1 December 2008

Committee Secretary
Senate Finance and Public Administration Committee
Department of the Senate
PO Box 6100
Parliament House
Canberra ACT 2600
Australia

Phone: +61 2 6277 3530
Fax: +61 2 6277 5809
Email: fpa.sen@aph.gov.au

On 14 October 2008, the Senate referred to the Finance and Public Administration Committee for inquiry and report by the first sitting day of April 2009:

The funding, planning, allocation, capital and equity of residential and community aged care in Australia, with particular reference to:

a. whether current funding levels are sufficient to meet the expected quality service provision outcomes;
b. how appropriate the current indexation formula is in recognizing the actual cost of pricing aged care services to meet the expected level and quality of such services;
c. measures that can be taken to address regional variations in the cost of service delivery and the construction of aged care facilities;
d. whether there is an inequity in user payments between different groups of aged care consumers and, if so, how the inequity can be addressed;
e. whether the current planning ratio between community, high- and low-care places is appropriate; and
f. the impact of current and future residential places allocation and funding on the number and provision of community care places.

The Secretary

I write to respond and make a submission to the terms of reference indicated above in the current inquiry.

I wish to limit my response to the Governments policy which attempts to keep as many of our elderly in their own homes for as long as possible. I understand this is the 'Ageing in Place' strategy.

What I present is based on personal experience but more recently on resposnes from over 2000 individuals from across Australia. These contacts were made following recent exposure in the The Senior Magazine, Radio National Program 'In the national Interest' broadcast on 8 August 2008 and the 7.30 Report broadcast on 01 October 2008.

The response from carers and individuals themselves has been very much about the lack of direct support for individuals to remain at home. Mixed with these responses were many comments on the lack of sensitivity and responsiveness of Care providers or funds holders to the needs of the aged person but also the family caregiver.

I trust the Committee will accept my submission.

I would be more than happy to speak to the contents of the submission should the Committee see this as being worthwhile.

For and on behalf of the Friends of EACH Action Group.

Submission.

Preamble.

As a community we have been beguiled by the Bureaucracy, the professionals in the aged sector, the leadership of the for profit companies who have entered the aged sector in large numbers and the non-for profit sector into believing that we have the right mix of policies to service the growing need for support to our vulnerable aged citizens.

All too often the sector has been mythologized and, made deliberately difficult for anyone but those intimately involved in understanding its operations and its basis for decision making.

Individuals needing care and their family caregivers are often relegated to the status of mere observers as our elderly citizens and family caregivers are assessed and determinations made about them without real inclusion or understanding about options that may me available. In some instances these options are the least costly and if well supported bring about the best quality outcomes for those whom we as a community entrust billions of dollars annually.

On the question of quality outcomes. There is very little consideration given by the monitors of the billion dollar aged care industry to determine whether we as a community and as tax payers get quality outcomes for the billions of dollars we expend. As indicated above I will concentrate on the packaged care of support in the form of CAPS, EACH and EACH DEMETNIA to illustrate my points below.

In fact in my dealings with Mi9nsterss, their advisors, Bureaucrats within the Department of Health and Ageing and Service providers I could find very little substantive documentation that covered such aspects as measuring the quality of care received by the above recipients, documented studies which spoke of the 'happiness' of individuals receiving care or whether individuals and their family caregivers felt 'well supported' or 'less stressed by the services or supports coming into the home of the individual or the family home should the individual be living with their family caregiver or carer.'

Another aspect that has crystallized over my period of interaction with the Aged Care system is that Non-profit Agencies (and most of these are Church based) are mimicking their for profit counterparts. This apparent development is quite frightening in that all of the for profit motives and behaviors are working towards developing a corporate image and style of operating. In essence this means that quite a deal of funds are being 'eaten up' in administration and case management costs. The non-profit sector is openly competing for customers in the market place. Furthermore in mimicking the for profit providers the non-profits are increasingly using the outsourcing principles to shift risk. In doing so they increase costs of operation and service provision to our vulnerable citizens. A most disturbing development. Provides of services a nowadays no more than 'brokers'. The impact of this development is that ''clients' or consumers' or 'end users' are increasing feeling alienated as to whom they have to deal with if there are issues to discuss. Does one deal with 'Case mangers' or the outsourcing agency that is directly responsible for the supply of the workers. An ethical consideration here is the apparent exploitation of the workers that deal directly

with the end user and the family caregiver. The recipient and their family do not get to deal directly wit the worker as often the worker is moved on or rotated or leaves out of frustration. Poor pay and lack of consistency in developing a connection or a relationship are the critical issues here.

