

AOC 2/9/08

July 11 2008

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

### **Inquiry into Better Support for Carers.**

#### **Preamble.**

It is with great pleasure that I make this submission. In doing so, I wish to pay tribute to those who have come before us who worked hard to allow us this opportunity to propose and to solve issues in a creative and civilized way in this great community. Furthermore I wish to state that we as community in this our Commonwealth have established institutions which are the envy of the world. All too often as a community we seek best practice models and feel that they are to be found outside of Australia. In fact these models we look for are already here and in many instances creative individuals and family caregivers have broken new ground and created pockets of excellence. However the lack of resources and sometimes the lack of willingness on the part of some elements of the Bureaucracy and vested interest are not sufficiently motivated or inspired to give life to these creative approaches by Carers. In most cases the Carers are family members. As Carers these family members do not have the financial and physical resources to spread the word.

Approaches by family members towards different and alternative models of care aimed at caring and supporting our most vulnerable are unique and out of the ordinary. These approaches are created by extraordinary people who simply have refused to accept the standard model offered by a care system that is driven by our centralized and cumbersome bureaucracy often supported by their satellites; the providers and peak bodies.

It is our belief that by co-operation and consultation and the exchange of ideas in a frank and fearless manner that positive outcomes in a quantitative and

qualitative sense can be achieved. Consultation has to be meaningful and respectful. Those with lesser resources need an avenue to have their voices heard by way of regular forums and open door policies of government and responsible Ministers.

In this way we believe that we can allow opportunities to permeate through the various layers of processes that we recognize as our care system. Exchange of information and ideas needs to be bottom up as well top down. Eventually with the oversight of government and responsible and dedicated Ministers who show vision and leadership new ideas that come from the grass roots can be given life and form part of the range of options in our care system. These ideas will eventually be taken up as 'a natural way of doing things'. We strongly believe that it is through opportunities such as this consultative process and in the future opportunities for regular forums that give voice to the ordinary citizen to have their ideas and issues heard, understood and hopefully acted upon by government.

### **The professionalization of the care industry and marginalization of the carers.**

Having said the above we wish also to say that we have seen the development of a community that is fast becoming 'professionalized' and also a society where knowledge is not being shared equally despite the developing technologies. Ordinary people who do not have access to knowledge cannot build capacity or gain from the progress made broadly in our community. Individuals who become Carers in many instances have been brought down to the level of dependents. As Carers we wait. We are told and all too often we are not told enough about what is available in terms of care and respite available for us as Carers. Neither are we told of options and care available for the people for whom we provide care.

As Carers we often hear local governments talk of the 'lack of uptake of services offered'. Yet we see in many local government environments an ever expanding level of infrastructure and bureaucracy which farms out or outsources the delivery of services to our aged citizens and Carers.

Disability service bureaucracies speak of families coming to them if they wish to propose an idea for a support or where they wish to do things differently. If Carers do not know how or are not able to seek independent support and advice then this proposition of the Bureaucracy is nonsensical

We hear in the area of aged care of the assumptions made by the professionals in this care sector that families do not wish to care of their elderly family member. This is not correct for the majority of dedicated and loving family

members who devote themselves to the care of their aged family member or person with a disability.

This dedication is taken for granted and often abused by the care system. Caregivers are exhausted and in many cases feel powerless to ask for more assistance. When they do they are placed on waiting lists or threatened with removal of services.

Furthermore the professionalized sector often makes statements and pushes these as factually based claiming that our elderly citizens are not competent or capable of looking after themselves. This may be true for some however there is a vast number of our elderly citizens who have been shut out of the policy development or the debate into how care services should be delivered and the extent of their involvement. Moreover this same professionalized sector together with their vested interests propounds the view that the elderly are abused. This again may be true in some instances however this is not true for all. Caregivers are committed to the care and welfare of those their family members for whom they provide care and support.

It is our contention that the professionalization of the care sector has created interests which crowds out the committed individuals who wish to provide care and support. In essence what we have now in Australia is big government, big providers and the peak bodies. As a consequence of this concentration of power in the few hands there is little room for the individual or small community agencies to propose or develop ideas. Many large agencies fit the bureaucratic model and often mimic it. Furthermore as the large agencies become corporatized they develop power and quite often hold the bureaucracy and government to ransom. There is always the threat of services being 'unplugged' or 'withdrawn' if the providers do not get what they want in terms of the resource dollars. Lip service is given to community capacity building. As a community we need to educate people how to become involved and take control of their caring situation. Indeed we believe the care system is imposing dependency upon our most vulnerable and the Carers. It is ironic that in a free market economy we do not value independent initiatives and giving people the option to manage and control their lives or support family caregivers to be in control when caring for an elderly family member or a person with a disability. As a community we have created the fiction that only governments together with their satellites in the form of providers and peak bodies as the spin doctors can provide care that is efficient and valued.

