

Submission No. 1216

(Inq into better support for carers)

AOC 18/8/08

31st July 2008

Committee Secretary
Standing Committee on Family, Community Housing and Youth
PO 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 enquiry into Better Support for Carers.

I am an Aboriginal Sole Carer for my two adult children with Additional Needs. My daughter Holly has Cerebral Palsy, Rheumatoid Arthritis and Scoliosis. She is twenty seven. My son, Warren, is eighteen and has an Acquired Brain Injury after being hit by a car ten years ago. We are only now coming to our first mediation process next month.. Anything that could have had a more positive outcome will come years too late to be of assistance.

As a **CARER** of multiple responsibilities I am;

Constantly on call
Always available
Resilient
Enterprising
Responsible

I have no formal qualifications but have become Speech Therapist, Occupational Therapist, Life Skills Coach, Legal Representative, Physiotherapist, Nurse, Chauffer, Secretary, Personal Care Assistant, Careers Advisor, Entertainment Facilitator, Financial Advisor, Counsellor, Cultural Educator, Medications Administrator, Behavioural Modifier and Case Manager for all of the above. In between all that, I try to be the best Mum I can be.

I believe my role is physically demanding, emotionally draining, socially isolating and intellectually challenging.

I am contributing to Australian society by caring for both my children at home, rather than placing them in alternative care, thus saving the Australian Government and taxpayers thousands of dollars every month. I am also contributing by being an active member of many Aboriginal Carer Improvement Committees and Consortiums. I do this because I can see so much needs to change.

I am an Ageing Carer, having celebrated my 50th birthday this year. I, too, have my own health issues to deal with and my biggest problem is who will care for my children and love them when I die? Who will be there to attend to their daily needs as well as showing them love and support? How do I tell my youngest daughter, Elise, this is the legacy I leave her? Will she have a life-time of worry and responsibilities and no support for her in place? She will need all the support she can get if my family is to remain together.

I am emotionally drained because of the overwhelming sense of responsibilities, knowing that if I don't prepare for my future as well as my childrens now, then my youngest daughter will inherit nothing from me but my mental health issues.

I am unable to enjoy much of a social life as many of my friends found coping with my sons and daughters behavioural problems too challenging and I have little or no time to form a close and loving relationship because of the constant strain of caring for my children. I have a full-time position caring for them and I am socially isolated because of their complex and varied needs.

I am financially struggling because I am unable to keep up with the rising costs of food, petrol, rent and daily living. I would very much like to gain employment in the Disability Sector but am restricted by the hours I could be available, the amount of travelling time involved and lack of formal qualifications. I am also restricted with educational opportunities. Last year I was offered a position at Macquarie University to do a Bachelor in Community Management Degree but was forced to decline due to my caring commitments and because the course, or modules of the course were not available at a closer campus.

I am very concerned about my future because of my age and feel I am missing out on so many opportunities to create the future I once dreamed of. Now I am a Carer and dedicated to looking after my children for the rest of my life and as a Sole Carer, all their disabilities may, in time, become mine. I am very concerned about my own Mental and Physical Health issues that will ultimately deteriorate as I grow older, probably at a much faster pace due to the added stress I am constantly under.

I am also stressed by the lack of respect Carers receive from many professionals. As Carers, we are often ignored or considered uneducated because although we have "life experience", we do not possess acceptable formal qualifications. We are often treated as neurotic individuals because we don't have the necessary skills to cope. This was my experience with a Case Manager provided by the responsible Insurance Company. She suggested I "get a life", as though the life I had as a Carer was insignificant. She also told me I, "couldn't blame the brain injury on everything he did".

This totally confused me because everything we do, everything we say, everything we think stems from the brain. She belittled me and laughed at my pain. She would often answer the phone with her screaming baby in her arms and just let it scream while I was trying to talk to her. She had no concern for my son and no consideration for me.

I am most stressed by the lack of and limited educational short courses available to help Carers understand and manage their disabled persons needs. When my son was diagnosed with an Acquired Brain Injury, I was given information and strategies but was not taught how to put the strategies into practice. I was denied entry to his Speech therapy sessions. The information, strategies and education would have been invaluable in helping me communicate with my son and I would not have felt so inadequate, depressed or overwhelmed.

I need help with Case Management for both my children. I have mountains of paperwork monthly and need to access someone to help me sort it all out and file it away. I get triple the paperwork sometimes because we access some of the same organisations and Government Departments.

I need assurance that the Bonnyrigg Community Housing redevelopment in which I live will take into account the current and future needs of Ageing Carers and provide single-level, four bedroom, modified dwellings with adequate storage and rehabilitational value. I need to know that in the event of my death, my childrens housing needs will be met.

I believe the Government can better assist Carers by continued consultation and increased Carer Payments, Allowances and Bonuses. I am upset by the continual waste of the \$5,000 Baby bonus paid to single per person/per baby under 21's. In this day of modern technology, there is no excuse for unplanned pregnancy. It is encouraging a generation of parents without partners. This money could be better utilised in off-setting Carer costs in transporting their disabled persons eg, petrol ID cards issued yearly with the Centrelink ID.

Having a child with additional needs puts added strain on heating, water and electricity costs as well as every aspect of family life and the budget. Increasing all payments will ensure a better quality of life for both the **Carer** and the person(s) they care for. Most people choose to be parents, Carers have no choice.

I am a **Sole Carer**, an **Indigenous Carer**, a **Carer** with multiple caring responsibilities, a **Carer** whose only source of income is Government dependent and I have had many problems accessing appropriate and adequate services in the past due to the complex variation of Federal and State funded services. This is especially true with respite services, having struggled for many years to get enough respite. Recently, I was able to access the DADHC Ageing Carers Flexible Respite Options Program. This probably saved my sanity along with the Seasons for Growth and Eight Stages of Healing training. These courses should be available to all Carers at first diagnosis and funded by both the Federal and State Governments in unified support for **Carers**. It is perhaps the best thing I have done for myself and my family and it has helped me to understand the importance of looking after me and coping with the grief and loss associated with being a Carer for multiple disabilities. It has also opened doors for me to find a voice and gain some renewed hope in gaining Accreditation as a Companion for the Disabled.

I also firmly believe that some professionals, eg, Insurance Companies, their Case Managers and treating Specialists should have a Governing Board of Accountability for cases where mis-management is an issue, such as was my sons case. This should be available to all Carers and monitored by the Government.

I also believe that Carers shouldn't need to reach a crisis to access support, as is often the case. Support is limited due to inadequate funding and infrastructure and often ceases long before the crisis has been resolved. Whether the Carer has recovered sufficiently is irrelevant. I have had many crises over the last ten years and had to manage for the most part, alone and unsupported even though many organisations were involved at the time, very few were actually involved.

Sometimes clinically appropriate is not what we need, sometimes its just a shoulder to cry on or a cup of coffee and a chat that still helps us feel human and appreciated. For the most part, a simple phone call once a month may be all that's needed to support and monitor how we are coping and what options are available if we are not. Perhaps a 1800 CARERS support number where Carers can get some helpful advice twenty four hours a day?. Isn't that what **CARER SUPPORT** is all about, getting the **CARE** back into the system? This will only happen as a result of **CARER** consultation and careful planning now.

Thank you for taking the time to consider my views as part of the Committees Inquiry. I look forward to reviewing any recommendations you make to improve the lives of **Australian Carers**.

Yours Sincerely

Wendy

(Sole, Ageing, Indigenous Carer)