Evaluation of Alzheimer’s Australia Services to Improve Access for Special Needs Groups

FINAL REPORT

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EXECUTIVE SUMMARY

This evaluation reports on the achievements of 11 Service Access Liaison Officer projects implemented by Alzheimer’s Australia to improve access to dementia services for specific needs groups. The projects, which have been implemented in all states and territories, have focused on the needs of Aboriginal and Torres Strait Islander people; people from Culturally and Linguistically Diverse backgrounds (CALD); Gay, Lesbian, Bi-Sexual, Transgender and Intersex people (GLBTI); people with Younger Onset Dementia (YOD); and people in rural and remote locations (R & R). Relevant literature has been reviewed to identify issues for specific groups and work being undertaken to address these issues.

The projects formally commenced in late 2010 but some projects which needed to recruit staff, only began in January 2011. Projects were designed to suit their particular demographic, geographic, organisational and service system context; they developed and implemented clear and credible strategies for achieving the objective of increased access to services.

Across the projects, three clusters of strategies have been used to increase access:

- Building knowledge – by identifying factors that reduce access to dementia services for specific groups and options for increasing access
- Addressing demand side issues – by raising awareness and knowledge of the signs of dementia and the importance of early diagnosis, raising awareness and knowledge of the availability of services and how they can be accessed, and changing negative attitudes of people with dementia and carers towards services
- Addressing supply side issues – by changing the way dementia services are provided to make them more appropriate, providing more individualised responses to consumers’ particular and changing needs, identifying and addressing gaps in services, and developing integrated service systems and referral pathways

Some projects have researched, developed and trialled new approaches for providing services for specific groups. New models for service delivery include training volunteer staff from ethno-specific agencies to provide community education to their communities, a key worker model for supporting people with younger onset dementia and a restorative therapies approach that provides individually tailored cognitive enhancement exercises, counselling and referrals to other services based on a detailed cognitive and psychosocial assessment. Family social events have proven to be an effective way of engaging the children of younger people with dementia.

Other projects have worked towards cultural change, within Alzheimer’s Australia and in external organisations, so that services are more sensitive to, and better able to respond to, the needs of specific groups.

Service system gaps have been identified and projects have worked towards establishing services to address unmet needs. Gaps include the need for age-appropriate respite services for people with younger onset dementia and Aboriginal specific assessment services.

One project has specifically focussed on sector development, establishing a dementia pathways forum that has engaged relevant service providers to prioritise and address needs in an area with a disjointed service system and rapidly increasing numbers of people with dementia.

The projects have developed new relationships with communities and service providers and increased the provision of community education to targeted groups.

The resources developed by the projects include community education packages, information sheets and CDs for specific CALD communities, information and tip sheets for people with YOD and information tailored for GLBTI communities. The processes used to develop resources - referring to the evidence base, working in partnership with consumers and service providers to identify needs and preferences, piloting information and community education resources - have ensured that they are relevant and credible.
Outcomes for Alzheimer’s Australia include increased awareness of the needs of specific needs groups and how to address them, and an improved capacity to provide more inclusive and individually responsive services. Alzheimer’s Australia has also raised their profile and has more credibility amongst specific groups.

The flexibility provided by the project management process has been important in allowing states and territories to develop plans to fit the level of funding and local factors, and to adapt the projects on the basis of feedback from consumers, communities and service providers, lessons learnt and opportunities arising during implementation.

Project achievements have been supported by working in partnerships with the specific target group and with relevant service providers, building on previous relationships, resources and skills, and integrating with other Alzheimer’s Australia services. Other factors contributing to the projects’ achievements were the skills, networks and expertise of the project staff and other concurrent projects or activities. The short duration of the projects and delays in recruiting project workers have been limiting factors.

Suggestions for improvement include increasing communication amongst projects and between the projects and the National Alzheimer’s Australia advisory committees, supporting continued learning by continuing to develop monitoring and evaluation approaches, and securing funding to permit longer term planning. This is considered particularly important for projects seeking to work with Aboriginal and Torres Strait Islander communities if relationships are not already established. The National Aboriginal and Torres Strait Islander Dementia Advisory Group has suggested that it may be more effective to use limited funds to broker additional resources than to establish short term projects that are unlikely to achieve sustainable outcomes. NATSIDAG also recommended local Aboriginal and Torres Strait Islander capacity development and that substantial long term funds in the future should be used in local Aboriginal and Torres Strait Islander communities to improve capacity, ensure more efficient use of resources, improve cultural safety, and ensure local ownership and participation in decision-making.

The project funding has provided a focus for developing more inclusive, individualised service responses to specific groups. All of the state and territory Alzheimer’s Australia organisations have expressed the view that the work being done to focus on, and increase capacity for working with specific groups, should be a part of core business. Rather than thinking in terms of ‘special needs’ groups, Alzheimer’s Australia recognises that providing quality dementia responses involves identifying the special needs of each individual, carer and family affected by dementia.

The second part of this report presents information about each project that includes: a project description; the project context and rationale; the logic underpinning the approach; activities and changes made during implementation; project outcomes, including resources that have been developed; what has helped or hindered; lessons learnt; the project legacy and future plans.
1. INTRODUCTION

1.1 THE DEMENTIA EPIDEMIC

By 2050, the number of Australians with dementia is expected to exceed 981,000 (Access Economics, 2010). The proportion of people with dementia who live outside capital cities is almost 40%, with variations between states and territories (Access Economics 2009a). Dementia is the greatest single contributor to disability at older ages and is responsible for more than half the burden of disease. As our population ages, dementia will continue to be an important driver of demand for health, aged care and disability support services (Australian Institute of Health and Welfare, 2009).

Table 1: Projections of dementia prevalence (people)¹

<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2050</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of people with dementia</td>
<td>% outside capital city</td>
</tr>
<tr>
<td>NSW</td>
<td>87,975</td>
<td>43.0</td>
</tr>
<tr>
<td>VIC</td>
<td>65,669</td>
<td>31.1</td>
</tr>
<tr>
<td>QLD</td>
<td>46,842</td>
<td>58.8</td>
</tr>
<tr>
<td>SA</td>
<td>22,751</td>
<td>26.1</td>
</tr>
<tr>
<td>WA</td>
<td>22,945</td>
<td>25.3</td>
</tr>
<tr>
<td>TAS</td>
<td>6,462</td>
<td>57.7</td>
</tr>
<tr>
<td>NT</td>
<td>795</td>
<td>37.3</td>
</tr>
<tr>
<td>ACT</td>
<td>3,090</td>
<td>0*</td>
</tr>
<tr>
<td>AUST</td>
<td>256,500</td>
<td>39.6</td>
</tr>
</tbody>
</table>

Sources: Access Economics (2010), and Access Economics (2009a)
# Data calculated from Access Economics (2009a), this data was revised in 2010
* It is assumed that the whole of the ACT represents a capital city

1.2 ALZHEIMER’S AUSTRALIA’S VISION FOR DEMENTIA SERVICES

Alzheimer’s Australia’s mission is to provide leadership in advocacy, policy, services and research, and their values include respect for all individuals and communities; innovation, creativity and flexibility; and strength and unity, with respect for diversity. The Service Access Liaison Officers projects are advancing these aims by increasing the responsiveness to diverse individual needs.

The Alzheimer’s Australia Service Access Liaison Officers projects were implemented within the context of increasing numbers of people with dementia and an increasing awareness of the needs of different groups in society. A fundamental principle that underpins all Government programs is the social inclusion agenda, which includes older Australians. This agenda supports older people to be independent, remain in their own homes for as long as possible, and to participate in the community as much as possible. This agenda is based on the premise that this is what older

¹In 2010 Access Economics used new data to revise the projections of dementia prevalence; the projected number of people with dementia by 2050 reduced from 1,130,691 (estimated in 2009) to 981,000. The data on the proportion of people with dementia living outside capital cities is based on the 2009 projections.
people want and that it will also be cost effective and reduce pressure on the aged care system (Productivity Commission, 2011).

The Service Access Liaison Officer projects were intended to improve Alzheimer’s Australia’s capacity to further develop diverse, flexible and responsive services. Specialist knowledge comes from working with people from the specific target groups: Aboriginal and Torres Strait Islander people, people who are culturally and linguistically diverse, people with younger onset dementia, people with a variety of sexual preferences and gender identities, and people in rural and remote locations. There are also categories of people not specifically targeted by the projects, for example, the homeless, people with a pre-existing disability and people living alone. Our diverse society does not confine people to discrete categories where their needs can be met in one way. For example, a person with younger onset dementia may be Aboriginal, gay, and living in a remote area. As the Productivity Commission (2011, S.3.2) report Caring for Older Australians - Draft Report points out, people may have several special needs and be counted in more than one group.

In addition to the diversity of our population, the Productivity Commission (2011) report points out that the context of service provision is also being shaped by the demand from the baby boomer generation for services that are tailored to their individual needs and preferences. They have high expectations of being able to exercise control over their own lives and, in particular, of having choice and control over support services. In response to these demands the Department of Health and Ageing is trialing consumer directed care (CDC) with 220 service users (Productivity Commission 2011: Box 8.6). The model adopted for the CDC packages is an individual budget based on a needs assessment.

A further important contextual factor for aged care services highlighted by the Productivity Commission (2011) and other reports, is workforce shortages. The Department of Health and Ageing estimates that under current policy arrangements the aged care workforce will need to increase by between two and three times by 2050, as a direct result of Australia’s ageing population (Productivity Commission 2011:p.360). The sector will need a well-trained and well remunerated workforce that is caring and sufficiently flexible to respond to diverse needs.

1.3 DEMENTIA SERVICES PROVIDED BY ALZHEIMER’S AUSTRALIA

Dementia programs are delivered at both the national level and by individual Alzheimer’s Australia Associations in each state and territory. The programs are slightly different across the states and territories as each Association has different models of operation and management (Alzheimer’s Australia 2009).

Alzheimer’s Australia administers Commonwealth-funded national dementia programs and services and provides national policy advice and advocacy for Australians living with dementia. The national programs provide information, support, counselling, training and education to people with dementia, their families and carers, as well as to professionals working in the dementia field. Many of these services are funded by the Australian Government through the National Dementia Support Program (NDSP) (Department of Health and Ageing 2010).

The main services delivered under the NDSP are:

- National Dementia Helpline and Referral Services
- Dementia and Memory Community Centres (DMCCs)
- Early Intervention and Counselling
  - Living with Memory Loss Program (LWML)
  - One-on-One and Group counselling
- Information, Awareness, Education and Training
- National Resources
- Dementia Awareness Week (DAW)
Alzheimer’s Australia National Network Groups include: National Consumer Advisory Committee (NCAC), Consumer Dementia Research Network (CDRN), National Cross Cultural Dementia Network (NCCDN), National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG) and Younger Onset Dementia (YOD).

The national office has a focus on Younger Onset Dementia, Aboriginal and Torres Strait Islander people and CALD issues; the work of the NATSIDAG and NCCDN are supported by Policy/Liaison workers who are knowledgeable about the issues for these specific groups.

1.4 SERVICE ACCESS LIASON OFFICERS FUNDING

In 2010-2011 Alzheimer’s Australia received additional funding from the Federal Government through the National Dementia Support Program (NDSP) to establish Service Access Liaison Officers in each state and territory to improve access to services for specific needs groups. This initiative was a recommendation of the National Evaluation of the Dementia Initiative. A total of $908,872 was allocated to Alzheimer’s Australia state and territory organisations for the 11 projects.
2. EVALUATION

PURPOSES OF THE EVALUATION

The evaluation has two major purposes: to inform decisions about whether and how to continue the initial short-term projects that were funded in 2010-2011; and to support learning and improvement across projects.

FOCUS OF THE EVALUATION

The evaluation was commissioned to examine the use made by Alzheimer’s Australia of the funding made available for Service Access Liaison Officers in the context of the commitment Alzheimer’s Australia has made to improving access for special needs groups over recent years.

Specifically, the evaluation was designed as an opportunity to:

- Consider the use that has been made of the additional funding provided by the Commonwealth through Service Access Liaison Officers to support the work of Alzheimer’s Australia; and
- Make a first assessment of whether the objectives have been achieved, whether the introduction of Service Access Liaison Officers has made a difference in awareness of dementia and access to services by special needs groups compared to baseline information
- Examine the lessons learnt in the partnerships established between state and territory Alzheimer’s organisations with CALD, Indigenous and other communities
- Document and assess the effectiveness of resources that have been developed to support this approach

The evaluation was described in the evaluation project brief as being intended to report on the effectiveness with which the new Commonwealth funding is being used, and strategies for further developing the commitment of Alzheimer’s Australia to inclusion, particularly for those people from CALD and Aboriginal and Torres Strait Islander backgrounds and gay and lesbian people.

2.1 METHODOLOGY

The evaluation reviewed the literature on dementia and access to services for CALD, Aboriginal and Torres Strait Islander people and GLBTI people and documentation of other activities that impact on awareness of dementia and access to services for these groups. Appendix 2 summarises this literature.

Project documentation reviewed included: project plans and progress reports that provided brief updates on progress to the end of December 2010 and to the end of March 2011, financial reports and additional documentation provided by some projects such as position descriptions and documented project rationales.

Visits were made to each of the projects in February and March 2011. The visits provided a deeper understanding of the context that each project was operating in and the rationale for the chosen approaches. Follow-up telephone interviews with each state and territory Alzheimer’s Australia organisations were conducted in June and July 2011.

The capacity of the new national data collection and management system to provide baseline data and evidence of the impact of the projects was reviewed to assess the usefulness of centrally collected program data for assessing project outcomes.

A sample of the external stakeholders that projects have worked with have been interviewed to verify the information provided by the projects and to seek their views on the impacts of the projects. This occurred for all projects except the
Alzheimer’s Australia Tas Restorative Therapies project (the Tasmanian University contact was overseas and unable to be contacted) and the NSW CALD/Aboriginal and Torres Strait Islander people project as contact details for staff from the ethno-specific partnering agencies was not provided as arranged. In most cases the external stakeholders were other service providers, although consumers were consulted to provide feedback on the ACT and Vic YOD projects.

A program logic model was developed for each project to describe how the project activities were expected to generate project impacts, in the short term and beyond the end of the current funding period.

The implementation and outcomes of each project has been detailed. Factors that have helped or hindered the projects have been identified and the lessons learnt by projects have been documented. Realistic expectations of the sustainable legacy of each project, and plans for extending current work beyond the current funding period, have been explored.

Two members of the evaluation team met with the NATSIDAG, the NDCCN and a joint meeting of the NCAC, NATSIDAG and NDCCN in Brisbane prior to the Alzheimer’s Australia national conference in May. These meetings provided opportunities for the advisory groups to provide feedback on the draft report and to discuss the projects’ progress. The National Cross Cultural and Aboriginal and Torres Strait Islander Liaison Officers were also consulted to seek information about current activities, relevant reports and articles and lessons learnt in previous work to address dementia in CALD and Aboriginal and Torres Strait Islander communities.

2.2 EVALUATION CHALLENGES

The evaluation initially intended to reconstruct baseline data for each project however, the implementation of a new national data management and reporting system, and the lack of confidence that most organisations expressed about the accuracy of data relating to specific needs groups, limited the availability of data about services being provided to these groups at the start of the projects. In some situations (such as a crisis call to the helpline) it was not considered appropriate to ask unnecessary questions about cultural identity. It is usually not appropriate to ask people to identify their sexual preferences.

2.3 EVALUATION REPORTS

DRAFT REPORT

A priority for the evaluation was to prepare a draft report by March 2011 that documented the work being undertaken by the projects. This initial stage of the evaluation documented information available at the time about the development and implementation of the projects.

The draft report provided information on how the funds had been used and the logic underlying the approaches taken by the projects, assessed progress towards meeting objectives and the outcomes for specific groups, and documented lessons learnt about strategies for increasing the inclusiveness of dementia services and plans for continuing to improve awareness of dementia and access to services amongst the identified groups.

FINAL REPORT

This final report provides updated information about project activities, any changes made during implementation, project achievements and what has been learnt. Outcomes for specific groups, and the resources developed by the projects have been documented.
3. OVERVIEW OF THE PROJECTS

A total of 11 projects have been established, three in Victoria, two in New South Wales and one in each of the other states and territories. Project funding levels vary between $167,335 for the Queensland project and $33,938 in the Australian Capital Territory. Table 2 shows the projects funded in each state and territory, the project start dates and when project staff commenced.

Three of the projects are mainly focussed on work with CALD communities (NSW, Vic and WA), two have a specific focus on work with Aboriginal and Torres Strait Islander communities (NT and Vic), two are working with people with Younger Onset Dementia (ACT, Vic) and one is working specifically with GLBTI communities (SA). The Queensland project is working with all of the target groups in regional and remote areas, the NSW Tweed Sector development project has a focus on service sector development in a regional area and it was agreed that the Tasmanian project would develop a therapeutic intervention for people with dementia rather than focus on a specific target group. There are very low numbers of CALD and Aboriginal and Torres Strait Islander people in Tasmania compared to the other states and territories (Access Economics 2006).

The project start dates varied considerably, the Victorian YOD project and the Northern Territory project had started prior to receiving project funding. Other projects commenced after project plans had been approved and funds were disbursed from the National Office.

Table 2: Funded projects

<table>
<thead>
<tr>
<th>Project</th>
<th>Target group</th>
<th>Funding</th>
<th>Project start date**</th>
<th>Date staff commenced</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NSW - Tweed Sector Development</strong></td>
<td>R&amp;R</td>
<td>$130,000</td>
<td>22nd Oct 2010</td>
<td>Jan 2011</td>
</tr>
<tr>
<td><strong>NSW – CALD &amp; Aboriginal and Torres Strait Islander</strong></td>
<td>CALD, Aboriginal and Torres Strait Islander</td>
<td>$130,000</td>
<td>22nd Oct 2010</td>
<td>Nov 2010</td>
</tr>
<tr>
<td><strong>Vic - CALD</strong></td>
<td>CALD</td>
<td>$64,424</td>
<td>1st Sept 2010</td>
<td>Sep 2010</td>
</tr>
<tr>
<td><strong>Vic - Aboriginal and Torres Strait Islander</strong></td>
<td>Aboriginal and Torres Strait Islander, includes R&amp;R</td>
<td>$78,625</td>
<td>1st Oct 2010</td>
<td>Existing staff</td>
</tr>
<tr>
<td><strong>Vic - YOD</strong></td>
<td>YOD, includes R&amp;R YOD</td>
<td>$58,404</td>
<td>1st July 2010</td>
<td>July 2010</td>
</tr>
<tr>
<td><strong>QLD - Special Needs Access Project</strong></td>
<td>CALD, Aboriginal and Torres Strait Islander, GLBTI, R&amp;R</td>
<td>$167,335</td>
<td>19 Oct 2010</td>
<td>Existing staff</td>
</tr>
<tr>
<td><strong>WA – Special Needs Project</strong></td>
<td>CALD</td>
<td>$85,070</td>
<td>31st Oct 2010</td>
<td>Jan 2011</td>
</tr>
<tr>
<td><strong>SA – GLBTI Dementia Community Project</strong></td>
<td>GLBTI</td>
<td>$72,943</td>
<td>25th Oct 2010</td>
<td>Jan 2011</td>
</tr>
<tr>
<td><strong>TAS - Restorative Therapies Project</strong></td>
<td>People with dementia</td>
<td>$47,513</td>
<td>30th Sept 2010</td>
<td>Existing staff</td>
</tr>
<tr>
<td><strong>NT – Aboriginal and Torres Strait Islander Risk Reduction</strong></td>
<td>Aboriginal and Torres Strait Islander, includes R&amp;R</td>
<td>$40,620</td>
<td>1st July 2010</td>
<td>Existing staff</td>
</tr>
<tr>
<td><strong>ACT – YOD Respite</strong></td>
<td>YOD</td>
<td>$33,938</td>
<td>1st Nov 2010</td>
<td>Existing staff</td>
</tr>
</tbody>
</table>

*With agreement, Alzheimer’s Australia Tas was funded to pilot a Restorative Therapies Project

** Date of funding unless an alternative start date was identified by the project
The projects are all adopting different approaches for increasing access for specific groups as summarised in Table 3.