This fiction that has been perpetrated upon our community has seen vast amounts of resources sucked out of the system to pay for the massive infrastructures that are required to satisfy the needs of the system that is broadly

paper driven. This system has very little time to consider what actually happens at the coal face. There is very little quality control or monitoring of the quality of services delivered or what we consider the 'happiness factor' for those receiving assistance from providers. The 'coal face' is the place where Carers carry the bulk of the burden of our care system. Fundamentally we cannot continue to grow the bureaucracy and the consequent investment in maintaining the system. In speaking of the Care System we seek to clarify this by referring to it as it pertains to the provision of care and support for those wishing to stay out of the institutional model of care. In most cases this means remaining in their aged person's home or living with the Carer.

It is becoming evident that the Care System can see the benefits in cost reduction in keeping people in their homes for as long as possible. The Care system is straining at the seams. Carers are becoming exhausted. Carers save the system 'bucket loads of money' as our Primer Minister recently stated on Four Corners. Yet Carers are being loaded up with ever growing burden of the care responsibility. Policy makers and governments are not listening to the cries for help by Carers.

Carers require greater opportunities for respite. However we need to link the respite to the packages available to the person being cared for. Furthermore information about options and how these can be accessed and controlled by the Carer and the care recipient should be made available.

### **Development of Independence and encouragement of ideas**

As a community we should be turning the tables and developing and valuing independence of action and thought as it pertains to the caring role of Carers. As a community we have been beguiled that others can do it for us. We now wait, we are case managed for services that fail to arrive, and we are placed on waiting lists for support and respite. It is apparent to us that many of the policy makers whether they be employed by governments, providers or peaks have had in their lives 'many years of air conditioning and ducted heating'. They are in many cases far removed from the trials and tribulations of Carers who 'are doing it tuff'. As Carers we wait for policies and guidelines' to be developed. In many instances these policies are developed without proper and respectful inclusion in the process. Sometimes individuals needing care and support die waiting. Often Carers die waiting for the support and respite they require. Some Carers refuse to die and carry one well into their nineties. Many Carers when they die they die without knowing what will happen to their child who may also be aged. These elderly Caregivers die without having being supported or assisted in the development of plans for the support of their loved one following their death.

In legislation especially as it pertains to the Disability sector Caregivers are not recognized and often are referred to as the 'the significant other' in the life of the person with the disability. In the aged care sector we need to strengthen the rights of Carers

In a legislative sense we need to have a national and accepted definition of a Carer or Caregiver. We do not have a defined legislative position on the rights and entitlements of Carers.

Furthermore the role and position of Carers is impacted upon by the operation of various bits of legislation and regulations of subordinate bodies. Practices imposed by bureaucratic bodies and providers also impact on Carers. These need to be investigated and dealt with. In many cases the Bureaucracy is impotent to act or direct how services are to be delivered or indeed how Carers are to be treated by recognized providers. The providers once they have received funds put into place their own practices or models of care which in most cases individuals requiring care and their Caregivers have had no input into nor any involvement.

These matters need to be addressed.

Additionally if Carers move from one state to another they confront the disparate rules and guidelines of states in our Commonwealth pertaining to the delivery of care and support if any for Carers. There needs to be a streamlining of approaches to the care of our disabled and aged and those caring for them. Furthermore we also need to address the differing approaches and responses to the need of Carers by local governments across our Commonwealth.

***It is our firm belief that Disability and Aged care support for the individuals and their carers should be the domain of the Federal Government.***

**We need to work collectively and respectfully.**

All too often carers are marginalized by the care sector which we define as the Bureaucracy administering the various funding packages, providers, peak bodies and local governments.

In most cases Carers are the least consulted and the least included. More attention is paid to the occupational health and safety needs of the workers and the risk management of the funded agency or local government authority than the needs of the carers and the person being cared for.

We believe that industrial issues take precedence in determining the role and place of Carers. Industrial issues are important as we also value the role of the care workers employed in the care of our most vulnerable however there needs to be a consultative approach whereby all players are included in the determination of employment policies and Occupational, Health and Safety concerns for workers working in the homes of our aged. All too often as has been reported to our group that providers find reasons not to deliver support based on Health and Safety issues.

