



## **EVALUATION OF THE DEMENTIA INITIATIVE Comments from Alzheimer's Australia**

### **Executive Summary**

Alzheimer's Australia welcomes the release of this important evaluation by the Minister for Mental Health and Ageing, Mark Butler.

The Dementia Initiative and the bipartisan support it has received since 2005 has been a landmark for people living with dementia, both people with dementia and their families and carers. Australia was the first country to acknowledge the economic and social impact of dementia and to begin the process of planning for the epidemic.

The Evaluation is consistent with the views expressed by consumers, namely that the Dementia Initiative has achieved much of its promise and has shown positive returns on the investment made by the Australian Government.

From a consumer perspective the highlights of the Dementia Initiative have been:

- The opportunity to improve access to specialist dementia services and demonstrate the potential of greater choice for consumers for access to Extended Aged Care at Home (Dementia) packages in the community.
- The increased community engagement through community grants and sector development grants and the community education activities made possible through improved funding for the National Dementia Support Program (NDSP) administered by Alzheimer's Australia.
- The much needed funding increases in dementia care research through the three Dementia Collaborative Research Centres and dementia research grants, which have increased research capacity, promoted collaboration, attracted young researchers into the field of dementia care and positioned dementia researchers to apply for NHMRC and other major grants.
- The opportunity after a slow start to improve the quality of dementia care through the Dementia Behaviour Management Advisory Services.
- The expanded opportunities for workforce education and training through Dementia Care Essentials and the Dementia Training Study Centres.
- The improved access to support for people with dementia and their family carers through targeted resources and improved funding through the NDSP.

However, as the Evaluation makes clear the Dementia Initiative falls short of the action needed to combat the dementia epidemic in key areas. These include the lack of a communication strategy or action on primary care.

The Evaluation is supportive of all the major elements of the Initiative. It is important to have transparency about the funding being provided for each element over the next three years.

The Evaluation flags the need for better coordination between the elements of the Dementia Initiative and in particular, the work of the Dementia Collaborative Research Centres and the Dementia Training Study Centres. Alzheimer's Australia would be well-placed to provide this coordination.

Alzheimer's Australia would go further than the Evaluation and suggest that the Initiative has failed to address other key areas such as acute care, end of life care, dementia risk reduction and cutting edge dementia research into the cause and prevention of dementia.

Nor have there been any recognition of the special issues that face those with younger onset dementia and the lack of access to age appropriate services.

Alzheimer's Australia recommends the Government's responses to the Evaluation should focus on four policy themes:

- **Increased awareness and reduced stigma:** engagement of the Australian community with dementia is the first step in achieving a level of political and policy engagement to support the on-going reforms.
- **Health infrastructure:** increased investment in timely diagnosis, dementia risk reduction and dementia research and knowledge translation
- **Quality dementia care:** founded on the funding of DBMAS, training programs, dementia care research, innovation in the NDSP and getting research into practice.
- **Access to care services:** expand the NDSP in recognition of the growing numbers of people with dementia of all ages and the need both through the NDSP and in other ways to better support the diversity of the Australian community.

It is critical that the Gillard Government commitment to reform in the area of health and hospitals, primary care, disabilities, aged care and mental health is actioned in a way that benefits people living with dementia. Whether it is people with younger onset dementia, those with severe psychiatric issues and dementia or people with dementia and depression, there is a need to ensure that people with dementia are not overlooked in the reform process.

In this submission, Alzheimer's Australia provides comments on:

- 1) The major elements of the Initiative covered in the Evaluation.
- 2) The gaps and priorities that need to be addressed in the development of the Initiative and its relationship to other parts of the Gillard reform agenda including health and hospitals, aged care, disabilities and mental health.
- 3) The preferred means of achieving coordination.

## 1. MAJOR ELEMENTS OF THE INITIATIVE

### Dementia Research and Innovation

Alzheimer's Australia supports the view expressed in the Evaluation that the National Dementia Research Workshop did not result in any sustainable outcomes, nor did it involve people with dementia and their carers. But the initiative taken through the Dementia Collaborative Research Centres (DCRCs) to partly fund the Consumer Dementia Research Network provides a valued opportunity to involve consumers in research and knowledge translation.

Alzheimer's Australia strongly supports the Dementia Research Grants program, providing as it does, a competitive opportunity for researchers to access grants for dementia care research. Alzheimer's Australia also strongly supports the partnership between DoHA and the NHMRC in the administration of the Dementia Grants.