**Table 3: Summary description of the project approaches**

<table>
<thead>
<tr>
<th>Project</th>
<th>Summary of approach</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NSW - Tweed Sector Development</strong></td>
<td>Working in partnership with services to develop an integrated dementia service system in a high need, under-resourced area. Establishing a dementia pathways forum, advocacy and peak body role, providing community education.</td>
</tr>
<tr>
<td><strong>NSW – CALD &amp; Aboriginal and Torres Strait Islander</strong></td>
<td>Developing a model for building capacity for CALD communities to increase dementia knowledge and access to services – implementing with 4 communities. Continuing work with Aboriginal and Torres Strait Islander communities in partnership with New England General Practice Network</td>
</tr>
<tr>
<td><strong>Vic - CALD</strong></td>
<td>Developing an education package template so that CALD community education provided by Alzheimer’s Australia Vic is more effective and will generate better access to services – trialling with 2 CALD communities.</td>
</tr>
<tr>
<td><strong>Vic - Aboriginal and Torres Strait Islander</strong></td>
<td>Building relationships with Aboriginal and Torres Strait Islander communities and health and aged care service providers. Providing community education and professional development, addressing service gaps.</td>
</tr>
<tr>
<td><strong>Vic - YOD</strong></td>
<td>Implementing a Key Worker model to provide individualised responses to changing needs, advocacy to improve access to services, educating service providers, developing YOD specific resources, facilitating peer support.</td>
</tr>
<tr>
<td><strong>QLD - Special Needs Access Project</strong></td>
<td>Place-based approach to developing relationships with CALD, Aboriginal and Torres Strait Islander and GLBTI communities and service providers, providing community education, building capacity by training community members to provide community education, developing database of Regional &amp; Remote contacts.</td>
</tr>
<tr>
<td><strong>WA – Special Needs Project</strong></td>
<td>Investigate issues that influence attitudes to dementia and dementia services to inform an evidence based approaches for increasing the cultural competency of service providers as a way of increasing the appropriateness of services for CALD communities.</td>
</tr>
<tr>
<td><strong>SA – GLBTI Dementia Community Project</strong></td>
<td>Building on links with GLBTI communities and service providers, identifying needs, developing GLBTI information resources, educating service providers, identifying GLBTI friendly services, developing GLBTI Dementia Advisory Group.</td>
</tr>
<tr>
<td><strong>Tas - Restorative Therapies Project</strong></td>
<td>Developing and trialling a cognitive education and psychosocial intervention to address individual needs identified through a comprehensive assessment to reduce the impact of dementia. Providing counselling and cognitive rehabilitation.</td>
</tr>
<tr>
<td><strong>NT – Aboriginal and Torres Strait Islander Risk Reduction</strong></td>
<td>Providing community education to Aboriginal and Torres Strait Islander people at higher risk of developing dementia in drug and alcohol rehabilitation services and correctional centres in Darwin, Katherine and Alice Springs.</td>
</tr>
<tr>
<td><strong>ACT – YOD Respite</strong></td>
<td>Identifying needs of people with YOD and their families, providing YOD group respite, and respite with partners and families. In partnership with service providers working to develop respite services.</td>
</tr>
</tbody>
</table>
4. ISSUES FOR DIFFERENT GROUPS

Issues identified by research into awareness of dementia and access to dementia services for Aboriginal and Torres Strait Islander, CALD, GLBTI and YOD are summarised below. The project approaches and understanding of the relevant issues for targeted groups is consistent with the literature. Further details about the prevalence of dementia and current activities are presented in the literature review summary in Appendix 2.

4.1 ISSUES FOR ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITIES

Garvey et al (2011) investigated understandings of dementia amongst Indigenous Australians and reported a poor level of understanding of dementia amongst Aboriginal and Torres Strait Islander people and common misconceptions of dementia (this also applies to non-Indigenous Australians). This research recommended that culturally appropriate awareness campaigns and education be provided to improve the level of understanding of dementia in Indigenous communities.

Very few Aboriginal and Torres Strait Islander people with dementia access mainstream programs in comparison to the rest of the population and, as a result, the awareness of dementia and related issues, such as use of early intervention services, is low among Aboriginal and Torres Strait Islander community members (Broe et al 2009: 1). There are many reasons for this:

- In rural and remote areas, individuals with dementia and caregivers in the community experience ongoing challenges of availability and access to dementia care support services (Pollitt 1997; Broe et al 2009; Centre for Remote Health 2010)
- In urban areas, “many Indigenous people have problems accessing services because they are socially isolated and have personal and health problems affecting their ability to use services” (Broe et al 2009: 2)
- While dementia is perceived and experienced in many different ways, eg, cognitive impairment in old age is often perceived as normal ‘tiredness’ or ‘childishness’ or in extreme cases as ‘madness’ (Pollitt 1997), it is often not recognised as a medical condition and many Indigenous carers and families are fearful of the medical system (Broe et al 2009). Yet Broe et al (2009: 3) point out that, “communities become very distressed and often call for help when the person with dementia breaks cultural taboos and norms”

Among those who do access services, there are linguistic and cultural barriers to becoming well informed (Centre for Remote Health 2010). Indigenous Australians remain heterogeneous in cultures, languages and histories, reinforcing the need for different models of information exchange about dementia and for offering support to families and carers (Centre for Remote Health 2010). They need staff and services capable of delivering culturally appropriate health services and care adapted to their language, culture and local circumstances (Broe et al 2009; Centre for Remote Health 2010). There is a need for training in cultural safety, cultural competence and cross-cultural communication at every level of the health service (Nguyen 2008; Davis and Smith 2009; Centre for Remote Health 2010). Solutions to the problem of dementia also need to take account of holistic approaches to wellness including the important elements of family, community and land (Buti 1996; Hampshire et al. 2005; Broe et al 2009). For example, for those who have lived in communities, it may be important to have care such that they can continue to be near, or in their land and kinship group (Access Economics 2009a: vi).

4.2 ISSUES FOR CALD COMMUNITIES

While different issues affect different individuals and different communities in regards to dementia, there are some common issues identified by members of, and workers from, CALD communities. These include:

- Lack of knowledge about dementia, its causes and its symptoms (Alzheimer’s Australia Victoria 2008).
Variations in perceptions of dementia: an illness, a normal part of ageing, a mental illness, or having no meaning at all in some communities (Alzheimer’s Australia Victoria 2008). Differences in perceptions regarding dementia have implications for recognising those with dementia and developing and implementing formal care within the community, and in residential care facilities. For example, individuals and their carers from CALD backgrounds have less information about formal community services, lower utilisation rates of community services and lower access to respite care (Schofield et al 1998; Ward et al 2005; Thomas et al 2007).

Stigma associated with dementia resulting in people being marginalised and isolated from their communities and sometimes from family members (Alzheimer’s Australia Victoria 2008).

Late diagnosis of dementia, often at crisis point, due to lack of knowledge about the early symptoms of dementia, where to go for help, or being ashamed of being labelled (Alzheimer’s Australia Victoria 2008).

Communication problems caused by low literacy levels in English, as well as in their own language. With the onset of dementia they may lose what English skills they have and revert to their native language (Lewis and Kirchener 1996; Department of Human Services 2004; Alzheimer’s Australia Victoria 2008; Runge et al 2009). This phenomenon complicates the provision of appropriate services and highlights the need for service provision to be tailored so that care can be provided by multi-lingual carers (Access Economics 2009a).

Lack of knowledge or acceptance of the service system. People from CALD communities are often unfamiliar with dementia services and aged care services in general and how to access them. This is often due to language barriers, lack of culturally appropriate services or strong preconceived ideas of the type of services that are available (Alzheimer’s Australia Victoria 2008). For example, some ethnic groups are strongly opposed to putting family members into residential care, preferring community care instead (Australian Institute of Health and Welfare 2007a; Australian Institute of Health and Welfare 2007b; Alzheimer’s Australia ACT 2010). Also Access Economics (2009b) found that residential aged care (RAC) facilities that can accommodate diverse cultural backgrounds and recreational needs, on an individual basis, were highly valued by informal carers.

Misconception that most people from CALD communities are cared for by family members, which is not always the case (Alzheimer’s Australia Victoria 2008).

### 4.3 Issues for GLBTI Communities

GLBTI Australians have specific needs that arise from their experiences of social marginalization and discrimination. For example, a recent survey of prejudice-motivated violence against GLBTI Victorians concluded that GLBTI people are subject to much higher levels of harassment and abuse than the general population and that the threat of such violence is part of the everyday lives of GLBTI people (Leonard et al 2008). The effects of this discrimination include: poorer health outcomes (Leonard 2002), reduced social participation and community engagement (Gray and Leonard 2009) and GLBTI people avoiding, or delaying seeking care, because of actual or perceived prejudice on the part of health care providers and institutions (Leonard et al 2008).

Although lesbians and gay men face many of the same challenges around dementia as heterosexuals, they may also face additional challenges such as social isolation, relationship recognition and steering through a complicated legislative environment (Birch 2009; Alzheimer’s Australia 2010a).

Significantly, many lesbians and gay men who are now facing a dementia diagnosis became adults at a time when social and legal discrimination was prevalent. As a consequence, the invasion of privacy that community services and residential care may involve can create a fear of coming out to services providers, and may lead to anxiety and depression (Barrett et al 2009; Birch 2009; Alzheimer’s Australia 2010a).

‘Family’ can be a concept fraught with complex emotions for lesbians and gay men of any age. Who is regarded as family can vary greatly depending on the personal situation and experience of each individual. Lesbians and gay men may refer to their ‘family of origin’ which may, or may not, be a part of their everyday lives, and their ‘family of choice’ which may include a same-sex partner and/or members of the lesbian and gay communities (Birch 2009: 14). This complexity leads to issues around assumed roles and responsibilities of the different people that make up a ‘family’. 

Although lesbians and gay men face many of the same challenges around dementia as heterosexuals, they may also face additional challenges such as social isolation, relationship recognition and steering through a complicated legislative environment (Birch 2009; Alzheimer’s Australia 2010a).
Issues for service providers and care workers to be aware of include: sensitivity around collecting information about a person’s everyday life and support systems; accepting support via community care may mean independence and personal privacy is threatened; aged care information may be based on an assumption that all people who use the service will be heterosexual; there may be potential issues of acceptance of lesbians and gay men by their fellow residents in aged care facilities; lesbians and gay men living in residential aged care facilities face difficulties relating to sexuality; there are special issues for transgender people with dementia as well as late-stage care issues (Barrett et al 2009; Birch 2009).

Barrett (2010) explains that some older GLBTI people need staff to understand that the grief and loss involved in having a same-sex partner with dementia is no less than that experienced by heterosexual couples. Sexual and cultural expression is important for the mental health of older GLBTI people. A positive response to the disclosure of sex/gender identity can result in GLBTI seniors feeling understood, valued and safe.

### 4.4 Issues for People with Younger Onset Dementia

Timely and accurate diagnosis is particularly problematic for younger people because there is low awareness of YOD among health professionals, limited access to specialist diagnostic service, and a lack of awareness of the availability of genetic testing (Access Economics 2010). In many instances, accurate diagnosis can take several years because symptoms are often attributed to other conditions, such as stress or depression (Runge et al 2009; Access Economics 2010). Also, younger people are less likely to be referred to a psychogeriatrician more familiar with the symptoms, and more likely to be referred to a neurologist (Ferran et al. 1996; Luscombe et al. 1997).

While many of the needs of younger people with dementia are similar to those of older people, there are significant differences primarily because of the life stage at the onset of dementia. For example, YOD is likely to impose greater financial stress because the person is often in employment, and the onset of dementia may result in a demotion, early (unplanned) retirement, or sale or failure of a business. Needing to leave employment unexpectedly, or the need for a spouse to leave employment in order to provide care, can generate a large emotional and financial burden (especially if that person is still supporting a family). Furthermore, people with YOD require access to dementia specific legal advice and specialist financial advice for future planning that is in line with their future health and personal care instructions. (Access Economics 2010: 36)

Issues for people with YOD and their carers include: challenging behaviours, activities of daily living, sexuality, employment, driving and common drug treatments (Hodges et al 2009).

Caring for someone with a YOD can be very challenging and stressful. Carers experience psychological problems, financial worries, loss of employment and family conflict, and children are affected. Also carers use support services, but express some dissatisfaction with the appropriateness and availability of such services (Luscombe et al 1998; Runge et al 2009). As younger people are generally more active, mobile and physically capable, caring for a younger person with dementia is often more demanding than caring for an older person (Hodges et al 2009). The act of caring for someone with YOD can lead to a change in relationships and carers may feel a sense of resentment that comes with the responsibility of looking after someone (Hodges et al 2009).

The provision of age-appropriate care and support is an important issue for people with YOD. Dementia services are generally structured to support the needs of older clients. Once a diagnosis has occurred, it is hard to obtain appropriate care as dementia support packages are tailored towards the elderly, and do not account for young people who are physically active (Ferran et al. 1996; Luscombe et al. 1997; Hodges et al 2009; Runge et al 2009). Entering high-level aged care at a young age is also demoralising for both the person with dementia and their family. In 2008, Council of Australian Governments (COAG) agreed that responsibility for this group should be included under a new National Disability Agreement (Access Economics 2010).
Greater support is required in the community care setting to enable younger people with dementia to continue to combine work and family responsibilities (Access Economics 2010).

There is a significant risk of younger people with dementia being shifted between disability and aged care services. When disability services are no longer able to meet a younger person’s needs due to the progression of dementia, the person and their family carers are required to navigate a second unfamiliar system (Access Economics 2010).

The progression of dementia in younger people can be quite rapid. The challenge is to develop a smooth and seamless service. One option might be to remove age limits for access to aged care services for those with dementia, and to ensure the services received are appropriate. (Access Economics 2010: 37)

### 5 PROJECT THEORIES OF CHANGE AND THEORIES OF ACTION

The logic models and the theories of change that underpin the projects are generally supported by evidence about effective strategies to improve access to services. The theories of change can be grouped into three types:

- **Building knowledge**
  - Identify factors that reduce access to dementia services for specific groups
  - Identify options for increasing access

- **Addressing demand side issues**:
  - Raise awareness and knowledge of the signs of dementia and the importance of early diagnosis, the availability of services and how they can be accessed
  - Change negative attitudes of people with dementia and carers towards services

- **Addressing supply side issues**
  - Change the way dementia services are provided to make them more appropriate
  - Provide individualised responses to consumers’ particular and changing needs
  - Identify and address gaps in services
  - Develop integrated service systems and referral pathways

The table on the following pages summarises the theories of change adopted by each project and actions that the projects have taken to implement the theories of change. The table illustrates the systemic approach taken by projects; each project has addressed both supply and demand side issues.

An intervention may be necessary but not sufficient to bring about change. For example, educating people about dementia and overcoming cultural barriers to seeking help is necessary for increasing access to services but if services do not respond appropriately to concerns about memory or behaviour, opportunities for an early diagnosis will be lost.

The projects have developed theories of action in response to contextual factors such as target group characteristics, the nature of the service system in the area and the availability of resources and expertise. An example of projects with the same theory of change and different theories of action are the NSW CALD and the SA GLBTI projects, both worked to overcome negative attitudes towards dementia and dementia services. The NSW project has put this into action by training ethno-specific agency staff to provide community education while the SA project has worked to identify Alzheimer’s Australia SA as a GLBTI-friendly organisation with credibility in GLBTI communities.
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<tr>
<th>Theories of change</th>
<th>Knowledge building</th>
<th>Demand side</th>
<th>Supply side</th>
<th>Provide individualized responses to consumers' changing needs</th>
<th>Identify and address gaps in services</th>
<th>Develop integrated service systems and referral pathways</th>
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<tr>
<td>NSW Special Needs</td>
<td>Identify factors that reduce access to dementia services for specific groups/options for increasing access</td>
<td>Raise awareness of: • how to reduce risks • signs of dementia, • importance of early diagnosis • dementia services</td>
<td>Change negative attitudes towards dementia and related services provided to make them more appropriate</td>
<td>Develop train-the-trainer model and train volunteer community members to deliver education</td>
<td>Develop carer education resources for CALD carers</td>
<td>Involve GPs to increase access to diagnosis</td>
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<td>NSW Tweed R&amp;R</td>
<td>Culturally appropriate education provided by trained bi-lingual, bi-cultural community volunteer. Develop DVD to supplement CALD education</td>
<td>Education provided by trained community member who understands community attitudes</td>
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<td>VIC Aboriginal and Torres Strait Islander</td>
<td>Culturally appropriate community education and information provided Promote AA Vic services via Koori media</td>
<td>Consultative process to support Aboriginal and Torres Strait Islander agencies to develop culturally appropriate services</td>
<td>In consultation with Aboriginal and Torres Strait Islander services identify and address need for Aboriginal and Torres Strait Islander-friendly assessment service and community education resources</td>
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<td>VIC CALD</td>
<td>Reviewing literature re CALD education and available resources</td>
<td>Culturally appropriate community education provided</td>
<td>Produce culturally appropriate community education package for use by AA Vic educators</td>
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<tr>
<td>VIC YOD Incl. R&amp;R</td>
<td>Consultant to AA Vic counselling and support services re YOD</td>
<td>Implement and evaluate key worker model of working individually with clients</td>
<td>Develop peer support mechanisms Develop information resources to meet identified gaps</td>
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<tr>
<td>QLD Special Needs</td>
<td>Provide culturally appropriate community education information</td>
<td>Train local dementia champions to provide dementia education in their communities – appropriate education for CALD and Aboriginal and Torres Strait Islanders and available in R&amp;R areas.</td>
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| WA CALD | Review research and consult with CALD, aged care, AA organisations to identify how cultural factors influence need for, and access to services | Develop and pilot culturally appropriate resources | Develop and pilot cultural competency training to improve the appropriateness of dementia services for CALD people |
| SA GLBTI | Review research and consult with GLBTI services and people | Develop a CD ROM to raise awareness of dementia and dementia services among GLBTI people | Identify AA SA as a GLBTI friendly service | Train service providers in GLBTI issues. Review AA resources to ensure they are GLBTI inclusive. | Develop links with GLBTI services Identify areas to work on together |
| NT Aboriginal and Torres Strait Islander – Incl. R&R Aboriginal and Torres Strait Islander | Review research and acquire relevant resources Pilot new cognitive therapies rehabilitation model | Deliver culturally appropriate dementia awareness and risk reduction information to Aboriginal and Torres Strait Islander people from R&R areas in correctional centres and drug and alcohol rehabilitation services | | |
| TAS Restorative Therapies People with dementia | Review research and acquire relevant resources Pilot new cognitive therapies rehabilitation model | | Provide counselling and other individualised psycho-social interventions | Develop and pilot comprehensive assessment and cognitive training program |
| ACT YOD | Review possible models for age-appropriate respite care | Provide social activities that include children of people with YOD and provide information about dementia and services | Develop training for diversional therapists too, so that service providers are aware of the needs of people with YOD | Provide social activities for people with YOD, and their families, Activity groups to provide peer support and respite for carers. Social functions for couples and families as a way of providing respite. |
6. PROJECT OUTCOMES FOR TARGETED GROUPS

Outcomes for the specific target groups, for Alzheimer’s Australia and for service systems are outlined in the following section, further details are available in the detailed project descriptions.

6.1 OUTCOMES FOR CULTURALLY AND LINGUISTICALLY DIVERSE COMMUNITIES

The three CALD specific projects in New South Wales, Victoria and Western Australia have contributed in different ways to an increased awareness of dementia and dementia services in CALD communities. The Victorian and NSW projects have developed improved community education resources. The Victorian resources are designed to support Alzheimer’s Australia Vic Community Educators and the NSW resources have been designed to support ethno-specific agencies to provide community education. Both of these projects have focussed on demand side issues – raising awareness of dementia and dementia services and addressing stigma and negative attitudes that can be a barrier to accessing services.

The NSW project has also taken a community development approach to address supply side issues by educating CALD communities about how to talk to GPs about memory concerns and through training ethno-specific agency staff who, in addition to providing training, have become initial contact points for their community.

As part of the process of developing appropriate CALD education resources the Victorian project developed and piloted CALD education resources with two Italian speaking groups and 2 Greek speaking groups. The longer term impact of the project is that future community education provided by Alzheimer’s Australia Vic educators to CALD communities will provide more accessible information that is more effective in raising awareness of dementia.

The NSW project has provided community education sessions to a wide range of CALD communities while developing and piloting new community education resources designed specifically for CALD communities that cover dementia awareness, risk reduction and carer education. Volunteer workers from Croatian and Assyrian community agencies have been trained to deliver the education sessions to their communities and have become community contact points for enquiries about dementia. Requests for community education from CALD communities have increased dramatically as a result of the project. There have been anecdotal reports of people being diagnosed with dementia as a consequence of the NSW project.

The WA project supported the Sikh community to develop an information resource in four Indian dialects however, the primary focus of the project was to research approaches for increasing access to services for CALD communities. A discussion paper identifies the need for service providers to move beyond cultural awareness training towards greater cultural competency. A group of service providers are exploring how to develop cultural competency throughout their organisations. It will take time to demonstrate the impact of increased cultural competency on access to appropriate dementia and related services for people from CALD backgrounds.

The Queensland project has also strengthened relationships with, and delivered community education to, a variety of CALD community groups and service providers in regional and rural areas.

6.2 OUTCOMES FOR ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITIES

The Northern Territory and Victorian Aboriginal and Torres Strait Islander specific projects have provided community education to increase awareness of dementia amongst Aboriginal and Torres Strait Islander communities. The Northern Territory project has provided culturally appropriate dementia awareness and risk reduction education sessions in correctional centres and Aboriginal and Torres Strait Islander drug and Alcohol rehabilitation centres in Darwin, Alice Springs and Katherine. The Victorian project has also provided community education by attending Elders lunches and other community events.
The Victorian project has also supported improved access to services by increasing the awareness of dementia amongst Aboriginal and Torres Strait Islander service providers. The project has been promoted amongst Aboriginal and Torres Strait Islander health service providers and a number of Aboriginal Health Workers have had specific dementia training. Access to diagnostic services has also been enhanced; the project facilitated meetings that have resulted in a specialist geriatrician being available at the Victorian Aboriginal Health Service on a monthly basis. The feasibility of using the Kimberly Indigenous Cognitive Assessment tool in Victoria is being investigated.

The Queensland and NSW Tweed projects have also provided community information to Aboriginal and Torres Strait Islander communities and service providers. Regionally based Alzheimer Australia Service Access Liaison Officers in Queensland have started developing relationships with Aboriginal and Torres Strait Islander service providers and one Liaison Officer was invited to set up a stall at an Aboriginal and Torres Strait Islander health forum organised by an Aboriginal Health Service. The Tweed project has also started to develop relationships with Aboriginal and Torres Strait Islander communities and has provided information at an Elders’ lunch.