Additionally Carers are further marginalized and excluded by the threat or potential of guardianship.

We believe that the voice of Carers is eliminated by some segments of the care industry who are more concerned about their power over the individual being cared for. The other element that comes into focus here is the fact that carers are not organized. This lack of organization and effective representation means that the voices of carers are not heard or taken seriously. Policy makers hear the voices they want to hear by funding those organizations that play to their tune.

Care for the Carers is a function too often of the location, the state and the provider who is the holder of the package of money. The manner in which the funding dollars are allocated focuses solely on the care recipient. We believe there should be no distinction between care for the individual and the Carer. To get the best outcomes out of the funding dollars available then the needs of care recipient and the Caregiver should be viewed in a holistic manner.

We are also of the belief that there is little independent information for both care recipient and caregiver. The so called peak bodies do not represent all of the Carers in a realistic and affirmative manner. Funded bodies cannot truly be independent especially if their work is determined by the dollar input by the funders.

The debate with respect to Carers needs and the manner in which policy is developed should take into consideration the inclusion of Carers in a meaningful way.

Forums and public meetings should be utilized more often at times more appropriate for government and policy makers to determine the needs and views of care recipients and Carers. Furthermore Caregivers should be given respite so as to attend such forums and meetings.

If we bring into the equation the experience of our minority communities we note that the issues faced by these are greater than those faced by the mainstream.

If the peak bodies represent the Carers and those being cared for then why do we still talk about the state of the care sector and the plight of the carers? We also have had develop in our community a 'Multicultural apartheid'. This approach relegates the needs of our minority communities to the poorly funded and in some instances non funded community groups to represent and argue for the needs of the care recipients and Carers from these minority communities. What is difficult to understand is that the mainstream services providers and state governments have developed policies for these minority communities. In reality these policies are just lip service to the needs of the carers in these communities. We need to stop thinking of the needs of CALD communities. We need to think of the needs of our vulnerable citizens and their Carers.

### **Growth of the Bureaucracy.**

As Carers we believe that the most frightening factor in the provision of care is the growth of Bureaucracy. By bureaucracy we mean the governmental bureaucracy and the bureaucracy of the providers that mimic the governmental bureaucracy. The infrastructure costs and the 'leakages' out of the care system going into Case management and administration is rising alarmingly. Added to this is the increasing intrusion of the for profit sector which is also adding to the cost of providing care. This leakage is taking resources out of the care system which are desperately needed to provide more hours of support of the care recipient. These extra hours provide more opportunities for respite for the Caregiver. As a community we need a reality check and ask whether we can continue to 'grow the bureaucracy'?

We believe that we cannot sustain this growth and the consequent leakages form the system of resources that can be more effectively applied if we thought and acted more creatively.

### **Proposal of a model of Care**

We believe that all things start off as ideas. We hope to contribute some ideas in this submission and allow the Standing Committee to determine the merit of this contribution.

Having made the comments earlier we wish to propose an idea that may be considered by the Standing Committee.

We have come to realize that ideas that come from the 'grass roots' are often ridiculed, disparaged and most often taken up by the professionals, repackaged and sold off as their own idea.

We do not mind this takeover. We all can be accused of taking ideas and repackaging these. What is important however are acknowledging where these came from and more importantly paying tribute to those at the coal face who dared and struggled and were able to achieve small changes that allowed others to think differently? In many cases these were in fact Caregivers caring for a family member.

We wish to acknowledge those Carers that came before us and struggled to achieve some changes for their loved ones and also changes that reduced their burden of care. More importantly it is these 'small people' that have inspired us.

There are many examples of individuals breaking new ground for others to build upon. Indeed many of our large care agencies which now run on the corporate models were in fact begun by family caregivers and community minded supporters. We must also pay tribute to the volunteers and the many fine examples of care provided by providers in both disability and aged care.

It is evident to us that Carers are the engine room of the care sector. They generate the energy and the drive that keeps our care system functioning. There are reports that the cost of replacing the care provided by Caregivers would cost the community billions of dollars. Caregivers are the drivers and development of ideas as they are the closest most often to the person being cared for. This closeness allows them to view problems and issues in a practical way and hence can make proposals and suggestions for the improvement of the care system we have in place.

We do not wish to disparage and eliminate the care system we have in place. However we do believe that we need to open up the system allow for ***choice and options*** for the support of our vulnerable and the way care is provided for them and the Carers. The proposal we make focuses on the care and support of our elderly citizens to remain at home. In many cases the bulk care provided for those wishing to remain at home is provided by the family as the primary caregivers.

