

Submission No. 749

(Inq into better support for carers)

AOC 7/7/08

THE MACARTHUR AGED & DISABILITY FORUM
(Sharing Information between State & Australian Government Programs)
C/- P.O. Box 284, Campbelltown NSW 2560

26th June, 2008

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

Dear Annette,

RE: BETTER CARE FOR OUR CARERS

The Macarthur Aged & Disability Forum is made up of over 100 representatives from variously funded projects that provide services to people who are frail aged, younger people with disabilities and their carers in the Macarthur area. The aim of the forum is to encourage the exchange of information between different sectors to ensure a cohesive and co-operative service provider network within the Macarthur area.

The forum is pleased to offer our submission as a contribution to the debate regarding the needs of carers in Australia and how best to meet those needs. We would encourage the Inquiry to acknowledge the great work of Carers Australia and their input into this Inquiry.

The role & contribution of Carers in Society and how this should be recognised

The contribution carers make to Australian society is immeasurable, in both \$\$\$ value and emotional wellbeing.

It is sad to note that:-

- o carers provide over 90% of the care
- o respite care workers get between \$20 & \$40 per hour
- o services charge respite workers out (due to on costs etc) at \$30 to \$50 per hour
- o carers on a carer's pension/allowance get between approx \$2 per hour
- o carers often have to become welfare dependent to continue their caring role being a carer is not considered employment, so if the person is classed as

unemployed. They still have to do volunteer work or training or risk having their benefit discontinued

A major part of recognising carers is understanding the stress they are under and to provide support that decreases that stress. Carers often say that the extra stress of trying to get into the service system is not worth the effort, especially when they end up with a service that "sort of" meets their needs.

The more stressful the caring situation becomes the more likely the carer will abandon their own support relationships. Often carer supports disappear one by one until the carer is completely alone. Relationship and family breakdown is a major issue and carers are often trapped between their caring role and the role of parent or partner.

The Barriers to social and economic participation for carers (finding/retaining employment)

Some of the major barriers that impact on carers include:

- Competing commitments
- Always being "on call"
- Little recognition of their caring role
- Poverty

How can carers accumulate wealth – their full time caring job does not pay wages, superannuation or provide holidays?

We believe that we as a nation needs to take a new look at carers. Honour them for the role they perform and pay them a wage to continue to care while supporting them with relevant timely respite when required.

The skills carers gain should also be recognized and transferrable to other industries. Many carers wish to get back into the workforce but their skills are not considered "relevant".

Caring is a 24/7 job regardless of whether the carer is live-in or not. A carer's mind is always occupied with their caring role. If the carer is employed they may seem distracted or unable to concentrate because of their other concerns. Over time this employee will be left behind or become redundant in a sector that demands 100%.

Workplaces that can be seen as carer friendly will have an edge in the future. If the private sector can support flexibility for carers they will have employees that are loyal to their employer.

Practical Measures required to better support carers (key priorities for action)

Our ideals and philosophy need to equal the dollar we are prepared to spend.

A system that is straightforward and caters to need

We need to make a community service system that meets the needs of people not programs.

There are so many services that have been set up for respite but all of them are run by different agencies and have different guidelines. In Macarthur no one service provides the range of respite options carers require. Funding has been made available however the competitive process has resulted in a confusing mish mash of services. Add to this the confusion caused with different guidelines for every State, Federal and State/Federal funded programs and people who work in the sector have difficulty making sense of it all, imagine a carer who is already stressed, tired and at their wits end finally deciding to get some respite and they are faced with the above – giving up is a very practical option.

Competition or co-operation

Over the past 10 years more and more players have entered the service system. Unfortunately those winning tenders are those that can employ professional people to write tender proposals. The tender process unfairly disadvantages small community based organisations. While some large providers are respected within the sector many tend to engage in strategic planning that concentrates on the growth of the service rather than the needs of the local community. Often this results in service types or areas becoming nothing more than a dot on a map. We have found that large organisations that receive funding do not engage in community development or partnerships with other services.

Locally based community managed services provide care that is managed by a particular community for its residents. Agency's are usually small and therefore can be flexible to changing need. These agencies may not necessarily have the most up to date technology, know how to use it or have policy manuals that could sink a ship but they do have:

- local people who know the local area
- a commitment to their community
- a base of good will within communities to draw upon (eg sponsorship from local businesses etc)
- a commitment to spending money on service not administration/management
- an eagerness to share ideas and resources
- the ability to try ideas and adapt them instead of spending money on consultants

Local v Regional

Setting up services that cover such a large geographic area they have no "real" knowledge of the area is counter productive causes a high level of frustration with other services and client's. In Macarthur the Commonwealth Information service that is meant to cover our area is not

based locally. A local providers reported one of their clients had said "oh I rang them, first I had to spell the name of the town I lived in, then they just read me stuff off a database". That same person through a local service provider was referred to another agency, informed of a local unfunded support group that had commenced recently and was invited to attend a consultation regarding their needs.