6.3 OUTCOMES FOR GAY, LESBIAN, BISEXUAL, TRANSGENDER & INTERSEX COMMUNITIES

The profile of dementia has been raised amongst the GLBTI people who have become involved in the South Australian project through the advisory group, participation in the focus group and in response to media articles. Staff members in a range of Alzheimer’s Australia SA services have reported that they are more open to discussing sexuality with clients and are more likely to pick up cues about sexuality. Clients are responding to the greater sense of openness around discussions of sexuality. Feedback from members of the GLBTI community is that they are encouraged that a mainstream service like Alzheimer’s Australia has committed resources to a GLBTI specific project. The visual stories resource will be specifically relevant to GLBTI people who have dementia, or are caring for someone with dementia and will provide information about how to access available services.

The Queensland project has also developed relationships with some GLBTI organisations that are publicising the services of Alzheimer’s Australia Qld as a way of increasing awareness of dementia. The NSW Tweed project has become aware of the need to focus on GLBTI communities because of the relatively large populations of GLBTI people in the area.

Data on the sexual orientation of people accessing Alzheimer’s Australia services is not collected, nor is it appropriate to collect in many circumstances. The evidence provided by the projects, and feedback from external service providers has verified that the projects are raising the profile of dementia amongst GLBTI communities and organisations.

6.4 OUTCOMES FOR PEOPLE WITH YOUNGER ONSET DEMENTIA

The Victorian and Australian Capital Territory projects with a specific focus on YOD have worked closely with people with YOD and their carers to identify and address their needs. Half of the participants in the Tasmanian Restorative Therapies project were people with YOD.

Victoria and the Australian Capital Territory provided direct services to people with YOD and their carers and families to improve their quality of life by reducing social isolation and providing support to navigate the service system. The Victorian project linked people with YOD with a key worker who was able to provide support and referrals as needed. The project also developed resources to meet gaps in information identified by people with YOD and carers. The ACT project had a focus on facilitating family re-engagement and providing age appropriate respite options.

The Tasmanian project provided a thorough psychosocial assessment and education about each person’s diagnosis and cognitive capacity. A new service model trialled by the project provided weekly counselling, referrals to other services and specific activities to improve the participant’s quality of life, and cognitive capacities.
Feedback from participants in the Victorian and ACT projects has verified the impact that the projects have had on improving their quality of life. De-identified test results and reports on the outcomes for individuals involved in the Tasmanian project have also verified the value of individually tailored services for improving the quality of life of people with YOD.

6.5 OUTCOMES FOR REGIONAL AND REMOTE COMMUNITIES

The projects in Queensland, and the NSW Tweed area worked in regional and remote areas. The Queensland project has provided community dementia education in regional, remote and very remote communities. Links in regional areas have been expanded and training a remote health worker has increased the availability of dementia awareness education in this part of the State.

Although the NSW Tweed project had a focus on sector development the project has also provided some community education sessions and has supported the work of the Alzheimer’s Australia NSW memory van when it visited the area. Other projects targeting Aboriginal and Torres Strait Islander, CALD and GLBTI communities in Victoria, have also provided community education, or been involved in other activities to raise awareness of dementia in regional and rural locations.

7. NEW RESOURCES

Collectively the projects have expanded the range of resources available for the groups targeted by the projects, resources include information sheets, tip sheets, training packages, CR ROMs and a documented individual assessment and intervention model. Many projects also utilised existing resources that had been developed for specific groups, for example, the NT project used a CD developed with, and for, Aboriginal and Torres Strait Islander people and the Qld project utilised its Train-the-Trainer and community education resources.

7.1 NEW GLBTI RESOURCES

The South Australian project is developing a CD ROM to share stories about the experiences of GLBTI people affected by dementia; this resource will be made available to GLBTI communities and will also form part of a training package for service providers. A collaborative project between the SA/NT and Qld Dementia Study and Training Centres is developing a broader sexuality training package for dementia and aged care providers.

National Alzheimer’s Australia information resources have been reviewed to ensure that they are inclusive and ‘GLBTI friendly’.

7.2 NEW CALD RESOURCES

Western Australia has researched a new approach to cultural competency development for mainstream service providers. The training resources developed so far will be piloted and further developed with a small number of service providers before being more widely disseminated.

Victoria has developed a template for a community education package that is consumer-focused, pitched at the right level and culturally appropriate. The education package is currently available in Greek and Italian and can be translated into other languages.

New South Wales has developed community education resources for community educators to provide dementia awareness and risk reduction sessions, and information sheets for community members in four languages: Croatian, Assyrian, Spanish and Serbian. Carer education resources are being developed. The resources can be translated into other languages and have been piloted using interpreters with a range of different cultural groups. The DVD “It’s not a disgrace, its dementia” has been produced and has so far been translated for the Croatian and Serbian communities.
7.3 NEW ABORIGINAL AND TORRES STRAIT ISLANDER RESOURCES

NSW supported the production of the booklet “Don’t Be Moogil, Think Ahead “ by the New England Division of General Practice as part of the “Taking it to the People” providing community education for Aboriginal Communities. The “Don’t be Moogil” booklet was inspired by the Alzheimer’s Australia Mind Your Mind risk reduction program and is one of a set of resources that will be distributed through General Practices and in ‘Yarn Up’ sessions with Aboriginal Communities.

7.4 NEW YOD RESOURCES

Victoria has developed additional ‘tip sheets’ and a YOD specific carer’s card in response to needs identified by their YOD reference group, and plans to develop a targeted resource directory that will help people to understand and navigate the service system.

The Australian Capital Territory is developing a resource kit for the children of people with YOD in collaboration with adult children of people with YOD.

7.5 OTHER RESOURCES

Queensland has extended its database of contacts (individuals and organisations) across the state to support ongoing work with dementia champions in rural and remote areas of the state.

Tasmania has developed a psychosocial restorative therapies model that includes; detailed session outlines, assessment protocols and resources, and cognitive education tools.

8. OUTCOMES FOR ALZHEIMER’S AUSTRALIA

8.1 GREATER AWARENESS OF THE NEEDS OF SPECIFIC NEEDS GROUPS AND HOW TO ADDRESS THEM

The Service Access Liaison Officer funding has focussed attention on the needs of the specific groups and enabled Alzheimer’s Australia to develop a greater understanding of how to address them.

As a direct result of the projects, training has been provided to Alzheimer’s Australia staff in South Australia and Queensland to increase awareness of, and sensitivity to, GLBTI issues. Queensland staff also had Aboriginal and Torres Strait Islander and CALD cultural awareness training and report feeling more skilled confident in establishing relationships with Aboriginal and Torres Strait Islander, CALD and GLBTI communities.

The expertise that project workers have brought to Alzheimer’s Australia has been of benefit to other staff and has raised awareness of the needs of different groups. For example, the Vic YOD project worker’s role as a consultant to other staff has increased the knowledge and skills of counselling and support staff working with people with YOD. In South Australia, the GLBTI project worker, in addition to providing staff training, is a resource for individual staff in developing their capacity for GLBTI-sensitive practice. The research that the WA project has undertaken has highlighted the need for cultural competency within Alzheimer’s Australia WA as well as other service providers.

The consultations and ongoing relationships with individuals, groups and service providers have identified new issues as well as refined thinking about how to respond. The NSW CALD project has identified issues regarding the practices of some GPs, and in response, has included information on available diagnostic tests, referral pathways and how to raise issues with GPs in the education for CALD communities. The Vic Aboriginal and Torres Strait Islander project has learnt that holding meetings at an Aboriginal and Torres Strait Islander organisation is more likely to be successful than inviting Aboriginal and Torres Strait Islander organisations to a meeting at Alzheimer’s Australia Vic. Alzheimer’s
Australia ACT has learnt that informal approaches and social gatherings for families are effective ways of engaging with, and supporting, the adult children of people with YOD and that there is a gap in the information resources available for adult children.

The NSW CALD project has found that a community development approach to providing community education to smaller and less established CALD communities has been an effective strategy for addressing negative beliefs about dementia that tend to isolate families affected by dementia. The WA CALD project has grappled with, and extended understanding of, what it means to be a culturally competent organisation in the context of providing dementia services.

There are examples of new services being directly provided, or facilitated by the projects to address identified gaps in services. The ACT has provided respite for people with YOD in the form of social activities. Tasmania has provided face to face counselling and developed assessment protocols and activities to enhance cognitive functioning. The provision of an Aboriginal and Torres Strait Islander specific assessment service at the Victorian Aboriginal Health Service was facilitated by the Victorian project.

8.2 AN IMPROVED CAPACITY TO PROVIDE MORE INCLUSIVE AND INDIVIDUALLY RESPONSIVE SERVICES

People with dementia have different medical conditions, different levels of ability and types of cognitive decline and different rates of disease progression. They also have different family arrangements, levels of support and financial resources. The projects have demonstrated different ways to be responsive to the changing needs of people with dementia, their carers and families and to the variability in community knowledge, perceptions and attitudes towards dementia.

The Victorian, New South Wales and Western Australian CALD-focussed projects started with an awareness that a ‘one size fits all’ approach to working with CALD communities does not work as there are differences between, and within, communities. Approaches that work with well-established communities do not necessarily apply to newly emerging communities, and there are differences between generations within communities. The community education resources and models developed by the CALD-focussed projects have taken the need for different levels of information provision and different approaches into account.

The South Australian GLBTI project is underpinned by an appreciation of the diversity of GLBTI people and their individual needs; there is no single ‘GLBTI’ community. People who are same-sex attracted may not have much in common with people who have alternative understandings of their gender, and within the gay community there are a multitude of subgroups. While people with alternative gender identities and people who are same-sex attracted often face particular issues when accessing in-home or residential care services, heterosexual people also encounter agencies and carers with attitudes and beliefs about sexuality and dementia that are incompatible with their individual needs and wants.

The Northern Territory project ensured that the dementia awareness sessions delivered to Aboriginal and Torres Strait Islander people stimulated discussion that helped people from different communities to make sense of the information in light of their individual experience and situation. Similarly, the Victoria Aboriginal project assumes that an approach that fits with one Aboriginal clan will not necessarily be appropriate when building relationships with another community.

The need for individualised responses is particularly apparent amongst people with YOD who have a wider range of types of dementia and symptoms. The Victorian YOD project is developing a key worker model that will be responsive to the individual and changing needs of people with YOD and their families and the Australian Capital Territory project is providing respite activities requested by people with YOD.
The Tasmanian restorative therapies project started its work with people with dementia by undertaking a comprehensive assessment that informed the development of a tailored intervention plan for each person. The specific circumstances and interests of each person were taken into account in developing activities to enhance the person’s quality of life, mental health and cognitive functioning.

The approach that Alzheimer’s Australia has taken to developing and implementing the projects - involving consumers and working in partnership with relevant organisations, as well as monitoring, learning from, and adapting projects in response to feedback from consumers and partners - has helped to develop more inclusive and responsive services.

8.3 ALZHEIMER’S AUSTRALIA HAS A HIGHER PROFILE AND MORE CREDIBILITY AMONGST SPECIFIC GROUPS

The projects have developed new relationships with a large number of service providers and community groups that has extended knowledge about Alzheimer’s Australia and Alzheimer’s Australia’s interest and expertise in working with specific groups.

In addition, information about some of the projects has been published in the mainstream media, discussed on national and local radio, published in industry specific newsletters and in publications targeting specific groups such as Blaze, the South Australian publication for the GLBTI community.

9. LESSONS LEARNT - WHAT CONTRIBUTED TO PROJECT ACHIEVEMENTS?

The responsiveness of the projects to the different contexts in each state and territory, and the specific needs of the chosen target groups, as well as the flexibility afforded to the projects to modify their plans based on lessons learnt and changing circumstances, contributed to the projects’ success. Working in partnership with relevant organisations, involving consumers, building on previous work and taking advantage of synergies presented by other projects were also important factors that contributed to the projects’ achievements. Finally, the attributes of the project staff, their local knowledge, networks within targeted communities and skills and experience were instrumental in enabling the projects to make progress in a limited time.

9.1 PROJECT PLANS WERE RESPONSIVE TO DIFFERENT CONTEXTS

The state and territory Alzheimer’s Australia organisations vary in size and the types of services provided, for example, the Northern Territory office employs less than 20 people, while Western Australia employs more than 250. The demographic profile and geographic area of each state and territory are also diverse. The level of funding available to each projects also varied considerably. Contextual factors that influenced decisions about which target group to work with, and what approach to adopt, included:

- the service system that the project was working within (both internal to Alzheimer’s Australia and external organisations)
- relationships and partnerships that projects could build on, and new partnerships that could be developed,
- resources that could be utilised, adapted or developed to support the work of the project, including the level of project funding
- workforce availability; options for utilising existing staff and factors influencing new staff recruitment
- the characteristics of the specific groups, and
- geographic challenges

Each of the projects gave thoughtful consideration to how to utilise the additional funds to achieve sustainable results that would increase access to services amongst the target groups. Some states and territories, such as the NT Aboriginal and Torres Strait Islander project, extended previous work with a specific target group. In contrast, SA which already
had established programs for working with CALD and Aboriginal and Torres Strait Islander communities choose to focus on GLBTI communities.

9.2 FLEXIBILITY DURING IMPLEMENTATION

The projects adapted to new information about the issues, changes in context, and lessons learnt. They also had the flexibility to respond to emerging opportunities and the changing priorities of communities and services. The detailed project descriptions in the next section describe changes made during implementation.

In some cases, projects needed to adapt to unanticipated staff changes and in the case of Qld, to extreme weather events that made travel to some parts of the state impossible. Western Australia changed the focus of its project as a new appreciation of the barriers to service access for CALD communities emerged following an extensive literature review. Rather than working with individual CALD communities, the project is now focussing on developing the cultural competency of mainstream service providers.

The NSW CALD project had initially planned to train community members to deliver community education to specific CALD communities however, it became evident that presenters needed a specific skill set; CALD agency staff have been trained to deliver the community education and interested community members will be supported to help people affected by dementia within their community. This project also became aware that GPs in some communities are reticent to diagnose dementia; rather than assume that increased community awareness would lead to increased follow up by GPs, they have adapted the community education so that people are informed about how to present their concerns about memory changes to their GP and what diagnostic tests they can request.

The SA GLBTI project is developing a multimedia resource in response to feedback from community members and has responded to the opportunity to become involved with a service provider committed to developing GLBTI inclusive services.

9.3 WORKING IN PARTNERSHIP

Isolated ‘stand-alone’ projects are not likely to make sustained differences to the service system. Working collaboratively with service providers and other organisations to develop and implement the projects has been important for all of the projects. Partnerships have generally been based on shared aims, collaborative work and reciprocal sharing of resources, rather than formal partnership arrangements such as Memorandums of Understanding. When developing new partnerships it has been important to be clear about what is being sought from working in partnership and to take the priorities, needs and constraints of the organisation, community or individual into account.

Collaborative approaches have included: information sharing between organisations, involving other organisations in project planning, establishing on-going advisory processes, and implementing projects in partnership with other organisations. Many of the projects could not have proceeded without the active support and involvement of other organisations.

For example, the Northern Territory project is actively supported by the correctional centres and Aboriginal and Torres Strait Islander drug and alcohol service providers who provide venues and promote education sessions to Aboriginal and Torres Strait Islander people. One of the drug and alcohol services has incorporated the education provided by Alzheimer’s Australia NT into its program structure. The Victorian Aboriginal and Torres Strait Islander project was able to access Aboriginal Health Workers at a state-wide forum through its close relationship with the Victorian peak body for Aboriginal Controlled Community Health Services. The NSW CALD project has been working in close collaboration with four CALD community agencies and the Victorian CALD project worked in collaboration with Greek and Italian service providers.
The Tweed Dementia Pathways Forum developed by the NSW Tweed sector development project supports the collaborative work of other service providers. By working in partnership with existing services, Alzheimer’s Australia NSW has gained credibility as a peak organisation and there is more communication and coordination between services that had tended to work in silos. The partnership between Alzheimer’s Australia Vic and the Royal Melbourne Hospital (RMH) has benefited the services offered to people with YOD at both RMH and Alzheimer’s Australia Vic and has helped to close the gap between the diagnostic services in the acute sector and the information, counselling and support that Alzheimer’s Australia Vic offers.

Examples of advisory processes include the GLBTI Dementia Advisory Group established by the SA project, the service provider focus group convened by the WA CALD project and the Victorian Aboriginal and Torres Strait Islander project that has established a Victorian Diversity Working Group.

Working in partnership with relevant service providers and other organisations has provided access to expertise and additional resources. Collaboration ensures that the projects are taking the complementary work of other agencies into account and are adding to, rather than duplicating efforts to meet the needs of the target groups. Developing and building on existing relationships has enabled the projects to extend their reach and enhance the sustainability of the project outcomes, as well as raising the profile of Alzheimer’s Australia. Maintaining partnerships requires time and resources, the Service Access Liaison Officer funding has enabled Alzheimer’s Australia to devote resources to addressing shared priorities.

9.4 INVOLVING CONSUMERS IN PROJECT DEVELOPMENT AND IMPLEMENTATION

Many of the projects involved consumers in identifying needs, informing the development of project plans and providing ongoing advice and feedback that shaped the implementation of the projects. The involvement of consumers included participation in focus groups and consumer advisory committees.

The ACT YOD respite project had a focus group with consumers at the start of the project to identify issues and respite needs which lead to a new appreciation of the value of respite that did not involve separation of the person with YOD and their carer. The SA GLBTI project has conducted focus groups to identify community priorities for improving awareness of dementia and access to dementia services for GLBTI people.

The NSW and Victorian CALD-focussed projects have each involved consumers in providing feedback and advice during the piloting of new community education resources with different CALD communities. The Victorian YOD project has an established YOD reference group that includes people with YOD and carers and regularly consults with consumers to identify gaps in resources and other issues.

9.5 BUILDING ON PREVIOUS WORK - RELATIONSHIPS, RESOURCES, SKILLS

Most of the projects would not have been able to achieve the same outcomes without the pre-existing relationships, resources and skills developed prior to the projects’ commencing.

The Victorian and Northern Territory Aboriginal and Torres Strait Islander projects have built on relationships with Aboriginal and Torres Strait Islander service providers that were developed over several years. Having Aboriginal and Torres Strait Islander-specific community education resources and prior relationships with Correctional Centres and Aboriginal and Torres Strait Islander Drug and Alcohol services has enabled the NT project to deliver as many community education sessions as possible, given the funding available. Without these prior relationships and established credibility in providing culturally-sensitive education, more time would have been needed to develop relationships with the service providers in order to reach Aboriginal and Torres Strait Islander people at high risk of dementia. The Victorian Aboriginal and Torres Strait Islander project has also built on relationships with Aboriginal and Torres Strait Islander communities and organisations that have been developed over time and has utilised the
relationships that Alzheimer’s Australia Vic staff in regional areas had already developed with Aboriginal and Torres Strait Islander communities.

The South Australian project specifically sought a project worker with established links to GLBTI organisations and communities. The Queensland SALOs have utilised relationships with individuals and organisations in their regions and Alzheimer’s Australia Qld’s Train-the-Trainer resources. The Alzheimer’s Australia Tas project built on experience in implementing the Active Cognitive Enhancement program designed to prevent or reduce cognitive decline amongst healthy adults. The Victorian YOD project benefited from its established relationship with the Royal Melbourne Hospital and was able to second a project worker with extensive YOD expertise.

Many of the CALD Communities working with the projects had been funded through the Dementia Community Support Grants program and had started activities to improve awareness within their community. These communities approached the Alzheimer’s Australia in NSW and WA for assistance to continue to develop and implement models for increasing awareness of dementia and access to services.

9.6 CONCURRENT PROJECTS – LEVERAGING OTHER RESOURCES

Working in partnership has been an effective way of leveraging the resources of other organisations with shared aims and priorities, as discussed in the section on partnerships. In some cases, another concurrent project, or work being undertaken by other organisations has been important in enabling the SALO projects to achieve their outcomes within the time period of the project.

The achievements of the NSW CALD project are partly dependent on a NSW State Government-funded project that has provided resources for dementia-specific project workers to be employed by two of the ethno-specific agencies that Alzheimer’s Australia NSW is working in partnership with. Without these resources, the capacity of these small community agencies to be as involved in the Alzheimer’s Australia NSW project would have been restrained.

In Western Australia and South Australia synergies between the priorities of the Alzheimer’s Australia project in each state and the priorities and resources of partnering service providers have contributed to project outcomes. In South Australia Uniting Care Wesley has committed resources to improving the appropriateness of their services for GLBTI people, and in Western Australia the Brightwater Care Group is undertaking a project to improve the cultural competency of their workforce.

9.7 ATTRIBUTES OF PROJECT STAFF

The projects either utilised existing staff, backfilling their positions, or increasing their hours of work; or employed short-term project workers to undertake the projects. Feedback from Alzheimer’s Australia managers and external agencies has confirmed the importance of having the right people to drive the projects.

Queensland, the Northern Territory, the Australian Capital Territory, Tasmania and one of the Victorian projects were able to utilise existing staff. An advantage of having existing staff work on the projects is that they already have expertise in dementia, established networks and learnings from the projects remain in-house.

The Tasmanian project was possible because Alzheimer’s Australia Tas psychologists were able to undertake psychological assessments, provide counselling and develop tailored activities for individuals. In the Northern Territory the educators were culturally aware and experienced in working with Aboriginal and Torres Strait Islander people. The ACT staff had established relationships with people with YOD and their carers and detailed knowledge of available community services. The SALOs in Queensland had experience in providing dementia education and knew the services in their regions, they also utilised personal contacts to build connections with targeted groups. The Victorian Aboriginal and Torres Strait Islander project worker had existing relationships with Aboriginal and Torres Strait Islander service
providers and understood how to approach developing relationships with new Aboriginal and Torres Strait Islander communities.