Having said the above we need to ask ourselves as a community can we do better?

Can we as a community be more effective in providing support for those with disabilities, those who are frail and aged and their caregivers?



Are we getting value for the dollars expended?

And finally are the recipients of the support and the caregivers happy with the support they receive. In other words are we getting quality outcomes for the dollars expended?

We believe we can do better as a community. We do not believe that as a community we are the best we can be. We do not believe that caregivers are well supported. Others submitting to this process will no doubt write on these issues in more detail. Suffice is to say that carers are not happy with the care provided and the manner in which care is provided. Carers are increasingly bearing the cost shifting and care shifting responsibilities thrust upon them by a Bureaucracy that is closely linked to the providers through legislation and practice. Practices such as the imposition of the case management model as the only model of support for those in our community needing care and support.

We say this because an incredible thing happened earlier this year. Following articles in the Senior Newspaper of March, April, June and July the "Friends of EACH Action Group has been inundated with emails and phone calls in response to the story of a real and operational Consumer Directed model of Care provided by an individual for the care of his mother.

The Bureaucrats and the funded bodies (the holders of the funded package) were adamant that the 'guidelines did not permit such a model of care in Australia. Furthermore the bureaucrats and providers alike were adamant that 'case management is attached to the funding' In layman's terms this means that the funding made available would only be provided to the care recipient with a case management component whether the receiver of the benefit wished to have case management or needed it. Factually speaking what has been discovered is that there is no legal requirement that funding must have 'case management attached'. Additionally some correspondents have reported that the only way support would be provided was if the family caregiver resided with the care recipient.

***These matters referred to above need to be addressed by the Standing Committee.***

This Consumer Directed model of care has now been operating in Australia in the Aged Care Sector under the EACH Dementia funding package since November of 2007. Prior to this the same model was operating under the HACC Linkages program in Victoria for a period of almost one year. Furthermore, there was an instance in the past where a similar Consumer

Directed model of Care was operating out of Bundoora Extended Care Center in the 1990's under the HACC program.

We provide an attachment which elaborates on how the Consumer Directed model of care operates. Incidentally this model of care was first proposed to Minister Julie Bishop, then to Senator Santoro then to Christopher Pyne and then to Senator Justine Elliot.

None of these people mentioned above considered the proposal that was put before them. We have yet to receive directly from them note telling us whether the proposal has merit.

The only reason the model is now operating is because of the sheer persistence of the family and the individual who dared propose and challenge the 'guidelines' and the 'Aged Care Act 1997.'

The same individual has attempted to make this available to other family caregivers however restrictions have been imposed. The development and availability of this model of care as an option is limited because of the current funding arrangements which means that funding can only be held by recognized providers. These providers may wish to allow the Consumer Directed model of funding currently in operation in Victoria. However in reality there has been a reluctance to open this model up to other individuals and family caregivers. Furthermore the lack of desire and willingness on the part of the bureaucracy to champion this model is indicative of the complicity one sees with the 'rusted on' flat earth believers who still believe in the Case management model as the only model of care that has any merit.

The Aged Care Act 1997 provides that only recognized providers can receive funds from the federal government for the care of our aged people. Family members are not considered as safe guardians of government funds.

***We beseech the Standing Committee before whom we bring this submission to recommend that family caregivers whether they provide support for people with disabilities or elderly should have an option to self manage or be in control of how the available funds are utilized. Consumer Directed models of care should be made available as an option of care and support to those individuals who wish to take up this option.***

The Consumer Directed Model of Care allows for the carer and the person being cared for purchasing many more hours of care and support than under the traditional case management model of care. Our correspondents report that Carers desire more hours of support to allow them respite and indeed time to take on positions of employment. Another important outcome is the

improvement in quality of care for the person being cared for as there is consistency in terms of the care support provided.

### **Brief Description of the Consumer Directed model of Care as it operates currently in Victoria.**

The following is not theoretical. It is in operation.

Normally under the case management model the funding is allocated and attached to a person seeking care. The funding is then allocated to a provider to determine a care plan and supports. The providers in 'consultation' with the Carers determine the care plan and puts in place care supports. This is intended to provide care and by extension respite time for the Carer. We say this because there exists an expectation from the providers that the 'only way a package will be granted is if the carer lives with the person for whom the package is allocated'. This is invariably a precondition for the allocation of the package of care. Here we refer to EACH and EACH Dementia packages as examples of that experience and precondition imposed by the provider. We are informed that this imposition by providers is common.