Respite

Regarding respite; we feel that we need less respite providers and those few that remain should provide a greater range of respite. One of the catch cries for competition is people need choice. That may be true when buying a car but if you are 85 looking after an 87 year old husband with dementia you don't care about choice you want one service that will:

- Listen
- Care about your situation
- Provide flexible services to meet your needs (not try and squeeze you into a box)
- Respond to any suggestions, ideas or complaints you have.

Financial Assistance

Carers need access to individualised financial assistance. For example: An elderly couple with an adult daughter with Down Syndrome versus a middle aged single mother with a child with a severe disability who is incontinent and needs tube feeding. The carers get the same pension/allowance. Carer one has said "that they don't need as much money to look after their daughter but they do need services, respite and future planning." Carer two needs additional funds to cater to her child's basic needs as well as access to services, respite and future planning. We need to develop a system with a baseline payment and incremental increases depending upon the complexity of the care provided.

Transport

Transport can be another issue that impacts greatly on carers. For carers who do not live with their loved one travelling often from one side of the city or many hundreds of kilometres in the country is a major stress, particularly with petrol costs increasing, however they get no reimbursement. Carers cannot access HACC funded Community Transport services unless the person they care for has a transport need. Community Transport needs to be open to carers in their own right to enable them to travel to their loved ones home.

Our hospital system

Some years ago a representative of this forum was involved in a steering committee that had input into Day Surgery admission procedures. The representative was vocal regarding the impact transport can have on the provision of day surgery services. The new Day surgery admission form contained a question regarding the client's ability to get to Day Surgery and the provision of information regarding transport options. While we acknowledge that clients are now

asked about their transport arrangements, often they are not given transport options and now they are also told that if they can't organise transport their procedure may be cancelled. We would suggest that being told that the procedure may be cancelled encourages the client to say they can organise transport whether they can or not. This system makes the client responsible for finding their own transport whereas it was the steering committee's intention to identify clients with transport needs so they could be linked by Day Surgery staff to the transport provided by the Area Health Service.

It is important that carers particular needs be taken into account regarding admission and discharge, this could be as simple as organising times of admission to fit in with carers competing commitments or listening to carers to ensure that the client is not unduly stressed in the hospital.

A forum member recently reported that a carer of a person with dementia attended an Area Health Facility. Apparently they had to wait some time before the client was seen. During this time the client became upset and began wandering and exhibiting some challenging behaviours. Unfortunately the carer reported to a local service provider that she was made to feel that her mother was "a nuisance" and no support was provided to her regarding limiting her mother's challenging behaviours by area health staff. We feel that this carer was placed in an extremely stressful situation that could have been prevented if staff had assisted her with strategies to minimise her mothers' discomfort (eg finding a quiet room for the client and carer to wait, providing refreshments).

Some quotes from some Macarthur carers

Self Neglect

Carers often neglect their own health because of the commitments of their caring role. Forum members have often heard carers make comments such as

"My Doctor said I should have an operation – but who would look after Dad – I can only get residential respite for a couple of weeks and I can't organise it to fit in with my surgery because the hospital won't give me a definite date for the procedure."

"I know I am not well, but even getting away from the house for a couple of hours is difficult and I don't like leaving my son with other people"

"I know I can get something from the Government but it's not much and when I looked at all the forms I had to fill out I didn't have the energy to bother with it"

Stringent rules (disguised as OH & S Risk management) can lead to neglect. With regard to a stay in hospital a local carer commented "I couldn't leave Mum there by herself, one day they bought lunch around and put it on the tray table and went to leave, I asked her if she could move the table so Mum could reach her meal, I was told that's not my job." This particular carer

did have to leave her Mum to return home to care for children when they returned from school and she said she felt so guilty and was constantly wondering whether mum was being cared for.

Transitional care is very important for carers. A carer commented that "you go to look at a nursing home and all you get is the sales pitch.....what's it like when I'm not around"

What happens when the caring role finishes. Members of the forum have had direct experience of carers "holding it together" while they are caring and then when their loved one passes away they crash. Then there are no services to assist them because they are no longer "carers".

When asked about work "you mean paid work, I haven't got the time"

"I started visiting Mum 3 times a week and the other 4 days she would come and stay at our place. Eventually she stayed full time at our place. I only visited her house to clean and keep the gardens tidy. There was not time for me to socialise and I couldn't anyway because I never knew about appointments; doctors, physio, hydrotherapy, orthodontist, banking, finances, social security and the list goes on. I attended to Mum's cooking, washing, personal care, health care, medications, shopping, basically everything. There were a lot of personal issues I felt I couldn't talk to anyone else about just because it was personal.

"When Dad went to hospital I wasn't told about any of the community services only the respite that could be provided in a nursing home"

It should be noted that the opinions/ideas and views contained in this documentation reflect the views of the Macarthur Forum Action Group and do not necessarily reflect the opinions/ideas and views of the person whose signature appears below.

Yours faithfully,

Macarthur Aged and Disability Forum