South Australia, Western Australia, New South Wales and two of the Victorian projects employed specific project workers. In some cases project start dates were delayed while project workers were employed however, they are confident that the delays in getting started have been compensated by the capacities of the workers employed.

In South Australia the project worker’s training background, experience in the health sector, links with GLBTI communities and communication skills has developed an increased level of sensitivity to GLBTI issues within Alzheimer’s Australia SA, enabled new partnerships to be developed with service providers and has supported discussion of what can be difficult issues for some people.

The Western Australian project worker has brought an industry perspective and project management and research skills to the position, as well as personal experience of the impact of dementia and the challenges associated with moving into a different culture.

The NSW CALD project worker had extensive experience working with CALD communities and with community-based organisations and the NSW Tweed sector development project worker, although new to the geographic area, was knowledgeable about dementia, had experience in working in the aged care sector and was able to ‘hit the ground running’.

The Victorian YOD project utilised and further developed the partnership with the Royal Melbourne Hospital’s psychogeriatric unit by seconding a psychologist from the unit to be the project worker for the YOD project. The Victorian CALD project worker brought extensive experience in developing and providing education programs for CALD communities.

### 10. LESSONS LEARNT - WHAT LIMITED PROJECT ACHIEVEMENTS

#### 10.1 SHORT PROJECT DURATION

Most of the projects are working on issues that will take time to generate changes, for example, changing community attitudes or perceptions of the appropriateness of services, will need ongoing work over an extended time. Similarly, influencing the appropriateness of dementia services provided by other organisations, or developing new culturally appropriate services are longer term endeavours.

The short project duration has been particularly important for planning work with Aboriginal and Torres Strait Islander communities. The two projects specifically focused on work with Aboriginal and Torres Strait Islander communities are building on relationships with Aboriginal and Torres Strait Islander service providers that had developed over several years. Without these prior relationships and established credibility in providing culturally-sensitive education the projects would have needed to spend more time building relationships with Aboriginal and Torres Strait Islander communities and organisations.

Experience in working with Aboriginal and Torres Strait Islander communities has identified the need to take time to develop relationships, to invest in maintaining relationships and the importance of not starting work that cannot be followed through. As a consequence of the short project duration some Alzheimer’s Australia organisations that had initially considered a focus on increasing access to services for Aboriginal and Torres Strait Islander people decided that this work was not within the scope of the project timeframe and resource levels.
The consultation with the NATSIDAG confirmed the view that short term projects working with Aboriginal and Torres Strait Islander communities are generally not successful if new relationships need to be developed. If time and resources available for working with Aboriginal and Torres Strait Islander communities are limited, the NATSIDAG suggested that Alzheimer’s Australia consider whether funds should be used to leverage other resources rather than aiming for outcomes for communities.

10.2 DELAYS IN RECRUITING PROJECT STAFF

Most jurisdictions waited until project funds were approved before recruiting new staff or allocating existing staff to projects. While project plans had been developed some project staff did not commence until late in 2010 or early in 2011. The projects have adapted to the shorter time frame, in some cases by extending the planned finish date or employing staff for more hours over a shorter period.

Two projects experienced unanticipated staff changes and needed to either recruit a new project worker or reallocate exiting staff.

11. LESSONS LEARNT – WHAT COULD BE IMPROVED

The Service Access Liaison Officer funding to Alzheimer’s Australia has been provided by the Department of Health and Ageing for an additional 12 months. The following recommendations for improvement, based on the findings of the evaluation of the projects funded through the initial 12month grant, are suggestions for how Alzheimer’s Australia can build on achievements so far.

11.1 COORDINATION AND INFORMATION SHARING AMONGST PROJECTS AND WITH THE ALZHEIMER’S AUSTRALIA NATIONAL ADVISORY GROUPS

While both the NATSIDAG and NDCCN reviewed the project plans and provided feedback, there has generally been little contact between the Alzheimer’s Australia national advisory groups and most of the projects.

A higher level of information sharing between projects, and between projects and the advisory groups, could avoid duplication of effort and support the sharing of expertise, conceptual models, emerging ideas and lessons learnt, including lessons learnt from what has not worked as intended. There may be scope for the collaborative development of resources for particular target groups that can be tailored as needed for different locations.

Possible mechanisms for sharing information include:

- Disseminating information about the project plans and updates on how projects are progressing in the NATSIDAG, NDCCN and other Alzheimer’s Australia Newsletters
- Video conferences and face-to-face forums for project staff, managers and representatives from the NATSIDAG, NDCCN, and the National Consumer Advisory Committee
- Creating subgroups of projects working with the same target group, who meet, either virtually or face-to-face, to keep each other informed about how projects are progressing and lessons learnt

11.2 CONTINUED LEARNING THROUGH MONITORING AND EVALUATION

Alzheimer’s Australia has recently introduced a new data management system for reporting on services funded through the National Dementia Support Program (NDSP). The system reports provides information about access to National Dementia Helpline, Counselling and Support and Information and Training services for Aboriginal and Torres Strait
Islander, CALD, Homeless, Rural and Remote people and people with YOD. Appendix 1 provides more detailed information about relevant data that is being collected.

Most states and territories were not confident that their service delivery data at June 2010 accurately reflected the use of services by these groups. In some cases this is because questions about cultural background or current living circumstances were not routinely asked. Cultural awareness training and further training and familiarity with the new data collection system will improve the quality of data collected over time. The current projects are providing an incentive to collect more accurate data.

There is no baseline data on the use of services by GLBTI people and asking about sexuality would often be inappropriate. Alternative data sources, such as the number of referrals made to dementia services by GLBTI service providers could be explored.

One challenge for the evaluation of some of the projects has been to differentiate between work being done as part of the funded project and work that has been supported by other resources. In some cases the projects have been clearly delineated, the Northern Territory and Tasmanian projects, for example, while building on previous work undertook activities and achieved outcomes that could be neatly attributed to the SALO funding. In other cases, for example the Victorian YOD and the NSW CALD projects, the SALO funding was valuable in progressing or extending work that was already underway. Asking states and territories to identify how other activities are contributing to the achievement of outcomes would be a useful addition to the project reporting template. If another jurisdiction set out to replicate a successful project, it is important that there is a clear understanding that additional resources contributed to the outcomes achieved.

Transferring learnings from one context to another is supported by understanding how the theories of change and theories of action were influenced by contextual factors. Theories of change often apply in different contexts, although theories of action might need to be adapted to local circumstances. Asking projects to report on changes made during implementation and the rationale for the changes would help to build knowledge about what works, or does not work, in different contexts.

Continuing to develop strategies for measuring outcomes in addition to project activities and outputs would help to build further knowledge about the effectiveness of the projects. Assessing the longer term impact of most of the projects would require specific research and follow-up. For example, identifying the extent to which the dementia education being provided to Aboriginal and Torres Strait Islander people in the Northern Territory is influencing attitudes to dementia in remote communities would require research that is well beyond the scope of the project.

However, there are some relatively low cost strategies that could be adopted to gather additional impact data, for example, collecting data on how groups or individuals requesting education sessions have heard about Alzheimer’s Australia or documenting or seeking feedback from community members and other agencies. Alzheimer’s Australia SA was contacted after advertising for a GLBTI project worker and congratulated for addressing the needs of the GLBTI communities, this type of information helps to build a picture of the impact of the projects.

Systematically seeking information from staff at Alzheimer’s Australia national office as well as states and territories about approaches from specific needs groups and projects being implemented in partnership with them would help to demonstrate that Alzheimer’s Australia is building credibility with diverse communities and is raising the profile of dementia.

Different views were expressed about the effectiveness and quality community education for CALD communities using trained community members versus professional community educators. Alzheimer’s Australia Vic chose to have Alzheimer’s Australia Vic educators provide community education because of concerns about maintaining quality and the currency of the information being provided. In contrast, the NSW project purposefully developed a train-the-trainer model believing that negative attitudes towards dementia would be most effectively addressed if a member of the
specific CALD community was providing the education. A research project that further explored these issues would help to clarify the importance of who delivers community education to different types of communities.

11.3 CAPACITY FOR LONGER TERM PLANNING

The lack of certainty regarding future funding was raised as an issue in the mid-term evaluation report, although additional funding has been provided, concerns about the short-term nature of the funding remain current. Certainty about future funding would enable the momentum that has been developed in the current projects to continue. If the organisations’ capacity to focus on increasing access to specific groups is reduced, there are risks that experienced staff will become unavailable and that partnerships will not be maintained, or further developed, at the same rate. A lack of certainty impedes partnership and service system development as projects are mindful of not making commitments that cannot be met.

The capacity to plan longer term varies across states and territories, larger Alzheimer’s Australia organisations have more resources available to support efforts to attract funding from a variety of sources including philanthropic and government funding. The availability of funding from state and territory governments also varies.

Given the particular concerns about short-term projects with Aboriginal and Torres Strait Islander communities, a commitment to providing dedicated funds over a longer period would support a focus on work to increase access to services for Aboriginal and Torres Strait Islander people. NATSIDAG recommended that any substantial long term funds in the future should be used in local Aboriginal and Torres Strait Islander communities to improve capacity, ensure more efficient use of resources, improve cultural safety, and ensure local ownership and participation in decision-making.

12. CONCLUSION

The evaluation of the work of the Service Access Liaison Officer projects has considered the following evaluation questions:

- Have the Service Access Liaison Officers made a difference in awareness of dementia and access to services by special needs groups compared to baseline information?
- What resources have been developed and how effective are they?
- What lessons have been learnt in the partnerships established between state and territory Alzheimer’s organisations with CALD, Indigenous and other communities?

The projects are making a difference to levels of awareness of dementia amongst the special needs groups. Education sessions have been provided to diverse communities including a range of CALD communities and to Aboriginal and Torres Strait Islander people and communities in the Northern Territory, Victoria and Queensland. As discussed, the baseline information available through the NDSP data collection and management system was not generally considered reliable in terms of services accessed by the specific needs groups.

The resources that have been developed by the projects have been documented. The processes used to develop resources - referring to the evidence base, working in partnership with consumers and service providers to identify needs and preferences, piloting information and community education resources - have ensured that they are relevant and credible.

The relationships that Alzheimer’s Australia organisations have developed or extended with CALD, Aboriginal and Torres Strait Islander, GLBTI and regional and remote communities have been described and lessons learnt about what worked well, what limited project achievements and what could be improved in future work to further develop inclusive services, have been documented.
The project funding has provided a focus for developing more inclusive and/or individualised service responses to specific groups. All of the state and territory Alzheimer’s Australia organisations have expressed the view that the work being done to focus on, and increase capacity for working with specific groups, should be a part of core business. Rather than thinking in terms of ‘special needs’ groups Alzheimer’s Australia recognises that providing quality dementia responses involves identifying the special needs of each individual, carer and family affected by dementia.
13. NEW SOUTH WALES - SECTOR DEVELOPMENT TWEED AREA

Start date: 22nd October 2011

Funding: $130,000

Staffing: 1 EFT

Staff Commencement Date: Feb 2011

PROJECT DESCRIPTION

This project has developed relationships with existing providers to create a Tweed Valley Dementia Forum. The need for improved service sector coordination and integration was identified through consultations with service providers in the area. The forum is a vehicle for improving the coordination and integration of dementia services, working in partnership to address gaps in services, ensuring that new resources are linked with existing services and lobbying to increase awareness of the growing need for dementia services in the area.

The project will also make links with community groups and organise the provision of community dementia education and information to increase awareness of dementia and of the needs of people with dementia in the community.

PROJECT AIMS

- Promote local community awareness of dementia and risk reduction strategies and encouragement of early referral for investigation of memory loss
- Support community building, health promotion and social inclusion outcomes in the local area in relation to dementia
- Collaborate with local service providers to advance service opportunities and the development of appropriate local service models for people living with dementia including the special needs of younger people and Aboriginal and Torres Strait Islander people with dementia
- Assist local dementia taskforces to identify local needs and to develop local implementation plans

PLANNED ACTIVITIES

- Undertake community awareness activities for dementia awareness including Mind Your Mind risk reduction
- Undertake stakeholder consultations with indigenous communities in the Far North Coast region to a) raise awareness of dementia and risk reduction and b) identify support and service needs
- Undertake stakeholder consultations to identify future service requirements and improvements across the region – this includes working in with existing networks and in addition, engaging local councils and community groups for community capacity building
- Document findings and make representation to Government for local community capacity building for dementia social inclusion and service growth/improvement
- Facilitate education for GPs, health service providers, local government and community organisations, families and carers

EXPECTED OUTCOMES

- Increased community awareness of dementia and risk reduction strategies
- Identification of future service requirements and improvements across the region to inform planning and development
- Community building, health promotion and social inclusion outcomes in the local area in relation to dementia

(Project aims, planned activities and expected outcomes from original project plan)
Consultations with key stakeholders in the Tweed Valley area at the start of the project led to a revision of the project focus and objectives. Revised project outcomes, based on the consultation with key stakeholders include:

- Shared vision amongst stakeholders on how to address regional needs
- Enhanced sector coordination in addressing key priorities for dementia awareness, dementia care and service development
- Referral pathways more visible & streamlined
- Improved access to assessment & diagnosis
- Increased opportunities for collegiate support
- Shared vision amongst stakeholders of a dementia-friendly community and local coordinated planning and development opportunities
- Local issues elevated to political level

(December 2010 Project Report)

SITUATIONAL ANALYSIS / CONTEXT

The Tweed Valley area, located in the Far North Coast region of NSW has the highest prevalence of dementia in NSW. The prevalence of dementia in the Far North Coast region, which includes the Tweed Valley, is projected to increase by 336.8% by 2050. The area has an ageing population and retirees moving into the area who often lack the informal support provided by family and friends.

Alzheimer’s Australia NSW does not provide services in this area but given the high prevalence would like to establish a presence in order to:

- facilitate support and advocacy on behalf of the community
- support local service coordination, responsiveness and future growth of services, and
- increase community awareness of dementia, dementia risk factors, the importance of prevention and early detection and available services

There is an established Far North Coast Dementia Pathways regional forum but no local dementia-focussed network in the Tweed Valley area. There are a number of dementia service providers in the Tweed Valley area but also notable gaps in services, particularly diagnostic and geriatrician services. There are new agencies taking on dementia care delivery in the area as resources increase. The service system has been described as fragmented.

BUILDING ON

This is a new area of work for Alzheimer’s Australia NSW, both in terms of having a presence in the local geographic area and playing a peak body role in service sector development.

The project will utilise community education services currently provided by Alzheimer’s Australia NSW such as the Memory Bus to deliver dementia awareness and risk reduction education to the community.

RATIONALE

Given the gaps in dementia services, the high level of demand and projected increases in prevalence, a lack of clear pathways for accessing services, cross-border issues and that Alzheimer’s Australia NSW is not a dementia service provider in this area, the project is focusing on supporting the development of an integrated service system and a ‘dementia-friendly community’.
Developing better pathways and more integrated responses in a fragmented service system that is currently struggling to meet the demand for dementia services is viewed as a necessary pre-requisite to work that focuses on increasing access for specific groups including people from CALD backgrounds, Aboriginal and Torres Strait Islanders, gay and lesbian people and people with younger onset dementia.

Increasing community awareness and acceptance of dementia is viewed as integral to improving the quality of life for people with dementia and their carers because of the current high prevalence of dementia and the anticipated increases in rates of dementia in this area. Increased community awareness has the potential to decrease the burden on carers, particularly those who are relatively new to the area and lack established support networks.
IMPLEMENTATION

ESTABLISHING THE PROJECT

Alzheimer’s Australia NSW approached key stakeholders in the planning phase of the project and organised consultative sessions with service providers to seek their views on how the resources being provided by this project could be best utilised. Prior to the forum, Alzheimer’s Australia NSW was aware of gaps in services and unmet needs, and the focus of discussion at the consultations was on the most productive use of the project resources, rather than the details of existing service gaps.

Consultations held in the Tweed and Northern Rivers areas were well attended. A total of 35 people attended including representatives from the Dementia Advisory Service, the Dementia Outreach Service, DBMAS services, residential care services, respite services, community care services, carer support services, and a visiting geriatrician from Queensland. The consultations identified the following issues.

Service system issues:

- a lack of diagnostic and assessment services in the region (there is currently no Geriatrician in the Tweed; no inpatient facility for acute dementia patients; low levels of diagnosis of dementia by GPs)
- lack of visibility of services and referral pathways for consumers who are worried about memory changes or who have been diagnosed with dementia
- problems with cross-border service coordination – many consumers access services across the border in Queensland
- low levels of sector coordination for identifying and addressing key priorities for current and future dementia awareness and support

Community issues:

- lack of dementia awareness activity in the region – service providers are too busy providing services to focus on dementia awareness and risk minimisation
- need for aboriginal communities to understand dementia
- lack of a shared vision in the community for addressing current and future dementia community needs
- special needs of sea changers who have moved to the area and who do not have established social networks or family support. Many of these people with dementia live alone and carers of people with dementia are isolated

Alzheimer’s Australia NSW’s strengths were seen as being able to work on developing public awareness and taking a peak body role in sector development, influencing policy and lobbying to meet the needs of people in the local area. Individual service providers were clear that they did not have the capacity, or the national links, to fulfil these roles.

The consultations led to a revised project goal: “To improve coordination, availability and responsiveness of dementia care services and support to people at risk of dementia, people living with dementia and their carers in the Tweed sector.” (Project scope document)

The project worker attended relevant network meetings and reviewed relevant Commonwealth, State and Local government aged care and dementia planning documents to refine the project scope and objectives.
**SECTOR DEVELOPMENT**

The Tweed Dementia Pathways Forum has been established and is meeting every two months; this forum has links with the Northern Rivers Dementia Pathways Forum that covers a much larger region. The Chair of the Tweed Dementia Pathways Forum, a manager at the Tweed Dementia Outreach Service also chairs the Northern Rivers Dementia Pathways Forum. The Tweed forum meets bi-monthly and has attracted the dementia service providers in the area as well as a range of health, aged care and community service providers including the local government Aged and Disability Development Officer. The Tweed forum has developed an action plan and identified priorities to address in collaboration. Two working groups have been established and meet monthly.

One working group is focussing on improving referral pathways for people with dementia with the aim of achieving earlier diagnosis and referrals to appropriate services. Services involved in this working party are The Tweed Valley General Practice Network, Dementia Outreach Service, Dementia Advisory Service, Dementia Behaviour Management Advisory Service and a psychogeriatric Clinical Nurse Practitioner working from the local hospital.

The working group has reviewed the resources available for educating general practitioners, and in partnership with the general practice network, has organised for dementia information to be included in both a monthly newsletter and a weekly email that is distributed to all of the general practices. A series of articles is being planned and will include relevant local information such as introductions to the role of the different dementia services in the area and information to support a dementia diagnosis.

Dementia related topics are being scheduled into the GP training calendar and education sessions for GPs on specific cognitive screening tools and referral pathways are being planned. The GP network holds quarterly practice nurse forums that attract between 40 to 50 people and dementia will be the topic of the next forum.

This group is also developing a referral pathways resource, and models for presenting referral pathways have been reviewed. The need for education amongst residential care staff is being explored.

The second working group is planning a memory walk as a community awareness raising activity in September 2011 as part of Dementia Awareness Week. The memory walk aims to raise awareness of dementia and promote walking as a way of reducing the risk of dementia. The Alzheimer’s Australia NSW project worker is working closely with the Tweed Valley Council health promotion unit who have close links with the NSW Health Promotion Unit walking groups. The NSW Health Promotion Unit is producing a booklet on walks in the local area and dementia prevention information will now be included in the booklet. A panel of service providers will be interviewed on the local Radio National station during Dementia Awareness Week.

An email list of around 50 people has been established to disseminate dementia related news to agencies in the area. The Home and Community Care Development Officer who distributes a regular electronic digest to HACC providers includes this dementia information extending its reach into the aged care sector.

**COMMUNITY ENGAGEMENT AND EDUCATION**

The local council is reviewing their positive ageing policy and the Alzheimer’s Australia NSW project worker has been involved in healthy ageing partnership meetings that involved a range of community organisations and service clubs.

The pathways forum has facilitated the distribution of information for the public; brochures on ‘know the signs’ and ‘worried about your memory?’ have been distributed to all of the GPs and pharmacies in the area. The project worker supported the Alzheimer’s Australia NSW Memory Van when it has visited the Tweed area. The Memory Van visited a shopping centre where it attracted a constant flow of people who were provided with information about dementia. The project worker has disseminated information about dementia to a variety of groups including giving a talk to an Aboriginal Elders’ lunch and setting up a stall at a Council expo.
The project worker attended a dementia carers’ meeting to consult with carers about their experience of the service system and strategies for increasing community awareness.

Where there are identified gaps in the provision of community education the project is taking on the delivery of Mind your Mind sessions. A volunteer who works in the peer support program of the Council of the Ageing (COTA) is being trained to deliver community education to raise awareness of dementia.

**OUTCOMES**

**OUTCOMES FOR THE TWEED SERVICE SYSTEM**

This project has successfully created links between the existing dementia service providers in the Tweed area. External service providers have confirmed that the Tweed Dementia Pathways forum is valuable and has supported the development of closer working relationships between service providers; the forum provides an opportunity to look at the bigger picture and to develop, and act on, shared priorities. The services in the area, because of their high workload have tended to work in isolation.