The Case management model as indicated earlier is jammed packed with Case management costs, administration costs and outsourcing costs. These costs accumulate and the end result is that between 70 and 80 percent of the package is dissipated in costs and is not utilized to purchase hours of support that is required to assist the person being care for and as indicated earlier the provision of respite for the Carer. There is very little scope for the assessment or consideration of the quality of care provided and support provided by this model to the person being care for and for the caregiver.

Under the Consumer Directed model the drivers of the supports are the person being cared for and the caregiver. The care recipient and the Caregiver determine the program of care, selection of the workers and the application of the available funds.

The power for the care recipient and Caregiver stems for the fact that there is now greater funds available for the purchase of hours of support. The Caregiver acts as the Case Manager. This simple action eliminates the unnecessary burden of cost and leakage of funds. In this model more than 70% of the funded dollars go into purchasing hours of support and items required for the direct care of the individual being care for. Under the Consumer Directed approach the Funder (government) allocates the funds to the provider and the provider becomes the keeper of record or 'banker'. The provider can be invited

to participate in the selection of the support workers and the development of the plan. The support workers would be paid by the provider and in a technical sense, because neither the care recipient nor the caregiver can be providers, the provider is the employer for legal purposes. The provider will issue the group certificates and be the keeper of record in terms of wages paid, workcover costs and superannuation.

However the worker belongs to the consumer. The care recipient together with the caregiver who acts as the Case Manager has control over the funding. This model can be simplified if the Caregiver Case manager is provided with a level of education to be able to learn how to comply in terms of accountability and reporting to the 'keeper of record'.

For the administrative support provided the holder of the funds is paid an administrative fee. This fee can be negotiated. Furthermore the Caregiver Case Manager can also purchase hours of support to assist in sourcing programs, development of a care plan or assisting care support workers.

The outcome of this model is that the Caregiver can increase the number of hours by a factor of 2 to 5 depending on the arrangement that would have been put in place by the provider that would have originally held the funds.

This calculation is based on factual information provided to the writers.

In establishing the model of funding that we have termed Consumer Directed the individual in question has been able to eliminate unnecessary case management and administration costs. We can further illustrate this by way of a case study below

### ***Case Study:***

On average an EACH Dementia package is worth \$48,000 at the time of writing.

Of this amount only \$15,000 worth of care hours can be purchased under the case management of care and support for our elderly citizens who wish to remain in their own homes. This is a maximum.

Indeed many of the correspondents to the 'The Senior Newspaper' article referred to earlier reported that they received between 4 and 12 hours per week. In fact many of the correspondents had no idea of the monetary level of their funding package.

What the above case study demonstrates is that there is about \$33000 that goes to Case Management and administration under the widely utilized model of Case management funding in use by many providers in Australia.

**We strongly urge the Standing Committee to investigate how much of each funding package (whether this is funded directly by the federal government or federal contribution is made towards the funding) actually reaches the person being cared for.**

Please keep in mind that carers have the Commonwealth governments to paraphrase our Prime Minister; 'bucket loads of money.'

The question the Standing Committee may wish to consider is the following.

***As a community are we providing the best range of options in a timely and cost efficient manner?***

Currently we have large amounts of funding some of which targets disabilities, aged care and support for Carers. It is our contention that the bulk of these community resources is expended on creating infrastructure to deliver services and is 'eaten up' by case management administration costs in delivering of services to our vulnerable citizens.

In the Case study above it has been demonstrated that more than 70% of the funded dollar goes to Case management and administration. Under the current case management model approximately 30% of the funded dollar goes to face to face support. The consequence of this 'leakage and obvious inefficiency is that the burden of care is shifted to the caregiver.

***Another example to illustrate the point.***

CAPS and HACC models of care are run under the case management model in most cases by local governments and large organizations. An average package in this model of delivery is worth about \$12,500 upon receipt from the funders (usually Federal, state government funding topped up by some local governments). This \$12,500 translates into 2 to 3 hours of face to face care. In fact 2 hours would be considered the care industry norm.

***\$12,500 dollars buys two hours of care per week!***

If we accept that workers at the coal face receive \$20 per hour (this would include oncosts per hour) then the weekly cost of delivering the face to face support would be \$40. Over one year that cost would be just over \$2000 per year.

### ***More than \$10000 goes missing!***

This approach is an accepted industry approach in Australia. In fact many local governments take pride in the delivery of the two hour average of direct care to our elderly citizens! As a community we need to take a good look at ourselves! This is sheer waste and scandalous that so little of the dollars get to where they are required. Carers could do with a lot more hours of support. Based on the above the Carers are being shortchanged. It has been reported to us that the expectation by those offering the support hours are that the 'Carers take up the slack'.

