

A.O.C. 14/7/08

## Submission No. 752

(Inq into better support for carers)

**Sent:** Sunday, 29 June 2008 8:36 PM

**To:** Committee, FCHY (REPS)

**Subject:** Submission

29 June, 2008

### **Submission to the Inquiry into better support for carers**

Although I have worn many hats over some 40 years as a carer – for both a family member with a disability and my ageing mother - this submission is provided in my current capacity as an independent advocate for family carers. My full *Curriculum Vitae* (not for publication), is attached as Appendix 1.

As a member of a Federal TaskForce investigating the needs of family carers, over a period of 4 years I advise that a current, fully researched and investigative report, truly representative of the needs of all family carers, already exists. This report was provided to previous Minister Senator Kay Paterson in November, 2005, and would be available to members of your Committee. I can but urge all members to ensure that they are fully cognizant of this Report, and the Recommendations. As the report was confidential to the Federal Government of the day, I am unable to comment publicly on its contents, other than to say that the word “Carer” in this Report was defined as:-

*“Unpaid family carers of people who were born with a disability or acquired a disability, prior to the age of 65years.*

While the nature of democracy ensures that Governments change – the needs of family carers do not. This never will unless, and until, the Federal Government, of whatever political persuasion is prepared to critically, and honestly, evaluate the use of the word “carer”, and is determined to implement the many recommendations made, to various Governments over the past 3 decades.

These recommendations – and they are also linked to advocacy – are as valid to-day, as they were when they were made. Such recommendations resulted from widespread national enquiries, surveys and public reports.

These comments should be seen as factual, rather than cynical. And my submission is limited to the terms of reference, as published, but based on my personal experience as both a dual carer and a community family and disability advocate.

#### **1. The role and contribution of carers in society, and how this should be recognised.**

The billions of dollars which carers – especially family carers, save taxpayers – and Governments - are a matter of statistical and historical record, but their role is not simply a financial one. They play a vital social role, as well.

This role has never been fully recognised, and cannot be fully recognised until the terminology of “carer”, which is now a generic term, actually delineates their role.

There are many different types of carers:-

“Life-time”	carer	<i>a disability from cradle to grave.</i>
“Time-of-life” -	carer	<i>usually the frail aged- whose caring needs (statistically) span a period of 5- 10 years.</i>
“Term-of life”	carer	<i>usually a disability acquired at some stage of life, genetically, medically or through trauma</i>
“Foster”	carer	<i>The caring role is one of choice.</i>
“Young”	carer	<i>The role is performed by a child/ adolescent</i>
“Paid”	carer	<i>properly termed “support worker”, but generically included as a “carer”. Unlike other carers they have workplace and choice entitlements</i>
“Wild-life”	carer	<i>An optional choice of caring for animals</i>

Now we seem to have “wilderness” carers, protecting nature and the environment. This is not to demean the valuable role played by all, rather to provide practical examples of the generic nature of the terminology. The move to the generic acceptance of the term “carer” was (historically) purely administrative – for ease of welfare and bureaucratic analysis and entitlements. It was strongly fought by parents and families at the time – to no avail.

This administrative trend blurs the various roles of all types of carers, and many of them do it tougher than some others.

The first step in addressing ToR (1) would be to address the terminology and better define the target group of carers. Even your Committee’s terms of reference give no indication as to your specific target group. Is it one, some or all of the various types of “carers” in the examples given – a relevant question, as the needs of all are different. .

## **2 The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment.**

Again, a complex issue – because it is different for all the types of “carers”.

A young carer is deprived of a standard education and critical social interaction which determines their capacity to enter and retain employment into the future.

A “*term of life*” carer could have family responsibilities, a mortgage, and might have to give up their existing employment to perform the caring role, depending on the stage of life and economic position of the person with the acquired disability. Historically this type of carer could be a parent, partner, sibling or relative. Compensation payments, if trauma is involved are not always relevant, and often do not meet the life-time needs, whilst placing some additional burdens on the family carer.

A “*life-time*” carer is often forced into a cycle of welfare dependency – on the birth of the child – especially if there are other siblings and, perhaps, the responsibility of having to provide care for ageing parents/siblings. Post school options, for children with lifetime disability are split between the Federal Government (employment) and the State Government(all other services). I am aware of an area where there were 140 applications in the region for post-school options by adolescents exiting the education system– but only 4 were provided. With no community services, some of those parents will now have to relinquish their professional positions to perform the caring role – at home. Despite all the “social inclusion” ideals there is little or no early intervention or allied therapies for infants, and education is a mess, nationally. The life-time caring role is, statistically, performed by females, with historical evidence of health issues, marriage breakdown and sibling impact. Life-time family carers are now ageing – with little or no provision for their needs and even less planning for the person with the life-time disability, who is prematurely ageing and now being placed, inappropriately, in nursing homes, because their family carers can no longer cope.

The barriers are reduced, commensurate with the type and level of disability of the person requiring the care. Where there are dual or multiple disability issues for carers, then the barriers are even more difficult. Again, where there is a “dual” caring role – further barriers are encountered. It is a statistical factor that lifetime disability, especially of a genetic nature, can mean that a family carer has one, or more, carees (persons requiring care). Additionally, where the disabled person has multiple disabilities, the barriers for the carer and their prospect of entering, or retaining employment are not just diminished but rendered impossible. Planning for a transition out of the caring role/s, and their future retirement has been impossible, to date.

### **3 The practical measures required to better support carers, including key priorities for action.**

These are many and varied but, over the years, Governments have been selective in implementing a long list of recommendations - and there are many reasons for that selectivity.