**OUTCOMES FOR AA NSW**

The project has highlighted the need for Alzheimer’s Australia NSW to have an ongoing presence in the area and has helped to clarify the potential role of an ongoing position. Value adding to what was already being provided has been an effective approach supported by other services.

Establishing links with the GP network has been very successful in raising the profile of dementia and is an approach that could be used by Alzheimer’s Australia NSW in other areas.

Alzheimer’s Australia NSW now has connections with Aboriginal and Torres Strait Islander organisations in the area.

**WHAT HELPED OR HINDERED?**

**PARTNERSHIPS**

Adopting a consultative approach and involving key stakeholders in setting the direction of the project has been crucial in building partnerships with existing service providers. Offering resources to implement a sector development project and doing more than identifying the issues has given Alzheimer’s Australia NSW credibility. The Project worker and Alzheimer’s Australia NSW managers involved in the project report that the sector has been supportive and have welcomed the project.

Consultations with external service providers as part of the evaluation have confirmed the value of this approach. The fact that Alzheimer’s Australia NSW consulted with existing services prior to setting up the project has been appreciated. The project worker has the capacity to follow up decisions made by the Tweed Dementia Pathways Forum working groups; without this resource the working group would not have progressed as far as it has.

The project worker has had to be mindful of the workload of direct service providers and to strike a balance between hassling people and maintaining contact and involvement in the project. The email list is a useful way of disseminating information and gently nudging people to stay aware of the importance of dementia.
STAFF

The project worker has a background in aged care, expertise in dementia, an understanding the service system and was been able to ‘hit the ground running’. The fact that the project worker was new to the geographic area has meant that she is not viewed as being aligned with any particular services. Feedback from services involved in the working groups is that the project worker’s collaborative style of working has facilitated the work of the groups.

BARRIERS

Fitting in with other people’s schedules has sometimes been hard given the high workloads of the dementia service providers. Although the project is focussing on a single Local Government area, there are large distances between communities and maintaining face to face contact with organisations in areas such as Ballina and Lismore is time consuming.

LESSONS LEARNT

Consulting service providers in planning the project has resulted in Alzheimer’s Australia NSW being welcomed in its sector development, advocacy and community awareness building roles. Consulting with, and being directed by the priorities of local service providers has been important in gaining widespread acceptance and support for the project. Employing a project worker who is knowledgeable about the service system but is not viewed as being aligned with any specific services has been beneficial.

While the Far North Coast Dementia Pathways forum covers the Tweed Valley area, having a local Tweed Valley focus is essential for developing the local service system. There is a need and willingness to build links between aged care and dementia specific services. It has been important to look at what can be done with the resources currently available in the service system rather than focussing solely on gaps in services.

PROJECT LEGACY

Alzheimer’s Australia NSW has clarified its role as a peak body supporting sector development. As an organisation, Alzheimer’s Australia NSW tends to focus on service delivery and the current project has developed a model for grass roots community development and sector development. Dementia and related services in the Tweed Valley have an established forum and agreed priorities for building a better integrated and more consumer-focused service system.

FUTURE PLANS

The need to establish an ongoing Alzheimer’s Australia NSW presence in the area has been identified. The office where the project worker is currently located is out of the way; ideally, a shop front would be established to provide a community resource centre and gateway for access to services. An ongoing Alzheimer’s Australia NSW presence would focus on community education and continuing its role as peak body in building service system capacity to respond to diverse community needs. It is anticipated that the forum will play a stronger role in lobbying for additional resources and coordinating service planning in the future.

The pathways forum has identified raising community awareness of dementia as a high priority for future work. The possibility of establishing short term projects to utilise funding so far unspent because of the delayed project start date is being explored. Possibilities include working with clubs to make them more dementia-friendly and setting up a GLBTI specific project to develop links with these communities. A project working with the 18 registered clubs in the area could identify whether they are accessible to people with dementia, what barriers exist and how they can be more ‘dementia-friendly’. The Northern Rivers region has the highest GLBTI population in NSW outside Sydney and
Alzheimer’s Australia NSW is interested in developing a relationship with ACON, the NSW peak organisation, to establish a collaborative project to address community education and access to appropriate services for GLBTI people.
### PROJECT DESCRIPTION

The project is working with four ethno-specific welfare agencies; Spanish, Serbian, Croatian and Assyrian. Each of the agencies has had a dementia community support grant and wants to address the need for increased awareness and better access to services in their communities. The work done by the agencies with 2009 funding from the Dementia Community Support Grant could not be sustained without ongoing funding, and at a 2010 dementia week event each of the agencies approached Alzheimer's Australia NSW for support to continue raising awareness of dementia and access to services.

The current project is working in partnership with each of the community welfare agencies to develop a Train-the-Trainer model as a sustainable approach to increasing awareness of dementia.

The model has a staged approach:

- **Stage 1** focuses on increasing community awareness through volunteer educators, members of the target community who are bi-lingual and bi-cultural who will be trained to present culturally sensitive community education aimed at increasing awareness, diminishing the stigma of dementia and educating carers

- **Stage 2** moves on to increasing access to diagnosis which involves developing links with and supporting GPs who work with the community

- **Stage 3** has a focus on increasing access to culturally appropriate support, including GPs and Alz NSW and other dementia service providers and the provision of culturally sensitive carer education

- **Stage 4** involves developing models of shared care and skilling members of the community to provide support to people with dementia, their families and carers

Each stage of the model will provide sustainable outcomes and also act as a platform for the next stage of development. The model is intended to have a cumulative impact; as awareness and acceptance of dementia increases and more people are diagnosed and access appropriate services, there will be less stigma, more awareness, greater acceptance of dementia and less likelihood that dementia will be hidden. The long term goal is access to integrated services from time of diagnosis, through changing needs as dementia progresses.

The trained community volunteers who provide education sessions will also be spreading information about dementia through word of mouth in informal settings. There are plans to link volunteer educators with people who have experience of dementia and dementia services. It is hoped that at least two people from each community can be trained so that they can provide peer support. The welfare agencies will provide ongoing support to the volunteers and monitor the quality of education being provided.

Material developed to support community education will be available in the community language with an English version on the other side so that younger people, who may not be literate in their parent’s first language, can understand the information. Access to the helpline via interpreter services will be promoted as being useful for getting personalised information.
PROJECT AIMS

To improve access to early intervention and education services for people from culturally and linguistically diverse (CALD) backgrounds and Aboriginal and Torres Strait Islander populations through the provision of culturally appropriate programs.

PLANNED ACTIVITIES

- Establish relationships with local CALD and Aboriginal networks within the targeted areas to identify service access needs and to obtain local expertise to inform the conversion/customisation of current education and early intervention programs including Understanding Dementia, Risk Reduction Awareness and Family Carer education.
- Customise/convert programs as identified to meet service gaps and facilitate service access
- Undertake train-the-trainer programs with targeted local CALD and Aboriginal and Torres Strait Islander service providers and develop co-facilitated programs for delivery
- Evaluate programs for relevance and effectiveness
- Provide assistance and project support for the National Cross Cultural Dementia Network (NCCDN) and the National Aboriginal and Torres Strait Islanders Dementia Advisory Group (NATSIDAG) to enhance the support and services provided by Alzheimer’s Australia and Alzheimer’s Australia NSW to these groups

EXPECTED OUTCOMES

- Increased access for CALD and Aboriginal and Torres Strait Islander groups to community awareness, early intervention, education and support programs
- Increased understanding of dementia and the services available; and increased confidence for living with memory loss and managing changes associated with dementia
- Increased capacity of CALD and Aboriginal and Torres Strait Islander services to deliver dementia awareness, early intervention and education programs

(Situation aims, planned activities and outcomes from project plan)

SITUATIONAL ANALYSIS / CONTEXT

Alzheimer’s Australia NSW has identified a need to improve access to services for people from CALD backgrounds and Aboriginal and Torres Strait Islander people based on the under use of dementia awareness, early intervention and education programs (AA NSW Business Plan 2009-2011). Alzheimer’s Australia NSW has been approached to assist in developing culturally appropriate approaches to improving awareness and understanding of dementia and access to services.

Providers of dementia services have identified a lack of understanding about dementia and dementia care amongst different CALD and Aboriginal and Torres Strait Islander populations, including myths and fears that can result in people not accessing diagnosis, treatment or support services. The stigma associated with dementia in some communities creates a hidden problem as families may deny, dismiss or hide the fact that a family member has symptoms of dementia. This stigma sometimes has a religious foundation.

Newer CALD communities have greater levels of unmet need because of low proficiency in English, there has not been time to develop services within the community and there is a lack of familiarity with health, aged and community care services in Australia. The welfare organisations that do exist are small organisations with limited staff resources, there is a need to be mindful of the limited resources of small ethno-specific welfare agencies and frame expectations
accordingly. Previous work by the agencies to increase community awareness could not be sustained once the Dementia Community Support grant funding ceased.

Existing community education resources are not effective for increasing awareness of dementia amongst some communities – simply translating written information does not mean that it is accessible or culturally appropriate. Bi-lingual and bi-cultural presenters are important for delivering community education that seeks to change community attitudes and raise awareness of dementia. Gaps in multimedia resources to assist in raising CALD and Aboriginal and Torres Strait Islander community awareness of dementia have been identified. CALD and Aboriginal and Torres Strait Islander communities are diverse, what works in one community may not be appropriate or effective for another community.

Experience of Alzheimer’s Australia NSW is that there needs to be a long term commitment when working with Aboriginal communities. Projects need to be developed in consultation with communities rather than approaching with a pre-set agenda, relationships need time to develop and it is important to gain acceptance and support from Elders in the community.

BUILDING ON

The project is building on the work of the CALD welfare agencies to raise awareness of dementia within their communities that was funded by 2009 Dementia Community Support Grants.

Alzheimer’s Australia NSW has an existing partnership with the New England Division of General Practice. The “Talking to the People” dementia risk awareness program is providing education and developing resources based on the Alzheimer’s Australia Mind your Mind dementia risk reduction signposts. The material has been developed with specific cultural sensitivity to the Aboriginal people of the New England region. The method of delivery and terminology were developed in consortia with the Elders of the aboriginal community and the Aboriginal Health Team of New England Division of General Practice. The design of the resource utilised artwork by a local aboriginal artist for appropriateness and sensitivity. The word “Moogil” was identified as the most recognised word for memory loss/dementia. Therefore the slogan “Don’t be Moogil – think ahead” was chosen as the title of the program. A booklet drawing on Mind Your Mind information has been reworked for relevance in relation to the local aboriginal community. The booklet was launched in February 2011 and ongoing gatherings are scheduled to present these resources to the local community.

RATIONALE

The rationale for this approach is that even if culturally-appropriate services were available they would not be utilised unless community awareness and acceptance of dementia increases and pathways for diagnosis are established.

The four communities were chosen because:

- There were high levels of unmet and often hidden need
- Some communities had a background of trauma
- Community welfare agencies were active in wanting to address dementia in their community, and
- The communities did not have self-initiated dementia-focussed support services established, therefore the project could focus on developing a model of community awareness and education without needing to also focus on service development with an existing service model

It is anticipated that presenting information in a culturally sensitive way will reduce barriers to talking about dementia; people will be less guarded if they feel that their culture is understood.

The work with CALD communities is the primary focus of the project. It was decided that there was insufficient time and resources to also have a significant focus on Aboriginal and Torres Strait Islander communities because of the long
lead time needed to develop relationships before initiating community projects and concerns about not being able to achieve sustainable change within the timeframe.
PROGRAM LOGIC DIAGRAM – THE CURRENT PROJECT IS IMPLEMENTING STAGES 1 AND 2 OF THE MODEL

Activities

- Develop staged model for sustainable increases in community awareness of dementia and access to services
- Identify communities with unmet needs and interest in dementia
- Develop partnerships with 4 CALD welfare agencies

Short term outcomes

Stage 1

- Develop culturally sensitive training resources in consultation with welfare agencies and AANSW educators
- Volunteer educators trained using train the trainer approach
- Quality culturally sensitive community education sessions provided
- Increased community awareness and acceptance of dementia
- Ongoing monitoring of quality of presentations

Stage 2

- Welfare agencies recruit bi-lingual, bi-cultural volunteers
- GPs have greater awareness of dementia and cultural issues
- Increased diagnosis of dementia and knowledge of services

Stage 3

- Develop relationships and skill GPs that work with selected communities
- Dementia services and carer education resources are culturally sensitive
- Increased access to culturally appropriate support services including carer education

Stage 4

- Develop culturally appropriate carer education resources for AANSW, other dementia service providers and GPs
- Capacity to support people with dementia located within the community
- Community supports people with dementia and carers

Longer term outcomes
IMPLEMENTATION

A four stage framework for CALD community and carer education that is responsive to particular cultural needs while maintaining a standardised base to ensure quality assurance and parity of information across cultures has been developed.

The project has developed three education modules for CALD communities:

- Awareness and understanding of dementia
- Risk reduction (based on Mind your Mind)
- Carer education

The modules consist of session presentations (PowerPoint) and handouts in the language of the targeted groups.

A DVD explaining dementia called “It’s not a disgrace its dementia” has also been developed. The DVD features a specialist geriatrician and a GP. The DVD has so far been translated for the Croatian and Serbian communities. The DVD will be part of the training kit and it is also being widely distributed to members of the community. The DVD reinforces messages about the importance of getting a diagnosis.

The awareness and risk reduction education presentations were trialled with over 20 communities with different languages and religions. Care was taken to ensure that the concepts and terminology were appropriate and that the presentation works equally well in all communities. The following communities were involved in piloting either the dementia awareness or risk reduction presentations: Italian, Armenian, Hindi, Italian, Korean, Chinese, Indonesian, Filipino, Laotian, Egyptian, Pacific Islander, Arabic, Turkish, Cambodian, Vietnamese and Muslim. The number of people attending these sessions ranged from 6 to 85 with an average of 30 people per sessions.

Dementia awareness education has been provided to each of the four targeted communities and numbers attending ranged from 16 Spanish speaking people to 45 people from the Croatian community. The risk reduction education session has been provided to 21 Spanish speaking participants.

The Alzheimer’s Australia NSW project worker supported the four targeted communities to apply for a second round of funding through the Dementia Community Support Grant however, none of the applications were successful. However, the NSW government has funded a CALD dementia project that has provided resources for the Croatian and Assyrian agencies to employ staff to work specifically on dementia.

As a consequence of the grant funding ending dementia-specific project workers are no longer employed by the Serbian and Spanish community agencies and it was hard for Alzheimer’s Australia NSW to maintain contact with the agencies. The Spanish speaking dementia project worker has moved to a different agency but contact has been re-established and the worker is interested in being trained to deliver education to the Spanish community in their own time. There is a risk that Alzheimer’s Australia NSW will not be able to do as much work as planned with the Serbian community.

Staff members from the Croatian and Assyrian agencies have been trained to deliver the education sessions. Alzheimer’s Australia NSW staff working on this project ran the initial sessions and over time, the volunteer workers have taken over the delivery of the education sessions. The education sessions delivered to targeted communities have been very successful with community members approaching the presenters after the presentation to talk about dementia and their specific concerns.

People who are caring for someone with dementia are starting to be identified; the project has reached the stage where it is possible to identify a potential community of carers within each targeted community. The Carer education module has been developed and piloted with Italian, Armenian, Italian, Chinese, Turkish and Cambodian participants. A three day carer education course has also been piloted with 18 members of the Serbian community; the Serbian version of the DVD was available for this course.
A stronger relationship has been developed with the Cambodian community, where there is a legacy of trauma. The need to get treatment for depression and anxiety is being promoted.

The project has maintained links with other work in NSW to increase awareness of dementia in CALD communities, in particular being a member of the Dementia Bilingual Community Education (BCE) advisory panel targeting the CALD community in the Campbelltown and Wingecarribee areas of NSW. The Fairfield LGA now has a CALD-specific dementia forum, at the initial meeting there were 50 staff from multicultural agencies.

The Alzheimer’s Australia NSW CALD working party has been established and is promoting the project in targeted communities and to other CALD communities. A recent presentation in Campbelltown provided information to five different language groups including people from Somalia.

Some community members have expressed interest in being involved in providing support to people with dementia and their carers, for example, by helping them to engage with health system and in positive activities.

While the primary focus of the project has been working with CALD communities, the project has provided resources to support the production of the “Don’t be Moogil – think ahead” booklet that has been developed as part of the partnership with the New England Division of General Practice and the “Talking to the People” Aboriginal and Torres Strait Islander dementia risk awareness program.

Aboriginal and Torres Strait Islander cultural awareness training was provided for all Alzheimer’s Australia NSW staff in the last quarter of 2010 and Alzheimer’s Australia NSW were involved in NADIOC week activities in 2011.

The application for funding for the production from an Aboriginal and Torres Strait Islander perspective of the DVD “It’s not a disgrace – its dementia”, an award winning DVD regarding dementia stigma and shame, was unsuccessful. However, Alzheimer’s Australia NSW has secured State Government funding for a three year project to target dementia in Aboriginal and Torres Strait Islander communities.

**CHANGES MADE**

The project has trained agency staff rather than community volunteers as initially planned. It is important that people trained to present the sessions are skilled and knowledgeable about dementia, the way that the story is told matters and it is important to get the first session right. It has become clearer that the best way to utilise community members interested in having a more active role is to support them to help others in the community who are affected by dementia. This is stage 4 of the project model.

The conceptual model assumed that increasing the awareness of GPs would lead to earlier diagnosis, however the project has discovered that in some cultural groups GPs and specialist geriatricians do not work together as had been expected. Some male GPs in some communities do not make referrals to a female geriatrician, despite her dementia expertise.

This learning was taken into account during the production of the DVD, a male GP was sourced to appear in the DVD to give credibility to the messages given by the female geriatrician, as her views may not be seen as credible by some community members because of gender bias, even though the geriatrician has more expertise in the area of dementia.

The project has received feedback indicating that in one community GPs are reticent to diagnose dementia and to make referrals to specialists. As it cannot be assumed that all GPs will follow up patient concerns about their memory or behaviour the education sessions are informing people about how to frame their concerns when going to a GP, the specific diagnostic tests that they can request and the importance of requesting referrals to specialists.
OUTCOMES

FOR CALD COMMUNITY MEMBERS

The project is giving dementia a profile and helping people to differentiate between dementia and age-related memory loss. It is anticipated that the DVDs will be widely distributed and watched by people at home, stimulating further discussion and dissemination of information about dementia.

The volunteer agency workers who have been trained have become the first point of contact in their communities for people seeking information or wanting to discuss concerns about dementia.

There have been some examples of people being diagnosed after learning more about dementia however, this information cannot be systematically collected and project staff may not hear if a presentation leads to someone being diagnosed.

As a consequence of the community education sessions some people who did not initially see themselves as carers, have a new understanding of their role and have identified themselves as carers. It is significant for someone to say 'I'm a carer', as the concept and language does not exist in some communities. As a consequence, discussions about support for carers have become relevant to them, whereas previous marketing approaches would not have reached them.

The interest of some community members in developing ways of supporting people within their community who are affected by dementia suggests that a level of understanding and acceptance of dementia has been achieved within these communities.

FOR ALZHEIMER'S AUSTRALIA NSW

The project is having an impact on Alzheimer’s Australia NSW educators who have been kept up to date with the project. The rationale for making significant changes to the existing educational material was disseminated and discussed with Alzheimer’s Australia NSW educators.

The profile of Alzheimer’s Australia NSW has been raised within a diverse range of multicultural communities. Requests for Alzheimer’s Australia NSW educators to provide education to multicultural groups have increased substantially, adding to the already full workload of the educators. It is estimated that there has been a 20-fold increase in requests from multicultural groups. While data is not routinely collected on how organisations requesting education sessions have found out about Alzheimer’s Australia NSW, it is reasonable to assume that the project has contributed to this increase in demand. The intake data collected by the education team is being reviewed and could start to collect this information to build a clearer picture of how different cultural groups are finding out about Alzheimer’s Australia NSW services.

The interpreter service available through the helpline has been promoted, however, data about changes in the utilisation of the interpreter service has not been analysed.

FOR SERVICE SYSTEM

As awareness of dementia in the targeted communities increases, needs are becoming more obvious and dementia is becoming more of a priority issue. Dementia had previously been a hidden problem and therefore had not been a high priority for these small agencies.

There is more awareness of the dementia services available from Alzheimer’s Australia NSW and the health system amongst multicultural agencies. The Alzheimer’s Australia NSW project worker has helped the small ethno-specific
agencies to develop their capacity to apply for funding and has encouraged agencies to look at multiple funding sources to shore up their resources.

**BROADER IMPLICATIONS**

The conceptual model and training material could be utilised by other states and territories. The decision to start to change attitudes by increasing awareness through work at the community level, rather than trying to influence referral pathways by educating health providers, has been validated.

**RESOURCES**

The community education module can be delivered in any community working with translators and is also a useful resource for English speaking groups.

**WHAT HAS HELPED OR HINDERED**

**PARTNERSHIPS WITH ETHNO-SPECIFIC AGENCIES**

The project has worked in partnership with:

- Croatian Australian Welfare Centre Cooperative Ltd
- Assyrian Australian Association
- NSW Spanish and Latin American Association for Social Assistance Inc
- Serbian Orthodox Welfare Association of NSW Inc

Building relationships and friendships has been important, attending events that are not directly related to the project and providing assistance to small agencies helps to build community validation. Being sensitive to the capacity constraints of small community agencies has also been important in developing effective working relationships. This has sometimes involved supporting agencies to build their capacity by helping them to develop more knowledge of funding sources and program management processes. Processes like completing electronic templates for funding can be very stressful for agency staff when they are unfamiliar with them. At times, this has meant focussing on an agency priority rather than dementia; however this builds trust and has paid off over time. Staff turnover in small agencies has a big impact and can make it hard to maintain relationships.