*We request that the Standing Committee demand of local government and providers why it is that this is the case and why is it that local governments can only offer only 2 hours of face to face support.*

*Additionally we respectfully request for the Standing Committee to investigate the reasons why we have this ludicrous system of 'full cost' recovery' if care recipients in receipt of federal funding request support from local government.*

The other question we need to ask ourselves as a community can family caregivers do more if they were able to have a measure of control over the available funds.

In the quest of the family caregiver in Victoria to obtain control over his mother's EACH Dementia package he requested control over the available funds.

He stated to the providers and bureaucrats that ***He did not want more***' All he wanted was control over the available package as he reasoned that he could get more hours of support out of the available funds.

Initially he was refused but eventually he succeeded in gaining control and developing the Consumer Directed model of care. He was able to find one caring Provider who was prepared to take a risk and allow him to operate this model of care with federal funds. The provider, Uniting Care Community Options in Melbourne is to be congratulated for their foresight and willingness to allow for innovation to strike fertile ground.

In obtaining control over the funds he was able to translate a \$48,000 into about 35 hours of face to face support. In comparison under the much lauded 'Case management model the best he could ever get was 15 hours per week. This depended on the time of day and the day of the week he needed the care for my mother. Under the Case management model more than \$33000 leaked into Case management and administration!

***We urge the Standing Committee to recommend that family caregivers should be given the option to choose the Consumer Directed model of care.***

However we wish to remind the Standing Committee that there needs to be a level of promotion and education that provides sufficient information which informs and teaches those who wish to self manage and take on the Consumer Directed model of care. Indeed there are individuals who are quite capable of self managing their own packages without the need for the direct involvement of a family Caregiver.

The benefits of self management are that the individual is in control and drives the dollars further!

The current model of funding is creating an atmosphere of dependence and reliance on the professionalized sector which clearly cannot deliver because most of the funds are not available for face to face support. Carers need more hours of support. Further, as we age as a community there will be a greater need for face to face support in order to allow elderly to grow old within their own communities. The option of self management is a win for the people being cared for and the Caregivers.

In giving Caregivers the option to self manage packages together with the person they care for does not of itself mean that we do away with the care system we have in place. There is still room for the institutional care and the care provided by government funded agencies. Consumer Directed models of care allow people to have quality of life within their community and around their family without causing exhaustion to their caregivers family members. Keeping people out of institutions is beneficial for the individual and the community. Individuals and family caregivers get better outcomes and the community saves resources.

For those fearing workforce implications it is quite evident if we increase the amount of available funds for direct face to face care then more work opportunities will be provided.

### **The need for Independent advocacy.**

We implore the Standing Committee to recommend that funding be provided for independent and meaningful advocacy support for individuals and their Caregivers. Independent advocacy will also assist care recipients and Caregivers assisting to receive information about the Consumer Directed model but more importantly the independent advocacy body will act as a check and

balance mechanism on the possible intrusion of the bureaucracy or the providers into the lives of individuals who choose to go down the Consumer Directed road.

In conclusion we wish to state that the Consumer directed model may not suit all care recipients or Caregivers. We propose that this model of care be made available as an option. This availability needs to be supported by information training and independent advocacy support.

We make additional comments below under the four categories of the terms of reference.

- *the role and contribution of carers in society and how this should be recognized;*

It is self evident that carers make an incredible contribution both qualitatively and quantitatively.

Carers' contribution can be recognized in a number of ways by government:

- i. Increasing the care allowance and carer payment.  
The current distinction between care payment and care allowance should be abolished. The level of monetary contribution should be determined by the level and nature of the care provided. We have already an accepted level of care assessment by various bodies recognized at a variety of governmental levels that could assist government in developing an appropriate assessment tool for this purpose. The carer payment should reflect the level of care provided and the need of the carer.
- ii. Allowing carers to cash out the carer package money so that they can be the drivers of the care provided.
- iii. Not including the care payment as a taxable income. Similar to the DSP.

- *the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;*



- i. There needs to be a cultural shift on how we value carers and the contribution they make. Valuing them financially will certainly remove the stigma and the financial burdens imposed. However there is a need for greater levels of respite to allow carers to maintain and sustain themselves so that they can have a life outside of caring. The Consumer directed model of care as an option will allow for more hours of face to face care that can be purchased by the available dollars

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

- i. Practical measures are dependent on the type of person being cared for the age of the carer and the location of the carer.

