

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600
AUSTRALIA

7th July 2008

Dear Secretary,

I respectfully request this letter be included as a late submission to the *Inquiry into Better Support for Carers.*

The last couple of days I have fallen into a 'carer hole' – hence the tardiness of my submission. The past few days have seen many hours spent in and out of hospital emergency departments with my 13 year old son who has moderate cerebral palsy and associated medical complications. Generally, I have learned to adapt to the ongoing demands of the daily care routine, but there are times when my life feels like it is in a 'holding pattern' as I put the needs of my son above anything and anyone else.

This is a child I love, for whom I will always attend his needs out of a deep sense of pride and an overwhelming sense of obligation. Like many carers, I am not sure I would even call it a 'choice', yet the past 13 years as his fulltime carer have not been without significant personal sacrifice.

I commend the Committee for giving ordinary, yet at the same time *extraordinary* Australians in a caring role an opportunity to contribute frankly to this Inquiry.

The role and contribution of carers to society and how this should be recognised;

- Before carers can be recognised by society, many need first identify with the caring role.
- Historically, the term 'carer' has been used to refer to a person providing a paid service under contract with an employer. Language is powerful, and a distinction between the terms 'carer' and 'care worker' needs to be plainly established. Once this is established, the term people choose to be identified by eg. 'parent/carer', 'family carer' is immaterial, yet the additional responsibilities undertaken by the person in that caring role are recognised.

Whilst not wanting to portray carers as martyrs, I feel a media campaign to raise community awareness of those in the caring role would serve to help carers self-identify, heighten the value society places on caring and in turn raise the profile of carers generally.

- The establishment of the Western Australian Carers Recognition Act 2004 is a positive step towards greater recognition and consideration of carers by service providers. Universal adoption of the definition of 'carer' contained therein would assist in avoiding any ambiguity around the term. Each State and Territory should enact similar legislation.

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

- Many of the barriers to social and economic participation come down to money it's true. Whilst I am thankful for the modest amount I receive from the Government, I find it crazy that a carer engaged in 24/7 complex care for someone with significant needs is entitled to no more financial assistance than a carer whose caring responsibilities are relatively minor by comparison.

In my personal situation, we access a number of alternative therapies for our son, many of which mean a fair drive in the car. Our allowance doesn't cover the petrol, let alone the cost of any therapy!

I may entertain a system whereby each individual caring situation is assessed, needs recognised and a suite of support tailored accordingly with review in changed circumstances. Part payment in the form of petrol / food / service vouchers may help to alleviate any abuse of the system.

- When I became a carer 12 years ago, I was working as a professional, yet, in my caring day the ability to keep abreast of developments in that field has been lacking, hence my practical skills have lapsed - as has my confidence should I one day choose to return to work. Into the bargain however, many carers have gained untold skills of organisation, negotiation, dedication, research, interpretation, communication

A carer career officer could provide advice and assistance to carers in order to smooth the transition back into the workforce with subsidised up skilling if necessary.

Prospective employers could be offered incentives to give carers returning to the workforce a go.

Employers should be encouraged to negotiate flexible working arrangements to enable carers to continue to fulfil their caring obligations and attend appointments etc.

- I find it very difficult to access respite through our service provider – we are unsuccessful more than successful with our requests, particularly during times of high demand such as school holidays. Finding and retaining workers is an ongoing problem for our NGO.

It is evident that more respite options are required so as to tailor a service to suit families, rather than 'one size fits all'.

Sibling programs need to be supported financially or we will simply see a duplication of the low wellbeing indicators in future generations.

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

(in addition to suggestions above)

- Urgent review of CAEP (Community Aids and Equipment Program). Unreasonably lengthy delays to receiving necessary aids and equipment – with the excuse being lack of funding – impacts *significantly* on the quality of life of the person receiving care AND the quality of life of the carer, possibly through unsafe transfers, inability to leave the home etc.

- Expansion of the Independent Living Centre's manual handling pilot program for all carers
- Access for the carer to 12 sessions per annum with an Allied Health Professional in a discipline that would be complementary to the maintenance of the carer's health and wellbeing (eg. remedial massage, chiropractic, physiotherapy, occupational therapy etc)
- Access for the carer to 6 professional counselling sessions per annum to assist with managing the emotional demands of caring – in order to avoid carers developing mental health concerns themselves. Alternatively NGOs should receive funding to allow employment of social worker to work specifically with the carer in their own right.
- Development and circulation to carers of a state-specific document enabling them to 'navigate the maze' of services and entitlements.
- 'Registration' of Carers and issue of a form of carer card to enable easy identification and accumulation of carer-specific data by way of optional survey and feedback to inform future policy and funding allocation.
- An across government 'Carer Policy' and adoption of the philosophy of the Western Australian Carers Recognition Act 2004 and Carers Charter across State sectors such as Education and Housing – perhaps initially without the reporting requirement.
- Current trend towards service providers becoming more of a 'consultancy', whereby a professional therapist will visit the family home once to instruct the carer on technique - is placing massive demands on already time-poor carers, adding pressures to families and compounding feelings of inadequacy and guilt if the routine can not be maintained. Service providers in the disability sector need to be funded sufficiently to enable needs to be addressed, not just give carers another job.
- Carers worry constantly about what will happen to their child / adult should something happen to them. Lack of ability to accrue superannuation is partially responsible for these feelings and I feel the government has some responsibility to address this situation.

Access to yearly financial advice for carers would assist in making sure carers are making the most of the resources available to them in their personal circumstances.

I thank you for this opportunity to put my passion to paper!

Clare