The State Government funded project that has provided additional staff resources for the Assyrian and Croatian organisations has been instrumental. The synergy between the State Government funded ADAC project and this project, has leveraged understanding and contacts that have benefitted both projects.

The Spanish and Serbian communities were not viewed as equally vulnerable and Alzheimer’s Australia NSW was not funded by the State Government to work with these communities. This put Alzheimer’s Australia NSW in a difficult position because they could provide resources that could help two of the targeted communities but not the other two.

There is a risk that information may become out of date if Alzheimer’s Australia NSW does not have the capacity to maintain contact with different communities and offer periodic re-training for CALD agency staff who are providing education and updating of material.

**DEVELOPING A DEEPER UNDERSTANDING OF COMMUNITY SPECIFIC ISSUES**

Knowing the demographic profile in each local area has been important, for example, one cultural community may tend to have different generations living in different suburbs.
Understanding culturally-specific beliefs that impact on how dementia and dementia services are understood allows education sessions to be tailored to take these factors into account. For example, in the Assyrian community hospitals, nursing homes and respite care are associated with places that people go to die and there is an expectation that people will die within three months of admission.

There are additional difficulties for refugee communities who commonly experience anxiety, stress and depression, often over a long time, and are therefore at greater risk of dementia. For these communities, risk reduction messages need to focus on mental health and the importance of seeking help to treat anxiety and depression.

There is a lack of general health education and very little engagement with mainstream services in some communities, they are therefore less likely to utilise any services and do not recognise that they may be at risk.

### FLEXIBILITY

The project has responded to feedback from communities and lessons learnt through experience. Having the flexibility to make needed adaptations based on what’s been learnt has been crucial to the project’s success.

### LESSONS LEARNT

The project has demonstrated that there was a gap in appropriate CALD dementia education and that CALD communities are responsive to appropriately presented information, there has been no lack of good will but the capacity and resources have not been available. The project staff have been surprised that the project has been so well embraced by older age groups as they had thought that older people would be more resistant to messages about dementia.

The first contact with communities and the first education session needs to be right, the presentations use analogies, are less medically-oriented and information is presented in a way that is not threatening. Dementia information has not been ‘dumbed down’ but has been made more accessible and relevant.

Although well intentioned, short-term funding creates problems, particularly in small agencies with limited capacity. The 12 month Dementia Community Support Grant funding has demonstrated that it is hard to develop sustainable change in 12 months, and this has an impact on project workers who not only lose their jobs but feel responsible because they cannot follow through after having raised awareness of dementia in their communities.

The strategy of working through communities, rather than focusing on the diagnostic pathway, has been demonstrated to be effective. The four stage model has also been validated however; it has become apparent that the stages do not need to be implemented sequentially as initially anticipated. For example, in the model, stage four involved supporting communities to develop their own capacity to support people with dementia and this work has developed directly from stage one; building awareness of dementia.

### PROJECT LEGACY

A conceptual framework and resources have been developed for engaging hard to reach communities. The community and carer education modules, including the CDs being developed for specific communities will be available as resources for educators after the life of the project. DVDs will continue to be available through the Alzheimer’s Australia NSW lending library.

The trained agency staff will be an on-going resource for increasing awareness of dementia in their communities and will be catalysts, along with the increased awareness of dementia within the community, for agencies to maintain a focus on dementia. It is hoped that a reasonable quantity of people contacting dementia services and having a good experience will raise the acceptance of services within communities, which in turn will lead to more people accessing
services. Alzheimer’s Australia NSW could use the resources developed by the project to provide education using interpreters, however, there would not be the capacity to recruit and train further ethno-specific agency staff without specific funding.

**FUTURE PLANS**

Alzheimer’s Australia NSW plans to continue to provide dementia education and carer education sessions to the targeted and other CALD communities. DVDs will be produced in other community languages and a second round of training will be provided utilising the DVDs. The possibility of have a short synopsis of the DVD on the Alzheimer’s Australia NSW website will be explored. Alzheimer’s Australia NSW plans to move through the next stages of the model:

- Providing information and resources to GPs
- Gather additional information on which language groups to initially involve in carer education, some carer education sessions will be for mixed cultural groups
- Support self-initiated support groups in the targeted communities as well as working to improve the cultural responsiveness of mainstream services to improve access for people from diverse cultures

Other plans include having a greater focus on educating younger generations and on developing links between CALD groups and the acute sector (DBMAS).

Education sessions will be provided for Aboriginal and Torres Strait Islander people across the state as part of Dementia Awareness Week.
This project mainly focused on developing training modules for use by Alzheimer’s Australia Vic community education staff when providing community education to CALD communities. The project initially focused on developing links with CALD communities to explore how CALD communities accessed Alzheimer’s Australia Vic services. When Alzheimer’s Australia Vic secured philanthropic trust funding to expand this work through the Better Practice project, the initial project worker moved to work on this extended project.

The new resources were initially developed in Greek and Italian and piloted with two Greek and two Italian community groups with revisions made on the basis of feedback during piloting. The package consists of:

- A poster invitation to promote information sessions in other languages
- A 10 minute presentation that can be used for radio or community events
- Information sheets on 8 topics in the community language with English on the other side
- A 30 minute PowerPoint presentation that covers an introduction and the 8 topics; with time for interpreting and questions it is anticipated that the presentation will take 1 hour to deliver
- An educator manual for the presentation

The PowerPoint presentation contained mainly visual images rather than written information, the images included artworks created by people with dementia. The training material was designed to provide information to aid discussion.

**PROJECT AIM**

The project had four main aims:

- to promote dementia information and service access to people from CALD backgrounds
- to develop a core CALD education resource(s) capable of adaptation to a wide range of ethnic communities
- to pilot develop and implement CALD dementia community education in partnership with ethnic agencies, and
- to incorporate an additional CALD dimension into family and professional education programs

**PLANNED ACTIVITIES**

The project was specifically designed to ensure that clients with CALD backgrounds had access to tailored and timely support and education services, through building sustainable relationships with key CALD communities. The resources developed by the Service Access Liaison Officer would extend the work of the Alzheimer’s Australia Vic CALD Best Practice Support Services pilot program and the Alzheimer’s Australia Vic Community Partners Program.

The activities were:

- A review of available dementia education resource materials
- Piloting of a CALD community education module suitable for community education, including PowerPoint, training notes and translated resources
- Testing the education module with 2-4 CALD communities, including the development of translated information and community education pilot sessions
EXPECTED OUTCOMES

The expected outcomes from this project were:

- A CALD Dementia Education resource module
- Adaptation of the core education module and testing its application with 2 to 4 ethnic communities
- Development of a strategy for extending the application of the core program to additional ethnic communities.

SITUATIONAL ANALYSIS / CONTEXT

It is estimated that about 35,000 people with dementia in Australia do not speak English at home and that by 2050, the prevalence of people with dementia speaking a CALD language at home will be around 120,000 (Access Economics 2009). “The tripling in the absolute number of people with dementia who speak a CALD language at home represents a very significant increase in the future demand for CALD trained dementia care providers and culturally appropriate services” (Access Economics, 2009)

There is a priority need to expand access to dementia information and services to support people from CALD backgrounds. The diversity of the ethnic population requires the introduction of approaches which will expand the reach to more communities and more people within those communities. It is also important that the ‘CALD dimension’ be expanded in the current offering of education and information sessions to family members and aged care professionals.

Families from CALD backgrounds living with dementia are less likely to know about dementia and use general health facilities. Alzheimer’s Australia Vic conducted a study with thirty-five focus groups involving 383 participants from twelve different cultural communities. The study found that common to these groups was a lack of knowledge of dementia, its symptoms and causes, people with dementia were being marginalised and isolated, and they tended to have a late diagnosis - often at crisis point. Families are likely to experience great stress when they are reluctant to seek help. There is a need to ensure clients from other cultures have access to tailored and timely support and education services, through building sustainable relationships with key CALD communities and by further developing the capacity of aged care professionals.

It is not sufficient to simply translate existing English information sheets to communicate dementia information to CALD communities. The existing resources are not well presented and often contain too much dense text, they tend to focus on medical and technical information and they are not consumer-focused. Current community education resources in languages other than English assume that readers are well educated and have a high level of literacy in their first language. If written information was better presented and conveyed in a clearer and simpler format (in the sense of being less technical) it would be better understood by people who do not speak English.

BUILDING ON

The project built on the project worker’s extensive experience in developing community education programs for CALD communities and her broad knowledge of issues related to ageing and cultural diversity.

Alzheimer’s Australia Vic had a multicultural program that had a particular focus on improving the access of CALD communities to dementia information and services. The project also built on the experience of Alzheimer’s Australia Vic staff in education programs, counselling and support services, and policy and advocacy program areas.
This work benefited from the relationships developed during the first phase and links were maintained with the Alzheimer’s Australia Vic CALD Best Practice Support Services pilot program and the Alzheimer’s Australia Vic Community Partners Program. These CALD focussed projects complement each other in building Alzheimer’s Australia Vic’s capacity to engage with, and provide services to, CALD communities.

**RATIONALE FOR ADOPTING THIS APPROACH**

It is important that information provided to CALD communities is accurate and clear; too much information, information that is not culturally sensitive and poor presentation reduces the value of translated material.

Information needs to be presented at three levels: the first level raises awareness, the second provides more detail on specific issues and the third level provides comprehensive information. This three-tiered approach allows the audience to use information provided at the level people are most comfortable with, and should encourage action based on this information.

Traditional, direct translations of English resources tend to start with comprehensive information, which can create confusion, and is less likely to be understood and therefore less likely to be acted upon.

Effective approaches to improving awareness of dementia in CALD communities also entail:

- A proactive approach to engaging with CALD communities
- Sensitivity to cultural and linguist needs
- An intergenerational approach to the design and delivery of resources

Maintaining consistency in the information provided to communities is important. To ensure quality and consistency Alzheimer’s Australia Vic prefers that community education for CALD communities be provided by Alzheimer’s Australia Vic education staff rather than using a Train-the-Trainer model.

Greek and Italian are the two most common languages, other than English, spoken in Victoria.
IMPLEMENTATION

Alzheimer’s Australia has a national advisory group, the National Cross Cultural Dementia Network (NCCDN), which reviewed the plans for this project.

There were two phases to the project and two project workers. The initial project worker developed links with CALD communities and then moved on to a related project which developed better practices working with CALD communities.

A second worker undertook the major part of the project which was to develop CALD community education resources to be used by Alzheimer’s Australia Vic educators when providing community education to CALD communities. Negotiations were held with Greek and Italian community groups to trial and provide feedback on the education materials.

There was liaison with Alzheimer's Australia organisations in other states and territories to gather feedback on the adequacy of existing CALD community education resources. Responses were varied, with some organisations satisfied with existing translated information sheets, while others welcomed the development of tailored information modules. Most areas expressed strong interest in using CALD material developed in Victoria. Consultations were also held with Alzheimer’s Australia Vic staff to identify issues and gaps in the availability of appropriate resources.

An extensive literature review of approaches to providing community education to diverse cultures was undertaken to inform assessments of the usefulness of current resources and the development of new resources. CALD education resources from the USA and UK were also reviewed.

Eight information sheets were developed and piloted with 2 Greek speaking and 2 Italian speaking groups, the following topics were covered:

- What is dementia?
- Signs of dementia
- Talking to your doctor
- Useful steps in living with dementia
- Information for carers
- Information for families and friends
- Planning for the future
- Getting help

Posters and PowerPoint presentations were also developed with simple text and pictures.

An external aged care CALD project worker in a rural area where the material had been presented was consulted as part of the evaluation. An Alzheimer’s Australia Vic educator presented the material at a one day workshop using an interpreter. Approximately 20 people attended; 14 carers and 6 Cultural Peer Facilitators. The Cultural Peer Facilitators were community members trained by the rural support agency to provide older people with information about services.

The material was useful and the educator facilitated informative discussion, much of which was in simple English which members could understand, with occasional help from the Cultural Peer Facilitators. Feedback from the presentation was that the material had too much text, the language needed to be simpler and more pictures were needed. Community members were most appreciative that Melbourne staff came to their area with information as they often feel isolated and excluded.
CHANGES MADE DURING IMPLEMENTATION

Once the project changed its focus to developing community education resources there were no significant changes to the project design.

PROJECT OUTCOMES

OUTCOMES FOR PARTICIPANTS

Members of the Italian and Greek communities gained information about dementia in accessible formats. Italian and Greek communities who attended information sessions are well informed about dementia.

OUTCOMES FOR AA VIC

Alzheimer’s Australia Vic now has a set of community education resources that can be utilised by community education staff to increase awareness of dementia amongst CALD communities. The project has also developed a process for consulting with CALD communities to develop materials appropriate for their specific needs.

OUTCOMES FOR THE SERVICE SYSTEM

The resources produced will be useful across the service system. The service system has consumers who are more informed about dementia and are in a better position to advocate for the services they need.

RESOURCES DEVELOPED OR ACQUIRED

A range of resources has been developed, tailored to the specific needs of the Italian and Greek communities. These are: eight information sheets on dementia, posters, two PowerPoint presentations, one with simple text and pictures and the other using only pictures. The resources have been designed so that they can be readily adapted for other CALD communities.

WHAT HELPED OR HINDERED THE PROJECT?

PARTNERSHIPS

The project worker established links with Alzheimer’s Australia organisations in other states and territories working with CALD communities.

The project worker introduced Alzheimer’s Australia Vic to new partnerships with the Greek and Italian communities who agreed to pilot the education resources. It is not clear if these relationships will continue.

As the project was developed in consultation with Alzheimer’s Australia Vic staff, their links have strengthened with the Alzheimer’s Australia Vic Educators delivering community education to CALD communities.

LESSONS LEARNT

An important lesson was that it is of primary importance that the educator providing dementia information to CALD communities has a thorough understanding of dementia. Further, it is quite satisfactory for this information to be translated by a professional translator.
With regard to the materials produced, it was learnt that:

- It is challenging to produce effective material with simple, or no written language
- Presentations need to be in simple language with lots of pictures, or only presented in pictures
- Material has to be continually revised to ensure it meets the needs of the CALD community

**LEGACY / SUSTAINABILITY**

The CALD community education package will provide an ongoing resource available for providing community education to Greek and Italian speaking groups, the framework can be readily adapted for other CALD communities.

The findings of the literature review and the review of existing resources can be a useful resource for all community education programs with all communities where English is not their first language, including Aboriginal communities.

The materials developed will be available to Alzheimer’s Australia Vic and other Alzheimer’s Australia services in other states and territories and to wider communities via the web.

The insights gained into developing and presenting material on dementia to CALD communities will be passed to existing Alzheimer’s Australia Vic educators from the special CALD educator who is to be employed in 2011.

The consultation and material development processes can inform the development of information on other topics to all CALD communities.

**FUTURE PLANS**

The 2011-12 funding for this project will employ an educator to deliver the new materials to CALD communities and support existing Alzheimer’s Australia Vic educators to use the materials. Further dissemination of the information and materials prepared is still needed.

Alzheimer’s Australia Vic is canvassing the possibility of Alzheimer’s Australia National using the process developed in Victoria to prepare new information material in a range of other languages.
16. VICTORIA - ABORIGINAL AND TORRES STRAIT ISLANDER SERVICE LIAISON OFFICER PROJECT

Start date: October 2010  
Funding: $78,625  
Staffing: 1 EFT  
Staff commencement Date: October 2011

PROJECT DESCRIPTION

The project was designed to build on existing relationships with Aboriginal communities and health services to increase awareness of dementia and improve access to services for Aboriginal people. The project’s approach was underpinned by building respectful and trusting relationships and responding appropriately to requests for information and education.

The project responded to identified gaps in culturally appropriate services, specifically the lack of an Aboriginal-friendly dementia assessment service. It also responded to the need for appropriate information for families and carers about dementia and risk reduction resources. The Certificate 3 in Aged Care and community education about dementia was provided to Aboriginal Health Workers and communities based on the messages in the Mind your Mind program. The style of communication was flexible and responsive to the participants and the setting. Community education often took the form of an informal chat or answering questions rather than giving a structured presentation.

PROJECT AIM

To increase the awareness of dementia and dementia services among Aboriginal and Torres Strait Islander communities and service providers.

PLANNED ACTIVITIES

The activities undertaken were:

- Facilitating positive working relationships with Aboriginal and Torres Strait Islander communities and Aboriginal health services
- Providing formal and informal education programs to Aboriginal Aged Care Health Workers and communities based on the Mind your Mind program.
- Developing and distributing appropriate information on dementia and risk reduction to families and carers

EXPECTED OUTCOMES

The expected outcomes from this project were:

- Increased level of awareness of dementia and dementia services in Aboriginal Health Services and Aboriginal and Torres Strait Islander communities
- Dementia given a higher health priority among Aboriginal Health Services
- Strengthened relationships with Aboriginal communities and organisations

SITUATIONAL ANALYSIS / CONTEXT

Alzheimer’s Australia Vic became aware that Aboriginal and Torres Strait Islander communities often have limited knowledge of dementia and strategies to deal with it, and that Aboriginal people often prefer to access health services designed to accommodate their cultural needs. Alzheimer’s Australia Vic also expected that it would take time to build
trust and a collaborative partnership with Aboriginal services. An Alzheimer’s Australia Vic project officer who was previously working with Aboriginal communities, to a limited extent, was employed using the project funds to significantly expand relationships with these communities.

Consultations with these communities informed the project officer of the difficulties Aboriginal people have using mainstream dementia assessment services which were not attuned to the needs of Aboriginal people and their culture. One example of a cultural difference, which excluded the use of services, was the need to make appointments well in advance in mainstream services.

Alzheimer’s Australia has a national advisory group called the National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG) which reviewed the plans for this project plans

BUILDING ON

This project built upon the positive relationships the project officer had previously developed with Aboriginal communities and organisations.

RATIONALE FOR ADOPTING THIS APPROACH

Priority was given to building positive relationships because Alzheimer’s Australia Vic was aware that positive working relationships with Aboriginal communities are essential to developing services that Aboriginal people want and will use. Also, Aboriginal people are more likely to attend an Aboriginal Health Service than visit a general practitioner (GP).
Aboriginal and Torres Strait Islander
IMPLEMENTATION

The project worker worked with the National Alzheimer’s Australia Aboriginal and Torres Strait Islander Liaison officer when developing plans for this project and consulted with targeted members of the National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG). The chairperson of this advisory group is the CEO of the Lowitja Institute, which was a partner in developing the project.

To facilitate the development of an Aboriginal assessment service, the project officer instigated meetings with the Fitzroy Aboriginal Health Service, a geriatrician and the Victorian State Department of Health. Resulting from these meetings, the Department of Health funded a geriatrician to attend the Fitzroy Aboriginal Health Service one day per week to conduct assessments for Aboriginal people from across Victoria. This was the first service of its type in Victoria and it complemented other medical services offered at the Health Service.

In conjunction with the Victorian Aboriginal Community Controlled Health Organisation (VACCHO), which coordinates training across the state, the project officer provided accredited training to Aboriginal Health Workers in Melbourne, Mildura, Warrnambool and Gippsland to ensure appropriate referrals were made to the assessment service. The aim was to ensure that workers could identify dementia symptoms and make appropriate referrals.

The Certificate 3 in Aged Care and additional training about dementia was provided by the project officer to trainees at the Aboriginal Community Elders Services (ACES); and relevant material was distributed at Aboriginal Health Workers forums.

The Coordinator of Planned Activities at ACES commented on the impact of this project. Five staff studied Certificate 3 in Aged Care provided by the project officer. The coordinator was unreservedly positive about the impact of the course on his staff because the course was delivered in a culturally appropriate and sensitive manner with an emphasis on oral instruction and assessment. He observed that his staff learnt a great deal from the course about caring for the aged, and they gained their first formal qualifications. He is negotiating for the project officer to extend the training for these staff to Certificate 4 in Aged Care.

DESIGNING AND ESTABLISHING THE PROGRAM

The project officer built upon existing working relationships with Aboriginal communities to ensure extensive stakeholder consultation contributed to the design of the project.

CHANGES MADE DURING IMPLEMENTATION

The project evolved through the consultations and did not have a specific predetermined plan which needed to be changed. The need for an Indigenous specific assessment service was identified through consultations with Aboriginal and Torres Strait Islander service providers and Alzheimer’s Australia Vic facilitated the development of an Aboriginal and Torres Strait Islander -friendly dementia assessment service by organising meetings between Aboriginal Health Services and the Victorian Health department and specialists.

PROJECT OUTCOMES

The project resulted in the strengthening of partnerships with Aboriginal communities and health services as well as National Ageing Research Institute (NARI) and the Lowitja Institute. These partnerships provided the means for developing the positive outcomes outlined below.
OUTCOMES FOR PARTICIPANTS

Aboriginal people from across Victoria now have access to a culturally appropriate dementia assessment service at the Victorian Aboriginal Health Service. This is the first such service in Victoria. Because of the training given to Aboriginal Health Workers, Aboriginal people with dementia are more likely to have their symptoms recognised and be referred to the new service when appropriate.

Five Aboriginal staff at Aboriginal Community Elders Services (ACES) will complete the Certificate 3 in Aged Care in August 2011. This certificate will provide these staff with their first formal qualification and it will give them increased employment opportunities. A further outcome for members of the Aboriginal community attending ACES day activities or residing in the nursing home is qualified staff from their cultural background caring for them.

