. This family advocacy of networking has now helped me and many others over the years with support and the ability to share information. We need a family funded advocacy so we family carers can be better informed and make choices of the needs for ourselves and those we care for Re Services example- Homecare, Personal Care, Day placements, Haac Programs, Respite options, accommodation options, community access, DHS, Protocols, Funding Bodies, Advocacy, Aides and equipment etc. A PILOT PROJECT OF THIS GROUP SHOULD BE FUNDED TO CONTINUE ON THEIR USEFUL WORK FOR US FAMILY CARERS.

Number Five- Participation in planning and delivery of services for family carers and the people we care for and involvement in developing these services further is needed. A lot of services provided are inadequate and do not meet the needs of the family. We

are expected to fit into their box of delivery. For example, some services require you to work within their business hours. This means that you pay time and a half or double after these hours. If you don't have some sort of financial package from the government you would not survive. Many families have no idea how to go about securing financial assistance.

Number Six- Remove the 25 hour rule from those on Carer's Pensions. It is not needed as we are already prisoners in our own home and work for no pay for more than 30 hours per week. We are already isolated. Having terminated my employment to only a very casual position many years ago, has caused a considerable financial burden, seeing that we have had to buy many large pieces of equipment such as their van and other various big purchases over the years. If I didn't have my Nursing background I'm sure my daughters would have spent much of their life in hospitals, they are very rarely in hospital, **ONCE AGAIN WE HAVE SAVED GOVERNMENTS MANY DOLLARS.**

Number Seven- We should be able to choose what type of respite we need at an affordable cost. Remove the 63 day rule from Centre Link. My caring role of my daughters goes on during the night and day. **WE SHOULD BE ABLE TO HAVE RESPITE WHEN WE NEED IT AND HOW WE NEED IT, AND NOT BE TOLD WHEN WE CAN HAVE IT.** It should be locally in the area we live also.

Number Eight- It is overwhelming not being able to plan appropriate housing. Accommodation for the girls needs to be appropriate and local. We need to have choice, we would like to be able to utilise shared supported accommodation. The long transitional phase would allow concerns to be dealt with. At the moment I am being penalized because I am asset rich, because a house we bought 22 years ago towards security for the girls is at the moment a rental, and it now shock horror puts me into the assets rich bracket. We are still paying this house off and have this as security should the government in the future still not be able to provide the girls choice of accommodation and 24 hour support just like it does for those people over 65 years of age. Again, we have no choice. You need to remove this ridiculous rule for folks on carer's payment who are trying to plan for accommodation for their adult high needs children. I wish to retire at the age of 65 and do my own things if I'm still alive and well.

Choice of group home accommodation with skilled nursing staff would be ideal. Carers need choices to effectively plan for the future, for themselves and those they are caring for.

Number Nine- Ongoing realistic funding must be provided to carers as payments for their services to assist with purchase with services and equipment, health and housing needs for carer's and consumers.

OPPORTUNITIES FOR RETAINING QUALIFICATIONS OR EMPLOYMENT SHOULD BE ENCOURAGED. We should not have to beg and demand for services once we have discovered what is available through family networks. Services providers do not tell you prior to asking, but how can you ask if you don't know what to ask about? Carers need flexible options for making choices and supports for their needs.

Our caring role does not go away once our children reach 18. Foster care families can choose to let their children go at the age of 18 and lead a normal life like the rest of

the community. Gippsland carers have been a great support to me over the years. We need a fairer deal dollar wise from the government to make choices previously listed, Day placements, HAAC services, Respite providers etc etc need many more dollars provided to them to be able to CARRY OUT WHAT THE STATE PLAN INDICATES.

Number Ten- There is no government legislation for the rights or entitlements of family carers to support services, for example aged care folks are assessed and services provided to them. Family carers need to ensure that legislation is changed so we have rights to services and entitlements, just like the rest of our society has.

Thank you for listening to me,
Yours sincerely,
Anita