A summary of possible measures would be as follows:-

- (1) Better identify the target group of “carers”
- (2) Provide those identified and targeted groups with practical, and resourced, advocacy – in line with the recommendations over the past 2 decades
- (3) “Carers” have no legal rights, so there is no obligation for Governments to include them in the development of policy, which influences the lives of these carers. Carer legislation – across Governments is needed. The supposed “whole of Government approach” is a fallacy – it does not exist
- (4) Reduce the burden created by the unnecessary red tape attaching to Centrelink entitlements and streamline the processes for this group of recipients.
- (5) Prioritise early intervention for infants and assistance for young carers.
- (6) Deal with the inefficiencies in the vision of social inclusion in education – and the realities.
- (7) Recognise that regional Australia does exist and that many of those regions are socially and economically vulnerable – especially with the current fuel and cost of living increases.
- (8) Advance the cause of uniform guardianship legislation – it’s been on the agenda for nearly 2 decades. Family carers should have some formal status when they have a proven record of care and responsibility.
- (9) Improve the ACAT process. It is currently being used as a tool to separate Federal financial responsibility from State financial responsibility. An accepted age limit of 65 is too high for people whose disability means they age prematurely.
- (10) Commence some accommodation planning for people with disability who are ageing. Little, or no planning, nationally, has gone into modeling and resourcing the type of services needed by this group. And it’s not just putting them into nursing homes.
- (11) Better collection of data to understand met need, inappropriately met need and unmet need – on a national basis.
- (12) End the “blame game”, which is being used to justify the lack of services and responsibilities between the two levels of government.
- (13) Know the networks that exist, regionally – and use them. Don’t start up new ones which add to duplication and wasted resources.
- (14) Identify the barriers which are government created – by both levels of Government.
- (15) Accept that having Health and Ageing (Aged care and HACC) in one department, and Disability (FACCSIA) in a separate department are internal barriers which create inefficiencies for Government and additional barriers for carers – irrespective of the *type* of carer . Many carers of people with lifetime disability are now also carers for their ageing parents, so they have to deal with two separate departments – as well as Centrelink and the medical fraternity. .

#### 4

***Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity of carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.***

In assessing the role and difficulties of carers it is necessary to understand that the services to assist carers to cope just don't exist – as they should.

More money, better efficiencies in the use of the extra funding, combined with a genuine voice for family carers and greater community assistance are required to make any strategies achieve the desired outcomes.

Choice and option can only be provided by services such as

1. increased and accessible respite,
2. early infant intervention with allied health services like speech and physiotherapy,
3. transport subsidies,
4. assistance with equipment costs
5. an education system with sufficient resources, and trained staff/aides, to make inclusion meaningful
6. a national palliative and hospice care service,
7. improved data collection, at Government level
8. incentives for community to be more involved The availability of volunteers is reducing – not increasing
9. More recognition of and assistance for the role of grandparents
10. Understanding the impact of life-time disability – especially severe disability on the siblings and family unit – whether it's nuclear, blended, single – or whatever. Culturally diverse and indigenous families face additional pressures.

Despite the best intentions of successive governments the reality is that family carers of people with lifetime and term of life disability do not have the same opportunities as the wider community. They are caught in a vicious cycle, exhausted, unable to lobby, caught between two levels of Government, and two departments within those two levels of Government.

Regional Australia is even more disadvantaged.

The current enquiry into the lack of uptake into the Disability Trust option can be summed up by saying that most people don't have the money to plan for the future – they are struggling just to plan for the present. In-home care is turning households into workplaces, and carers with a dual caring role – i.e. disabled child/adult and aging parent are even more disadvantaged.

The average non-disabled parent can do little to improve their financial position for retirement until their children become independent (if they ever do), and leave home. If this is the scenario for parents of the non-disabled, then family carers have an even more difficult task because, unless they are financially secure and have in-built family supports, they are trapped in a welfare cycle upon the birth of a disabled child/children.

The reality is that the needs of a frail-aged person and a person with a severe life-time disability, challenging behaviour, and/or multiple disability are different. The skills needed to deliver services for people with such disability are not generally understood in the aged care sector.

“Caring” is now an industry – it used to be a sector of the community. The number of people with a disability is ever increasing because of modern technology – more live premature births (often with higher levels of disability), increased disability resulting from mothers with substance abuse, more swimming pools, greater mobility because of changing lifestyles and motor vehicle usage increasing the rate of accidents with higher survival rates. Add to this the increased longevity and we have ageing parents caring for an increasing cohort of people with a disability who, themselves, are living longer.

It is difficult to develop strategies until :-

1. the target groups of generic “carers” is better defined,
2. family carers have a genuine voice to work with Governments on the development of policy,
3. there are more resources and services put into the industry
4. there is some genuine planning for the ageing of people with a disability,
5. a national palliative care and hospice service and
6. the “blame game” between State and Federal Governments is addressed,

The development of strategies, as required in ToR(4) assumes the generic “carer” issues are the same. They are not. They can, however, be addressed provided policy makers accept the recommendations of previous reports, and work with targetted carer groups to address their individual needs.

There is no single Carer group which can address the variety of need, an issue well recorded in previous reports. The needs of the deaf, blind, physically disabled, mentally ill and aged cannot be met by one group. This is a matter of record.

The same separation of need and response is required for their carers, otherwise we will still be trying to solve this problem 10 years from now – as we have for the past 2 decades.

The release of the autism package shows the Government is listening, but broader measures addressing the needs of their carers – in the holistic delivery of services is critically needed.

Thank you for recognising the need for public input.