Community education provided to Aboriginal and Torres Strait Islander communities in Melbourne and regional areas in Victoria have increased awareness of dementia.

OUTCOMES FOR ALZHEIMER’S AUSTRALIA VIC

An important outcome for Alzheimer’s Australia VIC was the strengthening of its partnerships with Aboriginal communities and health services, NARI and the Lowitja Institute. These partnerships facilitated the creation of the Aboriginal assessment service and training programs and future collaborative projects are planned. For example, the Aboriginal Community Elders Services (ACES) wants to engage the project officer to deliver Certificate 4 in Aged Care to eligible staff.

A further outcome from this project was the creation of the first Alzheimer’s Australia Vic Diversity Working Group. This Group will finalise policies by the end of the year to provide integrated services to people from the following communities: culturally and linguistically diverse (CALD); Aboriginal and Torres Strait Islander; gay, lesbian, bisexual and transgender (GLBT); and homeless. This Working Group will have close links with other aspects of the project because one of its members, Dr Kerry Arabena, is the CEO of the Lowitja Institute and the Chair of the NATSIDAG.

OUTCOMES FOR THE SERVICE SYSTEM

The first Aboriginal dementia assessment service has been created to serve people from across the state. In addition, dementia training and Certificate 3 in Aged Care has been provided to Aboriginal Health Workers and it is expected that, over time, they will change how assessments are made and support provided.

RESOURCES DEVELOPED OR ACQUIRED

The Aboriginal dementia assessment service is an important new resource now available.

The Certificate 3 in Aged Care was delivered in a culturally appropriate format with an emphasis placed on oral communication.

The new Diversity Working Group will be a useful resource for future service development.

WHAT HELPED OR HINDERED THE PROJECT?

There were no hindrances to the project. However, the project developed slowly as was necessary, to develop partnerships in a culturally appropriate manner.
PARTNERSHIPS

An important feature of this project was the partnerships developed with Aboriginal communities and health services, Aboriginal Community Elders Services (ACES), NARI and the Lowitja Institute. These partnerships were instrumental in facilitating the outcomes achieved.

LESSONS LEARNT

The key lessons learnt in this project were:

- It is necessary to build partnerships to facilitate service development, especially with Aboriginal communities.
- Relationships with Aboriginal communities need time to develop. Rather than pushing a message it is important to wait to be asked to provide education. It is also important to make contact with the right people, to be friendly and respectful and to take the time to develop personal relationships.
- It can be difficult to gauge how well a project worker is engaging with an Indigenous community because cultural dynamics are difficult for an outsider to understand. It is important to follow the lead of community members.
- The time limited nature of funded projects creates tensions because Aboriginal communities perceive mixed messages. On one hand Alzheimer’s Australia Vic states that it cares about dementia in Indigenous communities, but at the same time it cannot commit to activities beyond the life of the project and it cannot promise more than can be delivered. The short term nature of funding is in conflict with the longer time frame needed to develop trusting relationships and achieve outcomes using consultative processes.
- It is advantageous to have a project officer with existing relationships with Aboriginal communities when short term funding opportunities arise.

LEGACY / SUSTAINABILITY

The project leaves behind a legacy of the new Aboriginal assessment service, Certificate 3 in Aged Care delivered in a culturally appropriate format and better trained Aboriginal Health Workers.

Because the Aboriginal assessment service was developed in partnership with the Victorian Aboriginal Health Service (VAHS) to complement existing medical services, ongoing support will be provided by VAHS. However, the sustainability of the assessment service will be dependent upon ongoing funding from the State Department of Health. Their support may be determined by sufficient referrals coming from Aboriginal Health Workers. The dementia training provided by the project officer across the state is designed to contribute to these referrals.

It is expected that the partnerships developed will continue and new projects are also planned. The principle of developing partnerships with a wide range of stakeholders to create appropriate services has widespread application.

FUTURE PLANS

Alzheimer’s Australia Vic will seek further funding to work in partnership with the National Ageing Research Institute (NARI) and the Lowitja Institute to validate an existing dementia assessment tool for use in Victoria. It was developed in the Kimberley in Western Australia (Kimberley Indigenous Cognitive Assessment tool) and has been validated for use in Queensland. If this tool can be validated for use in Victoria it will assist in making accurate assessments and lead to the better use of support services.
**PROJECT DESCRIPTION**

In response to the diverse and changing needs of people with YOD the project was designed to:

1. Use a key worker approach to provide flexible responses to the needs of each of the younger people with dementia and their families or carers. Responses provided by the key worker were to include intensive counselling, on-going support and information and facilitating access to services. The key worker would aim to provide each person with what they needed, when they needed it, and in the way they needed it.

2. Facilitate peer support, particularly at the ‘Links Cafés’, and explore ways for experiences to be shared among people with YOD and among carers.

3. Facilitate access to services. The project worker will refer participants to services as needed. The project worker will also advocate for access to services to be streamlined and will educate service providers, both internal to Alzheimer’s Australia Vic and external, about the needs and issues of people with YOD.

4. Provide information tailored specifically for people with YOD in response to needs identified by the YOD Reference group and project participants. This will consist of Tip Sheets and an Identity Card.

**PROJECT AIMS**

The project aimed to test the effectiveness of the ‘key worker’ model of care at two levels: one being to provide flexible individual support, and the other to facilitate peer support. It aimed to:

- Provide individually based support (person-centred)
- Provide opportunities for participants to share their experiences (peer support)
- Develop information to assist people make decisions (resource-informed decision making)

**PLANNED ACTIVITIES**

a) *Linking Lives Project Group*

The Project Group participants were younger people with dementia, their families and carers. Project Group membership and participation was flexible, with people opting in or opting out as they wished. Any younger person with their family or carer could choose to participate during the life the Project. The Project Group was informal and participants shaped the activities undertaken.

b) *Linking Lives Facilitators*

The project was based on the ‘key worker’ model which uses a ‘person-centred’ approach designed to be responsive to the needs of the younger people with dementia. The facilitator’s role as mentor was to establish a relationship with participants and provide individual support and access to information as required, and to facilitate peer support. The role was designed to ensure participants had access to a professional with experience of YOD when needed, and that support was provided in a flexible manner responsive to participants’ wishes and requirements. The facilitator was not a case manager and did not monitor service provision. Rather, the facilitator provided information and referred when necessary. For example, if it became apparent that a family member needed to work through a specific dementia-related emotional/coping issue, the facilitator established the link to an Alzheimer’s Australia Vic counsellor experienced in working with
younger people with dementia; or if there was a question relating to services, the facilitator identified possible service providers and directed/referred the person as appropriate.

The initial facilitator commenced in July 2010 and was a highly experienced Alzheimer’s Australia Vic counsellor. After this facilitator resigned due to family relocation, she was replaced by another highly experienced facilitator from the Neuropsychiatry Unit of Royal Melbourne Hospital.

c) **Links Café** (A Linking Lives version of Alzheimer’s Australia Vic’s Memory Lane Cafe)

The ‘Links Café’ provided opportunities for informal semi-structured information sharing and socialisation. This concept was built on the Memory Lane Café model which exists for older people who have attended an Alzheimer’s Australia Living with Memory Loss six week program. The original concept was to be reshaped in partnership with younger people with dementia and their carers.

d) **Resource Development**

Younger onset dementia service directory - While there were (understandably) very few services specifically for people with younger onset dementia, there were non-aged services/resources which may be of use to participants and their families such as diagnostic service centres (ie centres with clinical expertise in younger onset dementias), respite, support groups, recreational opportunities etc. The plan was to develop a relatively brief web-based directory to provide useful information relevant to the needs of the families living with younger onset dementia. The directory would be selective rather than attempting to map all Victorian services and it could be expanded in subsequent years, if funding becomes available. This directory would be a positive development as no such resource/reference existed previously.

Tip Sheets - The need for the additional topics in the AA Tip Sheets of interest to people with YOD and their carers had been identified.

### EXPECTED OUTCOMES

- Improved quality of life for project participants (measured by Australian Quality of Life or similar scale).
- Improved knowledge of service options and improved access.
- An evaluation of the effectiveness of the ‘key worker’ concept as a method of providing individualised support.

### SITUATIONAL ANALYSIS / CONTEXT

A conservative estimate of the number of Victorians under the age of 65 with dementia is 2,500 (Alzheimer’s Australia 2007). The complexity of the disease is highly pronounced in people with Young Onset Dementia (YOD) and often includes people with rare forms of dementia which can stem from a genetic cause. Symptoms and prognosis differ depending on the type of dementia and the stage of the disease, and younger people often progress faster and have more severe symptoms, including frontal-temporal lobe deterioration that leads to challenging behaviours.

Diagnosing YOD is often complex as the dementia may be associated with Parkinson’s or Motor Neurone disease or may be a rare form. YOD is often misdiagnosed and people may have been through treatment for depression or other conditions for some time prior to an accurate diagnosis being made. Misdiagnosis creates distress for the person whose behaviour is changing and for their families.

The disease can impact acutely on younger people because they are often employed and have family responsibilities. They face loss of income, loss of ability to care for their family and probably an early death.

Existing support services targeted to older people can be inappropriate for people with YOD who have different issues, needs and preferences. Many people with YOD and their carers have relatively rapidly changing needs because of the rate of disease progression.
One of the biggest distinctions between younger and older people with dementia is that the pathway to services is more convoluted and difficult to navigate for people under 65. For example, to access residential respite it needs to be verified that the person has dementia and not an intellectual disability, psychiatric illness or acquired brain damage.

Partnerships with specialist medical providers are important to ensure that Alzheimer’s Australia Vic staff are well informed about the medical and behavioural issues of people with YOD, and because people with YOD need to be medically reviewed more often than others. Reviews are commonly needed every 6, or even 3 months because changes can be rapid.

**BUILDING ON**

The project was built on the existing service partnership with the Neuropsychiatry Unit at the Royal Melbourne Hospital which promoted the ‘key worker’ model of client support. The RMH had a YOD specific outpatient clinic providing families with information about Alzheimer’s Australia Vic services. However, families tended to not follow up with the service, either because they were still coming to terms with the diagnosis or because Alzheimer’s Australia Vic was perceived as an organisation that provided services to older people. Alzheimer’s Australia Vic staff have been based at the RMH clinic, their presence put a face to the Alzheimer’s Australia organisation and this personal contact encouraged families to follow up.

**RATIONALE FOR ADOPTING THIS APPROACH**

This project was designed to address the needs of people with YOD and their carers, particularly the needs identified at Alzheimer’s Australia’s consumer-focussed national forum held in Canberra in 2009. The project placed an emphasis on responding to individual needs because of the diversity, complexity and changing needs of people with YOD, their carers and families. The key worker model was chosen because of its potential to provide flexible responses tailored to individual needs rather than develop a fixed range of YOD services.

The Young Onset Dementia Reference Group developed the set of principles which guided the project’s development. The project was based on the following principles:

- **Consumer direction**: younger people with dementia and their carers should identify, shape, influence and control the support they receive
- **Partnership**: participants know their own needs, and services should work in partnership with them
- **Positive living**: the project should build on the participants’ strengths and capabilities, not limitations.

In line with these principles the Young Onset Dementia Reference Group and project participants directed the development of the project. Information resources and activities were developed in response to the needs and preferences of people with YOD.
IMPLEMENTATION

Fourteen people (originally 15) with dementia and their carers and families were linked to the key worker. The project was state-wide and included people from rural and metro areas. Contact with clients was a mix of face-to-face and telephone contact.

Peer support has been facilitated through the Links Café activities. People involved in the project wanted an activity that involved getting together around food. Three events were organised in 2010: a lunch at Monsalvaat, lunch at Studley Park Boat house and a BYO picnic at Studley Park.

Peer support has also been facilitated by linking individuals. For example, a carer whose wife had been recently diagnosed was linked with a man who cared for his wife for 10 years prior to her recent death. The man was happy to share his experience of having cared for his wife during the duration of her dementia.

The key worker is playing an important role as a consultant to counselling staff who are working with people with YOD, providing debriefing and secondary consultations.

People with YOD identified the need for tip sheets on additional topics and information about the service system.

PROJECT EVALUATION

The Commonwealth Department of Health and Ageing funded the National Ageing Research Institute (NARI) to evaluate this Service Access Liaison Officer project under a National Dementia Support Program Supplementary Grant 2010-11. The evaluation consisted of interviews, pre and post questionnaires and outcome measures with nine of the 14 family members and five people with YOD. NARI provided the final report to Alzheimer’s Australia Vic in June 2011 and the findings are drawn upon for this document.

DEVELOPING YOD SPECIFIC RESIDENTIAL SERVICES

Two members of the reference group established the Lovell Foundation to raise funds and work with Alzheimer’s Australia Vic to promote interest in, and explore and develop new models of appropriate late-stage residential care. They self-funded a trip to Europe to learn about innovative approaches to aged care.

CHANGES MADE DURING IMPLEMENTATION

The project changed incrementally in response to ongoing feedback from the Reference Group and the NARI report. In particular, a request was made for a service directory specifically for people with YOD to enable them to navigate the service system. Also, the Lovell Foundation partnered with Alzheimer’s Australia Vic to identify best practice in residential services for YOD, and the partnership is working towards establishing the first YOD-specific residential service in Victoria.

PROJECT OUTCOMES

OUTCOMES FOR PARTICIPANTS

The aim to provide flexible, individual support was achieved to some considerable extent with participants reporting that they found out more about dementia and services and they increased socialisation by meeting other people with YOD and their families. However, there was variation among participants in terms of the outcomes achieved and the extent to which they met their initial goals for joining the project (NARI 2011). A limiting factor was the gap of three
months between the first key worker leaving and the second worker commencing, which appears to have had a negative impact on some participants who lost contact and became disengaged. Despite this limitation, the two key workers reported to NARI (2011) that participants benefited by having home visits and easy access to the worker by phone and email. They also benefited when workers advocated with services on their behalf and when they provided information and debriefing counselling.

The peer support expected at the Links Café did not result initially for a number of reasons (NARI 2011). In contrast to the people resuming contact at the Memory Lane Cafés after getting to know each other at the Living with Memory Loss program, participants in this project met as strangers at the Links Café and had no common bonds. They discovered that they were at different stages with the disease and had varying needs. In response to these findings the model was changed to provide the Living with Memory Loss program first, which was modified for people with YOD, and subsequently for participants to meet in a café setting, as was the case with the model for older people. This model proved to be successful and the Victorian State government has funded a series of café projects, with one dedicated to people with YOD.

People wanted an activity that involved getting together around food. Three events were organised in 2010: a lunch at Monsalvaat, lunch at Studley Park Boat house and a BYO picnic at Studley Park. Later events were planned in consultation with the group and less structured and more flexible gatherings were most popular. Peer support was also facilitated by directly linking individuals.

### OUTCOMES FOR ALZHEIMER'S AUSTRALIA VIC

Alzheimer’s Australia VIC gained valuable information about meeting the needs of people with YOD and their families through implementing this project and the detailed feedback received. The key findings were:

- The key worker played an important role as a consultant to counselling staff who were working with people with YOD, providing debriefing and secondary consultations.
- The needs of people with YOD vary widely and can change rapidly
- The need for intensive counselling is most likely at the time of diagnosis and at significant transition points such as moving into residential care
- Even when Alzheimer’s Australia Vic staff are aware of YOD issues, the relatively low prevalence means that staff do not have as much experience and are not as confident in working with people with YOD, especially younger people in their 40s, or below. Different approaches are needed when working with younger people and the key worker’s consulting role was useful in increasing the confidence of staff in their work with people with YOD
- The long term aim is to integrate the key worker approach into the core work of Alzheimer’s Australia Vic support services to provide individually tailored services in response to the different and changing needs and aspirations of people with dementia, their families and carers

### OUTCOMES FOR THE SERVICE SYSTEM

The service system is changing as a result of this project. The links between acute sector and Alzheimer’s Australia Vic have been vital in closing the gap between diagnosis and access to support and information.

Action has been taken towards creating a residential service for people with YOD. Two members of the reference group who had established the Lovell Foundation are working in partnership with Alzheimer’s Australia Vic to establish the first YOD residential service in Victoria. Best practice examples were identified in Europe where the couple who established the Lovell Foundation travelled to investigate; from NSW where Alzheimer’s Australia Vic sponsored three people to travel and investigate; and from research into other Australian states.

Also, people with YOD and professionals have been consulted. Thirty people with YOD and their carers came together to a meeting to advise on their needs and preferences, and a professional advisory group has been created with experts.
in YOD from the Royal Melbourne Hospital and other relevant professionals. The partnership is now seeking a suitable service provider partner to implement the plans.

Overall, the NARI (2011) evaluation of the project showed that people with YOD can have difficulties accessing age appropriate services. Some GPs have limited knowledge of YOD and getting an accurate diagnosis can be difficult. Also, YOD results in financial difficulties because of reduced income from leaving work early and difficulties contributing to and accessing superannuation before 65. However, it needs to be noted that two of the five respondents to NARI’s post intervention questionnaire reported that services were accessible to them. The experiences of these two respondents appear to be more positive than others with YOD.

### RESOURCES DEVELOPED OR ACQUIRED

Additional Tip sheets for people with YOD and carers have been developed covering:

- Travel
- Younger onset dementia and sexuality
- Transition to placement
- How to access end-of-life support and services
- Genetics – how to talk to children

Information sheets about service pathways, that explain primary elements of the care system, for example what Home and Community Care (HACC) is and what it provides. Other topics include:

- How do I get a diagnosis?
- What do I do if I have got a diagnosis?
- What do I do if I need help around the house?
- What do I do if I need respite?
- What do I do if I need residential care?

### Service directory:

Following a request from the Reference Group and others with YOD, a service directory specifically for people with YOD is being established. A donation from a person with YOD enabled a project officer to be employed and it is expected that by the end of 2011 a relatively short, targeted service directory will be available. It will be organised around stages of diagnosis and tell people about the primary points of contacts at various stages of the disease. For example, it will tell people where to go for a diagnosis, where to go for assistance and information, their entitlements and which service providers specialise in YOD. Similarly, it will identify services for later stages of the disease and enable people to navigate the service system in a more informed and empowered way. Subsequently, the directory will be adjusted for older people with dementia.

A carer card has been designed specifically for people with YOD with a focus on acceptance of the person’s behaviour, rather than memory loss.

### WHAT HELPED OR HINDERED THE PROJECT?

Two factors hindered the project. One was the resignation of the first key worker and the three month gap before the second worker resumed the work. This resulted in loss of contact with participants and the perception by at least one participant that they had been abandoned. The second limiting factor was the 0.6 EFT position of the key worker when the work possibly warranted a 0.8 position.
PARTNERSHIPS

The Royal Melbourne Hospital (RMH) Neuropsychiatry Unit and the Eastern Cognitive Disorders Clinic (ECDC) were important partners. The partnership with RMH has been in place since the beginning of 2010 and resulted in staff exchanges to enhance understanding and cooperation. A doctor from RMH provided professional development for Alzheimer’s Australia Vic staff; Alzheimer’s Australia Vic staff worked at the YOD specific clinic at the hospital for two days; and a dementia-specific registrar was established and spent time at Alzheimer’s Australia Vic so that the registrar became aware of the range of services available. Alzheimer’s Australia Vic facilitated the registrar meeting people with dementia in their homes to develop an appreciation of the impact of a dementia diagnosis. The registrars also attended Alzheimer’s Australia Vic organised respite retreats for people with YOD, where Living with Memory Loss programs were provided. At the RMH clinic, families were linked to Alzheimer’s Australia Vic staff to facilitate access to Alzheimer’s Australia Vic services. Prior to this partnership, when people received a diagnosis they often did not follow up and make contact with Alzheimer’s Australia Vic. Finally, the partnership was useful to the project in allowing a highly experienced counsellor to be seconded as the second key worker after the first one resigned.

The partnership with the ECDC neurology clinic resulted in the clinic focusing on fronto-temporal lobe disorders one day per week and they provide specialist advice to Alzheimer’s Australia Vic regarding the impact of this type of dementia. Discussions are being held with Alzheimer’s Australia Vic to develop an information kit that would explain how Alzheimer’s Australia Vic can assist people with fronto-temporal lobe damage.

An important partnership was developed between Alzheimer’s Australia Vic and the Lovell Foundation, as described above. This partnership is providing valuable consumer perspectives and direction to service development.

One component of this evaluation was a telephone interview with a carer involved with the YOD program. The wife of a person with YOD spoke emphatically of the benefits resulting from the project and other services provided by Alzheimer’s Australia Vic. The six week Living with Memory Loss program was useful because of the information given and the opportunities to meet other people ‘on the same journey.’ Course participants have continued to meet informally each month independent of Alzheimer’s Australia Vic. Additional feedback was that having contact with an ongoing key worker was very helpful even though the gap of three months between workers and having to change workers was a limiting factor. Having stability and consistency is important to families, even though this cannot always be achieved.

ADDITIONAL RESOURCES

Financial resources from two sources contributed to the project. One was a small grant from the Department of Health and Ageing (via Alzheimer’s Australia) which was used to develop a Younger Onset Dementia Reference Group including carers and people with YOD. The second was a financial donation from a carer of a person with YOD to Alzheimer’s Australia Vic to develop better responses to people with YOD.

STAFF

The key workers each had expertise in dementia, and YOD in particular, as well as a detailed knowledge of the service system. Feedback from a project participant interviewed as part of the evaluation confirmed that the key workers having an in-depth knowledge of YOD was a critical success factor.