Options for carers should be increased to allow for a range of caring models dependent on the need of the individual being cared for and the needs of the carer.

One of the options proposed here is to allow as option consumer directed model of care.

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

- i. Unless carers have access to information and independent advocacy their choices are very limited. Furthermore if their language skills are also limited their choices are also limited. For far too long we have had develop an expanding bureaucratic structure aided and abetted by the 'peak bodies' As a community we have been talking for far too long, funding advocacy bodies to undertake 'Systemic changes' and yet we have not moved forward.
- ii. There are no opportunities for family caregivers to propose or test ideas for approaches to care that meet the needs of the individual and the caregivers
- iii. There are no opportunities for the caregivers to approach and deal with providers. Recent articles in the Senior Newspaper referred to above on the plight of carers and the options they have created have brought to the fore the need for additional support for carers and a recognition of their contribution as carers. Many carers across Australia, especially those caring for elderly family members were in fact alarmed to learn as to the level of the care packages. Many correspondents were alarmed to learn of the level of 'waste' in the

system. Many carers were alarmed to learn that it was possible to increase the number of care hours with little cost to the system.

To assist the Standing Committee we have attached the proposal that was submitted to Ministers' for Aged Care during the administration of the Howard Government and the current Rudd Government.

We have also attached correspondence sent to Prime Minister Howard and Prime Minister Rudd.

We wish also to make it known to the Standing Committee We are able to address the Standing Committee and elaborate on the Consumer Directed model of funding that is currently in place for one of an elderly mother in Victoria who is receiving an EACH Dementia package.

George Vassiliou for and on behalf of the EACH Dementia Action Group.

[Top](#)

3 March 2008

The Prime Minister of Australia

Mr Kevin Rudd

Parliament House

Canberra

ACT

Re: Care for our elderly

Dear Prime Minister

I have taken this opportunity to write to you to thank you for your interest in considering the needs of our elderly, especially those who are most vulnerable. I note too your interest in the care of those suffering from Dementia.

I am encouraged by your fresh and no nonsense approach to dealing with issues in our community. Furthermore I am encouraged by your willingness to listen to ideas and the invitation made to the community.

Prime Minister I have been lobbying as a citizen of this country for changes to the models of care available for the care of our elderly both at the state and federal level. On a personal level I have been successful in implementing a model of care for my elderly mother who is in the early stages of dementia.

I have tried to inform other families and individuals about my success and to get recognised providers to think differently and to offer alternative models of care. However their response has been less than what I would have expected given that I have trialled a very successful consumer directed model of care for my mother. This model of care had been operating since November Of 2006.

In the last week I have been able to get interest in the model of care operating for my mother in the media. 'The Senior' newspaper has run a story on this model. Following this story there has been a flood of emails sent to me by very concerned family caregivers from across Australia who wish to try the same method of care delivery that I have for my mother. Mr Prime Minister there are many families who are obviously happy with the standard model of care provided through the systemic model of care. However increasing I feel that the system is letting down families who care for older people and our elderly who want to try something different. Of great concern for the families was

the very limited hours of direct care provided to those through our various funded models of care. Time and time again the families that have written to me have complained about the need for more hours of care. Time and time again families have complained about the waste they can see in the system as it operates at the moment. Indeed on this very point I raised the same matter with the former Prime Minister Mr Howard. Additionally I have raised this issue with the previous responsible Minister who at last count numbered three that I had made contact with. (I have not approached the current Minister)

I have attached the letter that I sent to the Previous Prime Minister for your perusal. As the letter was addressed to the prime Minister I feel that the questions that I have asked are still pertinent and hence would request a response from you to that letter.

However of immediate concern for me is how do I deal with the ever increasing load of emails from very concerned family caregivers who are in most cases desperate to trial the method of care that is working for my mother.

I would like your assistance please to allow family caregivers to become 'drivers' of the care for their loved ones. I am more than happy to make a presentation to your advisors on this point.

I look forward to your earliest response and contact from your advisors.

Yours sincerely

George Vassiliou

September 23 2007

The Prime Minister

Parliament House

Canberra

Australia

Dear Prime Minister

I thank you for this opportunity to be able to write to you directly. I am proud of our country and I am proud of the consideration given to our vulnerable members of our community. The consideration I am referring to are the range of services and structures we have in place to support our most vulnerable. Having said the above I wish to express to you directly some concerns I have about some of our systems approaches to providing support for the care of our vulnerable, whether they be people with disabilities or aged people needing care.