In the view of Alzheimer's Australia the Dementia Collaborative Research Centres have been an important vehicle for the production of systematic reviews in key areas, promoting collaboration between researchers and funding emerging researchers. Consumers should have a greater say in determining priorities for research funding. The recent development of the Consumer Dementia Research Network, supported through the Dementia Initiative, should ensure this greater involvement and lead to research outcomes which are more relevant to people living with dementia.

### Dementia and Improved Care

Alzheimer's Australia regards the primary care project as a major lost opportunity. The final report of URBIS *Dementia in Primary Care Phase I* was not followed by Phase II, which was to be a demonstration project that would illustrate what a well planned, resourced approach to dementia and primary care might look like. The report highlighted the barriers and what we know about the failures of the primary care system rather than resulting in strategies for addressing issues that have been of concern to consumers for many years.

Primary care remains a major frustration and concern for those who are worried about their memories and for those who, when diagnosed look for ongoing support and referral to appropriate services. Alzheimer's Australia has proposed a review that would involve all stakeholders and the Department in an exercise to:

- Assess the evidence base on concerns about timely diagnosis and ongoing management of dementia.
- Develop proposals that address the concerns about timely diagnosis that could be further developed for consideration in the context of the Gillard Government's commitment to reform of primary care.

Part of the background for such a meeting would be supplied by the Phase I report of URBIS and the work of Professor Dimity Pond.

## **Dementia Behaviour Management Advisory Service (DBMAS)**

Alzheimer's Australia is strongly supportive of the DBMAS projects because they represent knowledge translation in action through the availability of advice to family carers and to community and residential service providers. Alzheimer's Australia considers that priority should be given to a review of the different models that have been adopted in respect of DBMAS with a view to expanding the number of services as soon as possible. There is a need to increase the funding of DBMAS services in states such as Queensland that have dispersed population centres with poor access to specialist services.

## **Dementia Training Study Centres**

As a result of a slow start to the project the Evaluation does not capture much of the activity of the project, which has mostly occurred in the final year. As recommended by the Evaluation, Alzheimer's Australia supports the continuation of the Centres, but has identified a need for a more co-ordinated collaborative approach. The emphasis on pathways to dementia training requires additional core and project specific ongoing funding to instigate long term systemic change within a significantly rigid education (tertiary) structure. Moderate amounts of success have been indicated by the development of sustainable and accessible health professional development opportunities which may be the entry point for dementia training. Closer linkages between University-led Centres and Alzheimer's Australia would strengthen the work undertaken and develop more seamless provision of knowledge transfer and translation. The development of pathways outside the tertiary sector will also continue to need to be addressed and acknowledged within the project as integral to the development of future health professionals.

## **National Dementia Support Program**

Alzheimer's Australia is pleased that the Evaluation found that the National Dementia Support Program (NDSP) "was a comprehensive integrated suite of early intervention and support services" that was "operated professionally and compassionately and was highly valued by consumers and stakeholders".

As regards the specific observations made by the Evaluation, it is worth noting that:

- As recommended by the Evaluation, the Commonwealth has provided one-off funding in 2010/11 for special services access officers in each State and Territory to promote access for CALD communities, Indigenous communities and other hard to reach groups. This funding needs to be extended for the remainder of the NDSP contract until end June 2013. A higher priority should be given to social inclusiveness. People from other cultures living with dementia are not proportionately supported by the existing service system. There is a need for significant service system capacity building. Currently diagnosis is occurring late in the disease process and there is only limited information, education or professional support and counselling available. Over 3 million people speak LOTE (language other than English) at home and their needs require a greater policy response.

- The new NDSP contract has been streamlined and overcomes many of the structural weaknesses highlighted in the Evaluation. There are ongoing discussions between Alzheimer's Australia and the Department to further streamline administrative processes that would be consistent with both greater efficiency and accountability.
- The core funding for NDSP was not been increased between 2007 and 2010 to reflect the increased numbers of people with dementia (16%) or indeed, in the new contract for the period 2010 to 2013 (14%).
- As recommended by the Evaluation “provision should be made within the NDSP to address innovation and access, enabling the Program’s core services to respond to emerging needs, apply research findings and trial innovative models of service delivery”. Alzheimer’s Australia welcomes this recognition in the Evaluation.