I made reference earlier to the for profit sector. One of the key learnings I made with regards the aged sector is the increasing intrusion of the larger financial institutions that are entering the hostel and nursing home sector. This development is alarming as the element that is the most important element and worthy of consideration by government and policy developers is the community at the local level that is being forced out by the slicker and better resourced applicants for government resources to provide care in this sector. I urge the Committee to consider giving some consideration to the role of the local community recognition as the provider of care of our elderly in the community.

As a point of comparison I wish to refer the Committee to the child care sector in the provision of child care support. As this sector became increasingly privatized costs to the end user escalated. However what we came to realize was that we lost community. We lost that community response that was the basis of child care for many generations in Australia. Having gone down the private provider road we now pay the costs as the profit takers now decide to exit the market. Child care is in a very precarious position.

If we extend this experience I can foresee somewhere down the track when we experience closures of nursing homes and institutional care as the profit takers bow out of the market. The burden of responsibility will then shift back to the individual and their families. It is my contention that aged care should not be a 'for profit' driven sector. Furthermore it does not make sense to grow institutions to 100+ beds. Economies of scale may seem attractive but in a welfare sector where there should be a premium on quality outcomes profit should not be entertained. The care of our elderly citizen's should be a local response if we refer to institutional care in the form of nursing home or hostel care. Wherever possible where individuals can live at home or with families then this option should be made available. The Productivity Commission recently made the point that to keep a person in an institutional arrangement could cost anywhere from $100000 to $200000 per year depending on their level of care. Thus it makes sense to focus policy direction on providing more support to individuals and their care givers to keep those in need of support at home for as long as possible. I maintain that we have a need for a range of options.

It is unfortunate however that current government policies plow a greater proportion of funds into institutional care whilst ignoring the flexibility and cost savings offered by providing supports to keep people at home for as long as possible. Currently funding for flexible aged care packages ranges from an average of $12500 per annum CAPS Packages, to an average of $48000 per annum for the EACH Dementia package.

a. whether current funding levels are sufficient to meet the expected quality service provision outcomes;

As indicated above I will make reference to the flexible packages which target those individuals of both high and low care who wish to remain in their own home or at home with a family caregiver or carer.

It is my understanding that the Packages that a federally funded and fall within this description are as follows:

Low care Packages

Community Aged Care Package (CAPS)	$12,500

High Care packages

Extended Aged Care at Home (EACH)	45,000
Extended Aged Care at Home Dementia (EACH D)	48,000

I wish to examine the EACH D package as this is the package with which I am most familiar with. This package is for High Care needs individuals who are in the early stages of Dementia. In my documented experience more than $33000 of this package was earmarked for 'Case management and Administration'. A sizeable proportion of the package as determined by the recognized provider was designated for this coast to the Provider. This meant that the end user could only access $15000 of the package to purchase 'direct hours of support' to meet the needs of the elderly family member. On the surface the system can justify expenditure on case management and administration as it follows accepted procedure. There was nothing wrong in terms of the legalities of what the agency was doing. It drew up a proposed Care plan did all of the necessary statutory and risk analysis and came up with a figure of $15000 that was available for purchase of direct hours of support. In fact the allocation of $15000 dollars to purchase of direct hours of support was at the upper end of the care support spectrum. Some families have come to me stating that they only get 5 hours of support. There are no stated minimum hours of support that each package must purchase for the end user.

A disturbing factor that became apparent was that recognized providers determine the menu of supports, the level of expenditure and who goes into a person's home. There appears to be 'negotiation' in the development of the model of care for each individual. However in reality the end use or the end user and their family care giver are often told what they will receive. In fact many respondents have come to me to state that they were never told as to the type of package or the dollar level of the package of support offered to their family member.

As a person who has trialed Consumer directed models of care in the Disability sector I felt that it would be an easy transition to apply the same model of care in the aged sector. It became apparent to me that governments and the Bureaucracy could not intervene nor direct providers to allow for innovation or to direct provides accept models at variance "with their business model' as one provider told me. It became apparent to me that recognized providers would not consider a consumer directed model of care even though there were demonstrable advantages to the person being cared for, to the primary caregiver and to the system as a whole.