I have tried to engage for a number of years now with the 'care system' at the state and federal level. It is apparent to me that there is a lot of energy spent by the bureaucracy in deflection and marginalization of family caregivers.

Mr Prime Minister I have in place for my mother a self determined/family governed model of care, which utilizes HACC linkages money. Primarily this means that my mother and her family are responsible for the design and management of the program put in place to keep my mother in her own home. This has positives for her, the immediate family and the care system. The care system saves money whilst at the same time we are able to provide a quality program for my mother.

My mother needs face-to-face support. She has been assessed as a candidate for an EACH Dementia package. It is her wish and her families wish for her to remain at home. The EACH Dementia package will allow her to do this.

We waited for the package went through the correct procedures until we were able to get such a package.

I asked the funded agency that EACH Dementia package be managed by the family via a financial intermediary. The package my mother is already receiving is ostensibly a state funded package; this is the HACC LINKAGES package. We wanted the EACH Dementia package to be managed in a similar fashion. This self management would give the family flexibility in terms of the determination of the program of supports and the people who could be employed to care for my mother. Importantly it was also a consideration for the family that maintenance of continuity and high levels of care were high priorities.

The organization that received the EACH Dementia package was more interested in managing their risk and are averse to being creative and meeting the needs of the person for whom the package was designed and allocated.

It is apparent to me Mr Prime Minister that an EACH Dementia package is worth \$48,000. The package in question is a discrete package which has an identifiable amount of money attached to it. From this amount, the Recognized provider takes out an amount of \$18,000 for case management and administration. It maintains control over the remainder and does not offer the remaining amount for the direct personal care needs of my mother. The provider claims that 'it controls the \$30000 for personal care and contingency related matters. Furthermore, it has become apparent to me that once the money has left the Commonwealth recognized Providers become a law unto themselves and can set parameters, as they seem fit in determining who is eligible to receive support from the package allocated in the first instance. This means that once a person who has been on a 'wait list' becomes eligible for an EACH Dementia package then has to go through further assessments despite having being assessed by the ACAS Assessment team in the first instance. The duplication, time wasting and costs are enormous. You have indicated in the past that the most important consideration with government programs is the outcome and not the process. It appears to me Mr Prime Minister that in the Aged Care Sector that more emphasis is placed on the processes and less on outcomes.

I could go on but do not have the space allocated to describe further the inequities and the negative outcomes from what is a good funding source.

I would like to ask the following please Prime Minister. The question relates to EACH Dementia packages

How can it be justified that \$18,000 out of a package of \$48000 goes to case management administration? Prime Minister, my mother does not need to be case managed. We have indicated to the funded organization that we do not need case management. In fact, I have indicated that we are prepared to pay the organization a fee for administrating the consumer directed package we wish to implement with the EACH Dementia money. Please keep in mind as indicated above us as a family is running a very successful HACC Linkages program for my mother.

I have asked for the organization in question to show flexibility to allow my family to manage the EACH dementia fund. To do exactly what we are doing under the HACC Linkages model of funding.

My mother has a family that is keen to provide supports but is also becoming alarmed at the sheer waste of resources that is becoming more and more apparent. Prime Minister I wish to state that I do not want more money. I just want to be given the opportunity to be able to manage my mother's EACH Dementia package so that I can get more value for the package as it exists.

I have asked the funded organization in control of the EACH Dementia package how many hours am I likely to get from the remainder of the package, which is \$30,000. The best that the organization could offer me is 15 hours of face to face support. This support will cost on an annualized basis about \$15,000 per year. This means Mr Prime Minister that from the time the package leaves the federal government coffers and reaches my mother some \$33,000 would have leaked out. This leakage by any reckoning is exorbitant. It is not acceptable and certainly does not benefit the person being cared for or the family caregivers. In most cases, Mr Prime Minister families require hours of direct care.

***Please explain to me how \$33,000 leaks and does not reach the intended target.***

I am one of the 'sandwich generation' and I need your immediate intercession. I have presented my 'model of family governed/ consumer managed care' to your Aged Care Ministers beginning with Senator Julie Bishop through to your current Minister Pyne.

I have also spoken to your Mr Alan Singh and others in your Department. It is also apparent that they are impotent and have cowed to the Aged Care Bureaucrats in Canberra.

I seek your support so as to amend the current care system so as to allow families and the person they care for to **self manage Commonwealth funded packages**

I seek you urgent response. No one in the Aged Care Branch seems to be listening. The Aged Care Sector needs your leadership. I need your help please.

Yours sincerely

George Vassiliou