The National Dementia Support Program is Alzheimer's Australia service platform, essential to our role as the peak body for dementia. Not only does the Program reach 100,000 people each year through a range of quality services, it also informs our policy development and other leadership activities such as publications, and education and training that support the aged care sector in its quality improvement and services for people with dementia and their families.

In that way, Alzheimer's Australia believes that it has been able to partner with the Commonwealth in policy development to the benefit of people living with dementia and the effectiveness of the range of dementia support programs.

### **National Dementia Communications Strategy**

The Evaluation observed that “The **National Dementia Communication Strategy** should be accorded a central place in any continuation of the Dementia Initiative”.

The consumer perception is that an awareness campaign is central to reducing stigma and removing the low value afforded to people with dementia relative to people with better understood organic conditions even though the economic and social implications of dementia are now well documented.

The first step in addressing the enormity of this challenge is to engage the Australian community, in an understanding and acceptance of dementia and secondly by developing preventative health programs that engage Australians in lifestyle practices that will benefit both their physical and their brain health.

If in the present financial climate, a major communications strategy is beyond the resources of Government, Alzheimer's Australia suggests there are three possible strategies.

- 1) To build on and better resource the awareness activities of Alzheimer's Australia. Through the NDSP, about \$160,000 is provided for awareness. Evidence has been provided that the advertising equivalent value of this funding is a multiple of 15-20 times this amount through media attracted by new publications, overseas speakers and other activities.

- 2) To fund **Mind Your Mind**® as a way of both promoting a more positive approach to an understanding of dementia and enabling people to possibly reduce their own risk of dementia in the longer term. The budgeted proposal put to Government is \$4.5 million over three years.
- 3) To fund the national roll out of educational materials on dementia for schools across Australia as supported by the Ministerial Dementia Advisory Committee.

### **Community Support and Development Grants**

Alzheimer's Australia welcomes the recognition in the Evaluation of the support Alzheimer's Australia gave to CALD and to a lesser extent Aboriginal and Torres Strait Islander organisations to assist them in accessing community grants. This is consistent with the approach that Alzheimer's Australia is promoting through the Special Access Officers referred to above.

### **Extended Aged Care at Home (EACH)**

This is the major element of the Dementia Initiative (70% of the \$320.6 million budget) and one that Alzheimer's Australia has strongly supported. The packages provide choice for people with dementia to stay at home for as long as possible and for carers to be able to access appropriate care and support services. Alzheimer's Australia considers that the Evaluation provides useful information and insights into the way that EACH (D) packages have worked and believes this will be helpful in policy and program work on graduated care packages.

Alzheimer's Australia believes that a supplement designed to assist with the costs of delivering the care and support associated with the Behavioural and Psychological Symptoms of Dementia across the range of future care packages would be justified. Dementia is a major reason for entry into residential care and it is important that community care is positioned to provide the appropriate care needed by people with dementia in the community.

Consumers are concerned that a large proportion of the value of EACHD packages may be allocated to management. The Alzheimer's Australia Consumer Advisory Group in Victoria for example believe that consumers do not have sufficient access to a reasonable proportion of the package funds and that there is inherent inflexibility in allocation. It is reported that a package of services is initially negotiated and thereafter there is little flexibility to increase services in line with increasing need because the funds have been allocated to others. There is as a consequence strong advocacy for increased consumer-directed management of available funds to overcome lack of flexibility in service provision.

### **Dementia Curricula and Training**

Alzheimer's Australia agrees with the positive assessment made of Dementia Care Essentials (DCE) in the Evaluation. DCE has been an important element of maintaining and improving the dementia skills of the aged care workforce. However, there are opportunities to further improve the effectiveness of the program by:

- Reviewing the consistency, quality and standards of DCE offerings against new unit requirements.
- Developing and delivery of new options at a high level to provide a pathway of dementia specialists and new strength and leadership of dementia care. Promoting training appropriate to the needs of Indigenous and CALD communities.
- Liaising with RTO's providing training certification for PCW's to elevate the component of training related to caring for those living with dementia.

It is not clear what has been achieved in respect of the development of resources for training police and ambulance workers. This is an important area of activity and one which needs some further attention.

Alzheimer's Australia welcomed the opportunity of undertaking the dementia caring pilot embracing the concept of consumer directed care. It is the role as innovators that Alzheimer's Australia welcomes and the reason for which it has undertaken the National Quality Dementia Care Initiative.

## **2. GAPS AND PRIORITIES HIGHLIGHTED IN THE EVALUATION**

The importance of acting on a Communications Strategy and primary care has already been emphasised.