Eventually I was able to put into operation a Consumer Directed model of care for the care of my mother. The assistance given to me was a very proactive service provider by the name of Uniting Care Community Options located in Melbourne Victoria I was able to get some 30 hours of direct support and Consumer control albeit somewhat limited. If I had total control I believe I could have obtained more than 30 hours of direct hours of support.

As with most families caring for an elderly member or individuals living at home alone their basic requirement is direct hours of support and dollars being spent on their care needs. I like many other individuals could self manage the fund, determine the program, employ the workers and organize with the assistance of the funds holder, (the recognized provider) payment of the workers. I have attached for the Committee's benefit a copy of a document which explains in a little more detail how this model can operate.

The point I wish to make is that to keep people at home we a community do not necessarily have to use more money. We need to be smarter about how we use existing funds smarter and more effectively. For every year I kept my mother out of institutional care arrangement I was saving the system anywhere from $100000 to $200000 per annum. The cost to the system was my time and a contribution in 2007 to 2008 of approximately $48000. I had at my disposal an amount under $40000 to pay for all of the direct costs of care. I got twice the number of hours out of the same dollar value package.

I wish to remind the Committee that as a community we cannot continue to grow the infrastructure and the care system without exploring a range of options for care in the home. We must also consider the benefits in terms of quality outcomes for the individual being cared for and the family caregiver by allowing the consumer directed model of care to be driven or directed by the family or the individual if the individual is competent to do so. Additionally I was able to crate another 15 hours of paid work. This example is one where I can quite confidently say that there are benefits for all

concerned however I wish to state this option is not for all. Again I wish to state that the more than 2000 people from across Australia are willing to have more hours of support if it means they will need to put in some hours to 'run' their Consumer model of Care.

b. how appropriate the current indexation formula is in recognizing the actual cost of pricing aged care services to meet the expected level and quality of such services;

With regards the packages I have referred to I believe indexation is appropriate however I believe there had to be consideration given to regional and state pricing differences. Additionally there should be a travel cost factor in rural and regional areas where the cost of travel to and from care placements becomes a major component.

c. measures that can be taken to address regional variations in the cost of service delivery and the construction of aged care facilities;

Again I make reference to regional price differentials and the cost of travel as a factor that needs to betaken into consideration when determining the level of the flexible packages. A package of $48000 for an EACH D package in a metropolitan area can buy a lot more support or programs than it can in rural areas. It is impossible to determine why a recipient of an EACH D in outback Queensland would receive a package of $48000. Government policy planners with all of their data and research behind them should be able to understand that it would cost more dollars to get supports in place for an individual in this location. There should be a deliberate increase in the fudging level to take account of these regional; factors.

d. whether there is an inequity in user payments between different groups of aged care consumers and, if so, how the inequity can be addressed;

It is quite evident that the package care differential between those getting flexible care and those entering institutional care is quite large. Furthermore there is a large gap between low and high care for those wishing to remain at home. It is my contention that greater expenditure be placed in the provision of not only more flexible packages but these packages should be considered on an individualized basis. This will require greater training of the ACAS assessment teams and the inclusion of family members the individual and the medical sector in planning and determining the most appropriate form and level of financial care to implement a care support package. Wherever possible the care package should be directed by the individual or by the family caregiver under the principles of Consumer Directed Model of Care as referred to elsewhere in this submission.

e. whether the current planning ratio between community, high- and low-care places is appropriate;

I believe the government should spend more dollars in flexible care packages to allow individuals to remain at home for as long as possible. Institutional care as has been reported to me by many respondents is nit their preferred option. The care system must be able to offer a range of options. As demonstrated above there are benefits and cost savings to the system by keeping people at home in their familiar environment.

f. the impact of current and future residential places allocation and funding on the number and provision of community care places.

It is my belief that government should give greater weight to funding flexible packages and try to keep people in their own homes or in the homes of willing family caregivers. In recognition of this factor governments should consider greater financial support to caregivers in the form of respite hours for the provision of the support in their homes. I would also suggest the Carers payment should be non means tested to allow Carers to take on this role should they chose to do so without this decision impacting on them financially. Another consideration is for the government to increase the Carer payment to make caring a much better option financially for many who have to forego work as an option.