The Initiative has not touched acute care or dementia risk reduction beyond the funding of DCRC II.

Nor has there been any recognition of the special issues that face those with younger onset dementia and the lack of access to age appropriate services.

There is a need to take further steps to ensure high quality end of life care. Many people with dementia experience poor quality care at the end of their lives. Issues can include inadequate pain management, inappropriate hospitalisation or medical intervention, and a lack of timely and appropriate consultation (with the person with dementia or their family carers) over their choices regarding end of life care. The Dementia Initiative has failed to address these concerns.

The gross under funding of dementia research has been well documented by Alzheimer's Australia in other contexts, particularly in respect to the cause and prevention of dementia.

## **3. COORDINATION**

At a number of points the Evaluation draws attention to the need for improved coordination between the various elements of the Dementia Initiative. Alzheimer's Australia is not convinced that new bureaucratic structures are the answer.

Alzheimer's Australia believes that coordination will best be achieved through an action oriented approach that is driven from the consumer perspective. This could take the form of knowledge translation projects which tap into the collective

knowledge of the various elements of the Dementia Initiative and be used to improve the services provided through the Initiative.

The funding of both research and service provision under the Initiative provides a unique opportunity to ensure that this gap between evidence and practice is reduced. Some research suggests that it can take up to 17 years for basic medical research to be put in to practice. Alzheimer's Australia believes that a focus on improving practice and care through uptake of research is the best way forward in improving coordination and collaboration across the Initiative.

This coordination could be based on the ongoing National Quality Dementia Care Initiative (NQDCI) which is administered by Alzheimer's Australia with \$3million provided by the ANZ Wicking Trust and Bupa Care Services. The objective of NQDCI is to improve the quality of dementia care through the rapid dissemination and uptake of research evidence via the various mechanisms of knowledge transfer. The Consumer Dementia Research Network, which is largely funded by the three DCRCs has set broad priority areas in which to seek expressions of interest for projects. The first projects will be commissioned early in 2011.

Although the NQDCI was not originally designed for coordination, many of the elements of the Dementia Initiative are represented in the NQDCI. The NQDCI is overseen by an Executive Committee which is chaired by Professor Henry Brodaty (DCRC - ABC) and includes the directors of each of the three DCRCs, the Consumer Dementia Research Network, BUPA Care Services, DoHA and Alzheimer's Australia. The Executive Committee could be expanded to include a representative from DTSC and DBMAS and would then include representatives from all of the major elements of the Dementia Initiative. This Executive Committee would have a similar makeup of the suggested 'Implementation Steering Group' in the evaluation of the Dementia Initiative but would have a active role in mixing and matching available project funding for knowledge translation to improve the quality of dementia care.

Additional funding for NQDCI would increase the capacity for funding projects which bring various different elements of the Dementia Initiative together to develop innovative ways to improve the quality of dementia care in Australia through the rapid uptake of research evidence.

However it is done, the preferred approach is to make funding result in the coordination, not in the funding of structures.

The Ministerial Dementia Advisory Group has worked well and Alzheimer's Australia suggests that it should be used as a point of consultation on issues relating to dementia in other reform processes. This submission has argued strongly for that to take place in the context of health and hospital reform and primary care. Over the next 12 months or so, the need will become equally evident in respect of disabilities and mental health as well of course, as aged care.

It is recommended that the terms of reference of the Minister's Dementia Advisory Group be expanded beyond monitoring the Dementia Initiative and prioritising gaps to advising the Minister on the aspects of dementia relevant to other areas of reform including aged care, disabilities and mental health.



#### 4. CONCLUSION

Alzheimer's Australia acknowledges the Australian Dementia Initiative as a landmark decision. Governmental responses to the Evaluation should focus on four policy themes:

- **Increased awareness and reduced stigma:** engagement of the Australian community with dementia is the first step in achieving a level of political and policy engagement to support the on-going reforms.
- **Health infrastructure:** increased investment in timely diagnosis, dementia risk reduction and dementia research and knowledge translation
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It is critical that the Gillard Government commitment to reform in the area of health and hospitals, primary care, disabilities, aged care and mental health is actioned in a way that benefits people living with dementia. Whether it is people with younger onset dementia, those with severe psychiatric issues and dementia or people with dementia and depression, there is a need to ensure that people with dementia are not overlooked in the reform process.

Alzheimer's Australia  
5<sup>th</sup> November 2010