LESSONS LEARNT

The findings show that the key worker model has merit and is worth continuing. Further, the key workers need skills in individual counselling, group facilitation for a reference group and participant socialisation, individual and community education and resource development, community development and advocacy skills to challenge systemic barriers.
Alzheimer’s Australia VIC became more aware of the special needs of people with YOD and their carers and how to successfully facilitate peer support through a key worker model for individuals and groups.

The Links café is useful for maintaining already established contacts but is not an effective model for facilitating peer support and relationships amongst people who do not know each other and who are at very different stages of dementia.

A secondary consultation model that involved having a staff member with expertise in YOD available for both formal case consultations and informal discussion has assisted other Alzheimer’s Australia Vic staff in developing skills and confidence in providing counselling and support service to people with YOD and their families.

LEGACY / SUSTAINABILITY

There is an increased profile for people with YOD within Alzheimer’s Australia Vic and increased Alzheimer’s Australia Vic staff confidence in working with YOD, particularly the ‘young young’ which requires different approaches, skill set and language. Additional YOD-specific information resources will remain available.

The first Victorian residential service for people with YOD is being planned.

The benefits of the project will continue after the second round of funding finishes in 2012. Alzheimer’s Australia Vic is considering the possibility of integrating key workers into their general service model, additional ongoing benefits will be:

- Partnerships with the Royal Melbourne Hospital (RMH) Neuropsychiatry Unit, the Eastern Cognitive Disorders Clinic (ECDC), and the Lovell Foundation
- Staff continuing to increase knowledge and skills from exchanges between the RMH and Alzheimer’s Australia Vic to bridge the gap between diagnosis and services

There are lessons for other services from the lessons learnt by this project particularly in terms of how to develop services in partnership with different stakeholders, develop staff skills and provide relevant information to service users.

FUTURE PLANS

The continued funding for 2011-12 will enable the plans outlined above to continue.

- The development of a residential service for people with YOD
- Continuing Peer support through Links Café
- The additional tip sheets will be made available on the Alzheimer’s Australia Vic website
18. QUEENSLAND – SPECIAL NEEDS ACCESS PROJECT

**Start date:** 19 October 2010  
**Funding:** $167,335  
**Staffing:** 2 x .25 EFT SALOs and 1 EFT coordinator  
**Staff commencement date:** Existing staff

**PROJECT DESCRIPTION**

The project has taken a place-based approach to developing links with, and providing education to: CALD, Aboriginal and Torres Strait Islander, and GLBTI communities in regional and remote areas throughout the state. Service Access Liaison Officers (SALOs) are each covering different geographic areas of the state and are working with all of the target groups within their geographic area. The geographic regions are:

- Rockhampton (covering Northern, Central West, Central Queensland and Mackay)
- Maryborough (covering Wide Bay and Burnett, Sunshine Coast and South West) and
- Brisbane- Coordinator (covering South East Corner, , Far North, Cape York, North West and Gold Coast)

Within each area the SALOs have:

- Identified and liaised with CALD, Aboriginal and Torres Strait Islander and GLBTI community groups
- Identified and liaised with the service providers who work with these communities, in particular Home and Community Care (HACC) and Commonwealth Carer Respite Centres (CCRC).

The SALOs have increased awareness of dementia and dementia services through:

- Providing information and community education sessions to CALD, Aboriginal and Torres Strait Islander and GLBTI communities
- Recruiting and training appropriate and influential people using the existing train-the-trainer package so that more dementia education can be provided to targeted groups in regional and remote areas
- Extending a network of interested individuals and organisations in regional and remote areas who are contact points for Alzheimer’s Australia Qld in the local area; this contact is instrumental in helping to organise contact with communities and service providers when Alzheimer’s Australia Qld staff plan visits to the area

An integrated, organisation-wide database of contacts across the state has been developed as part of the project.

**PROJECT AIMS**

The aim of the project was to improve and enhance access to services for people living with dementia from special needs groups by establishing strong collaborative partnerships and linkages with key special needs organisations and communities throughout Queensland.

**PLANNED ACTIVITIES (ADAPTED FROM PROJECT PLAN METHODOLOGY)**

The project will expand the team of Liaison Officers that provide community education programs in their local regions and base Service Access Liaison Officer’s (SALOs) in strategic regions to provide state-wide coverage and an integrated approach that extends to Far North, North West and Northern Queensland; Central Queensland and Mackay; Central and Central West, Wide Bay and Burnett and the South East Corner and South West.
The SALOs will focus on building links into special needs communities, organisation and facilities in their regions by:

- improving access to information and education for carers, the community and support networks
- assist with development of local partnerships and empowerment
- assisting smaller communities and organisations to understand and manage their health and social priorities

The major focus of the SALOs’ role for this project will be to engage with special needs community organisations within their region and deliver basic dementia information sessions and information about services and how to access them. In some communities the team are identifying a suitable community member to train in Alzheimer Australia’s Qld’s capacity-building Train-the-Trainer community education program so they can then deliver sessions to their own community.

SALOs will also contribute to the development and maintenance of the Alzheimer’s Australia (Qld) contact database specifically developed as part of this project.

The Community Education Coordinator will:

- support regional SALOs and collate data for the database
- coordinate the project, including the development and establishment of partnerships, linkage and networks throughout the state
- take the lead in reviewing all marketing, promotional materials and also
- be responsible for the review of organisational policies procedures

**EXPECTED OUTCOMES**

- Well-established partnership and linkages with special needs organisations. supported by a current and continuously updated database and cross referral system. This will include CALD, Aboriginal and Torres Strait Islander people, Homeless and GLBTI
- Provision of a capacity-building community education and training program into special needs groups and organisations utilising existing resources and tools
- Assistance and support with service delivery across NDSP programs to improve access for people from special needs groups

(Project aims, activities and expected outcomes from project plan)

**SITUATIONAL ANALYSIS / CONTEXT**

Alzheimer’s Australia Qld has eight member organisations, six of these are staffed by volunteers, each member organisation has links with communities, services and networks in their area.

Working with GLBTI people is a new area of work for Alzheimer’s Australia Qld, there is an established GLBTI population in the Rockhampton area.

There are Aboriginal and Torres Strait Islander and specific and strong ethno-specific organisations in Far North Queensland (FNQ) including well established, large Italian and Greek populations.

Alzheimer’s Australia Qld is increasingly using online approaches to getting information out to people because it is covering such a large area, but special needs groups in particular need face to face contact, needing to travel such large distances has resource implications.
There is a low awareness of Alzheimer Australia Qld services in the general community, and amongst specific groups, until a dementia diagnosis.

Alzheimer’s Australia Qld covers a large geographic area that includes very remote areas, with very limited services. There is a high demand for information in remote communities when educators visit, Alzheimer’s Australia Qld therefore looks at how to build its capacity to stay in touch with the community, for example, by providing training to someone and then maintaining telephone contact or sending newsletters to maintain contact.

Alzheimer’s Australia Qld has developed ‘dementia champions’ who have been trained to provide dementia education in their communities. The Train-the-Trainer package enables people to provide entry-level dementia education in a less formal way, or as a more formal presentation.

**BUILDING ON**

Alzheimer’s Australia Qld worked with 8 radio presenters from very remote Aboriginal and Torres Strait Islander communities, providing information that they could translate into community languages to use as a segment in radio shows and being interviewed about dementia to produce program segments that the presenters edited as part of a media training program. Dementia was recognised as an issue by the presenters, who are very influential in their communities, and they were very keen for the information. A spin-off from this program is that Alzheimer’s Australia Qld has been invited to attend a large HACC forum in Cairns that people from remote communities in the Cape attend.

The project is utilising the Mind Your Mind and the Memory and Ageing education resources as well as an Alzheimer’s Australia Qld Train-the-Trainer education program that targets “Dementia Champions” within community organisations who are trained to deliver this community education program into their specific community group. The Dementia Champion translates information provided so that it is relevant, appropriate and understood by participants who may otherwise be excluded due to language barriers and cost constraints. This community education program has been designed as a capacity-building tool and is delivered as an entry-level education program. Education tools include Help sheets, newsletters and website details. Educators who are delivering the session are firstly trained in the program and then assessed for competency prior to delivering any education sessions. Evaluation feedback is monitored by Alzheimer’s Australia Qld staff to maintain quality.

**RATIONALE**

Queensland covers a very large geographic area that has many small remote communities as well as rural and regional centres. This approach is building on the contacts and networks of Alzheimer’s Australia Qld’s member organisations.

In order to best service regional communities it is important to have a network of people that have in-depth knowledge and contacts in local communities. Feedback from member organisations and clients is that this approach is appreciated locally, is cost-effective and often leads to better outcomes for people living with dementia and their families.

As with the project that worked with the radio presenters from remote Aboriginal and Torres Strait Islander communities, Alzheimer’s Australia Qld is seeking to build its capacity to educate Aboriginal and Torres Strait Islander, CALD and GLBTI communities about dementia by finding and resourcing interested people who are influential in their communities. Providing training and resources, and maintaining ongoing contact with suitable people with the skills to provide dementia education in communities extends the reach of Alzheimer’s Australia Qld into rural and remote areas, and has the potential to extend the provision of community dementia education in Aboriginal and Torres Strait Islander, CALD and GLBTI communities.
IMPLEMENTATION

The SALOs have participated in a total of 71 meetings with a diverse range of organisations that include Aboriginal and Torres Strait Islander, CALD, GLBTI and homelessness organisations. They have covered regional, rural, remote and some very remote areas. 70 education sessions have been provided to a total of 1,842 people, the number of people at each session has varied: three forums attracted 100, 200 and 400 people. and the number of people at the remaining 67 sessions varied from one person (2 sessions) to 57 people. The median number of people attending was 16. It is estimated that 75% of the meetings and sessions were as a direct result of this project. The education sessions have been provided to staff in a range of health and community organisations and to community groups.

A health worker in Mt Isa who travels to remote areas including some Aboriginal and Torres Strait Islander communities has been trained using Alzheimer’s Australia Qld’s Train-the-Trainer package to deliver community education. This woman has also enrolled for the dementia competency course which will deepen her knowledge of dementia.

The SALOs are based in Rockhampton (covering Central Queensland and Mackay and Central), and Maryborough (covering Wide Bay and Burnett, Sunshine Coast). The Brisbane based Coordinator is covering South East Corner, South West, Central West, North West and Gold Coast and the Cairns region.

The SALOs and the coordinator attended intensive induction training program that included:

- Organisational induction and program induction: including revision of aims, objectives and outcomes of the project
- Training in Alzheimer’s Australia Qld Community Education train-the-trainer program
- CHCAC319A Dementia Competency training
- TCM and other database training
- Revision of services offered by Alzheimer’s Australia Qld including NDSP & DBMAS

In addition, all Alzheimer’s Australia Qld staff participated in CALD and Aboriginal and Torres Strait Islander cultural awareness training and training in dementia and sexuality with a focus on GLBTI issues. The Dementia & Sexuality workshop was a full day of training specifically developed for Alzheimer’s Australia Qld by the Queensland Association for Healthy Communities (QAHC), the state peak organisation for GLBTI organisations.

Alzheimer’s Australia Qld services have been advertised to the GLBTI community via QAHC. A relationship has been developed with the GLBTI community in the Cairns area through a contact of the SALO who works in the GLBTI community and is familiar with the work of Alzheimer’s Australia Qld. Relationships with GLBTI communities in Brisbane have also been developed.

The Alzheimer’s Australia Qld Services Manager attends meetings of the Gay and Lesbian Seniors Action Group providing opportunities to disseminate information about Alzheimer’s Australia Qld services. The group provides feedback to Alzheimer’s Australia Qld about strategies for engaging with gay and lesbian people and provides opportunities to link with planned events. Alzheimer’s Australia Qld has been invited to talk at a forum organised with the police about age-related issues for the GLBTI communities. This is a double pronged success because Alzheimer’s Australia Qld also wants to develop their relationship with the police.

Contact has been made with some agencies that provide direct services to homeless people, such as the Salvation Army food vans. A person in Cairns, who is a volunteer with a homelessness food service, and who is also familiar with Alzheimer’s Australia Qld facilitated making initial contact.

An organisation-wide database detailing existing relationships with individuals, organisations and contact people across the state has been consolidated. The database identifies who within Alzheimer’s Australia Qld has established this
relationship and the nature of ongoing contacts. The database includes details of people who have been trained to deliver dementia community organisation and people who are influential within their area.

**CHANGES MADE DURING IMPLEMENTATION**

The project has been largely implemented as planned, however a newly appointed SALO in Cairns had to resign for family reasons early in 2011 and the Brisbane coordinator took over the Cairns region (Far North, Northern Queensland and Cape York).

Travel to more remote areas of the state was delayed due to the floods and cyclone in parts of Queensland early in 2011. Over the last few months there has been more focus on making contacts in very remote communities that had been difficult to visit earlier in the year due to extreme weather.

**PROJECT OUTCOMES**

**OUTCOMES FOR COMMUNITY MEMBERS**

Education sessions to increase awareness of dementia have been provided to a diverse range of communities in settings that include retirement and aged care homes, cancer support groups, carers forums, Aboriginal and Torres Strait Islander communities, health centres, service clubs, social groups and churches.

Information about dementia has been provided in more regional and remote areas and made available for Aboriginal and Torres Strait Islander, CALD and GLBTI people.

Relationships with Aboriginal and Torres Strait Islander communities have developed over time and the SALOs are now being invited to speak at Indigenous Health Forums organised by Aboriginal Health Services for their communities. CALD communities have been continuing to request community education sessions.

Providing morning or afternoon tea when giving presentations to community members has given participants who are affected by dementia an opportunity to approach the SALO during a break. Some people are more comfortable discussing their specific concerns individually rather than in the group.

**OUTCOMES FOR AA QLD**

There is more integration across Alzheimer’s Australia Qld services as a result of the project. SALOs talk about what can be offered by the whole organisation and stronger links have been developed between different services within Alzheimer’s Australia Qld. For example, the SALOs might make initial contact, leave information and identify the need for follow-up by the clinical team on particular issues. Alzheimer’s Australia Qld managers have developed an annual calendar to better coordinate and integrate contact with communities across the range of Alzheimer’s Australia Qld services.

The SALOs have extended links with CALD, Aboriginal and Torres Strait Islander and GLBTI groups by utilising local knowledge, regional and local service provider networks, and the relationships that the eight Alzheimer’s Australia Qld member organisations have with their communities.

The awareness of GLBTI issues within the organisation has increased as a consequence of the sexuality training and relationships that have been developed with GLBTI communities. Issues related to dementia amongst homeless people have also been highlighted and some initial contacts have been made with homelessness organisations.

**OUTCOMES FOR THE SERVICE SYSTEM**

There is more awareness of dementia and the services provided by Alzheimer’s Australia Qld amongst a range of
service providers. The work that the team of SALOs has put into establishing contact with more diverse services is now paying off and they are being invited to a range of events including multicultural and Aboriginal and Torres Strait Islander health events. GLBTI and some homelessness services are more aware of dementia and of the services provided by Alzheimer’s Australia Qld and have resources available for their staff and community members.

RESOURCES DEVELOPED OR ACQUIRED

Resource packages based on existing Alzheimer’s Australia Qld and Alzheimer’s Australia national resources have been developed to support the project team in providing information and education to CALD, GLBTI and Aboriginal and Torres Strait Islander communities.

Two flip charts developed by Alzheimer’s Australia NT to support community education in Aboriginal and Torres Strait Islander communities have been purchased and are used in presentations to Aboriginal and Torres Strait Islander communities. The helpline number has been added to national Aboriginal and Torres Strait Islander brochures (in consultation with the National Aboriginal and Torres Strait Islander Liaison Officer).

The integrated database has been important for improving coordination between different Alzheimer’s Australia Qld teams.

WHAT HELPED OR HINDERED THE PROJECT?

PLACE BASED APPROACH

Frequency of contact (even if only a couple of times a year) and having a dedicated position has been very important (even if the staff person changes) as people in the regions know that there is someone they can contact who has a specific interest in, and knowledge of, the area.

It has been easier to form relationships with Aboriginal and Torres Strait Islander people in areas that are relatively close to where the SALOs are based. Even though the Cairns region is now being covered by a Brisbane-based SALO spending blocks of time (2 weeks) in the Cairns area has enabled relationships to develop with Aboriginal and Torres Strait Islander communities.

Comments from external service providers contacted during the evaluation have confirmed the importance of utilising local contacts in helping to organise information sessions in remote areas. Local knowledge is important in being able to build on what’s happening in the area and for identifying barriers to participation in planned education sessions. In Aboriginal and Torres Strait Islander communities it is important to have up-to-date local knowledge as an event such as a funeral will stop people from attending planned education sessions.

Having ‘someone on the ground’ and local to the region means that the SALO has background knowledge and knows how to relate to locals.

PARTNERSHIPS

Working in partnership with local organisations has been essential in enabling the project to extend its geographic reach. Local organisations assist by helping to organise and promote education sessions and they play an ongoing role in distributing printed information about dementia in local communities. Without support from local organisations Alzheimer’s Australia Qld would not have the capacity to reach as many people, particularly in remote areas.

HACC forums have been particularly important as opportunities to meet providers, and trips are planned around forums, they provide useful networking opportunities that lead to follow-up meetings with service providers.
STAFF

The SALOs were existing Alzheimer’s Australia Qld community educators located in the regions they are covering. They have utilised professional and personal networks to establish new contacts with Aboriginal and Torres Strait Islander, CALD, and GLBTI organisations, as well as homelessness services.

Feedback from external stakeholders is that the staff team have the right skills and experience to establish effective relationships with new organisations and groups; they are comfortable approaching and introducing the project to new groups.

Similarly, the staff team are skilled and experienced in providing education sessions that are appropriately pitched and engaging for diverse audiences.

FLEXIBILITY

Flexibility has been important in allowing the SALOs to follow up on opportunities as they arise and to respond to requests from specific groups. There are different distributions of special needs groups in different areas and the project has needed to be able to adapt to, and have the flexibility to, focus on different needs groups in different locations. In addition, many service providers in the regions are providing services to all of the groups being targeted through the project.

BARRIERS

There is a high initial investment in training staff, ideally a Liaison Officer would have been based in Cairns, as initially planned, but when the initial SALO had to leave it was not feasible to employ and train a new SALO for the remaining months of the project.

It is costly to work in regional and remote areas; even when Liaison Officers are based in the region there are considerable travel-related costs.

The short-term project funding limited the capacity of the SALOs to forward plan and make commitments to organisations to provide education, knowing that the funding for the project has been extended has enabled the SALOs to make future commitments which supports developing relationships.

LESSONS LEARNT

Cultural awareness training has been valuable in supporting staff to develop confidence in approaching Aboriginal and Torres Strait Islander, CALD and GLBTI groups and provided staff with an appreciation of how they might be received.

It is important to ensure that a geographically-dispersed project team feel engaged in a team; regular teleconferencing is used to stay in touch and ensure that staff are not feeling isolated.

In remote areas liaison with HACC area managers and attendance at regional HACC meetings provides access to workers located in more remote regional and rural areas. Once the focus of the project is understood, people readily introduce the SALOs to others working in the area and contacts ‘snowball’.

Different approaches work with different communities: Gay and Lesbian community organisations are happy to receive information, tend to be protective of the groups they have contact with, and Alzheimer’s Australia Qld needs to build trust to work with these communities. A marketing approach has been advised for getting information to GLBTI people.

Building relationships with Aboriginal and Torres Strait Islander communities takes time, effort and energy, it is easier to create links if Alzheimer’s Australia Qld, or an organisation that Alzheimer’s Australia QLD is working in partnership with, has contacts with Elders in communities. Finding someone who has links open doors, it is important to maintain relationships and have follow-up contact. Alzheimer’s Australia Qld has been surprised by how accepting Aboriginal and Torres Strait Islander communities have been once contacts are made and relationships developed, as Alzheimer’s Australia Qld had been given the message that communities had higher priorities. Dementia is still seen as a normal...
part of ageing (as it is also amongst many non-Aboriginal and Torres Strait Islander people) but once more aware of dementia, people are recognising that dementia might be the cause of behavioural changes in older people and are more open to seeking assistance.

CALD communities and older people in regional, rural and remote areas have welcomed community education sessions. Alzheimer’s Australia Qld has links with Diversicare and Multilink, larger CALD organisations that have liaison people provide a good way to access CALD communities. The response of CALD groups has been very positive; speakers are welcomed, memory and ageing programs are popular and SALOs are invited back to give further presentations. Having different modules and resources such as PowerPoint presentations keep presentations engaging.

CALD communities like to have information from within their community which is why finding the right person in the community to deliver education and providing them with training and resources is important.

**LEGACY AND SUSTAINABILITY**

Ideally Alzheimer’s Australia QLD needs to maintain regional positions as working with communities over time builds the level of understanding. The education sessions are providing entry-level dementia information, over time more complex issues such as end-of-life planning can start to be addressed.

Staff are more culturally aware and are more confident when engaging with Aboriginal and Torres Strait Islander, CALD and GLBTI people.

The trained ‘dementia champion’ in Mt Isa will enable more dementia education to be provided to remote communities, including Aboriginal and Torres Strait Islander communities, in the surrounding areas.

The integrated organisation-wide database will enable staff to leverage trips to remoter areas to maintain relationships with people in the area.

The place-based model used by Alzheimer’s Australia Qld could be a useful approach for other states that cover large geographic areas as it has been a useful way of getting out to those in remote areas. However, Alzheimer’s Australia Qld is unique in having member organisations and has built on the contacts that its member organisations have in different regions.

**FUTURE PLANS**

Alzheimer’s Australia Qld plans to continue to focus on extending contacts with diverse groups and to provide education to organisations and communities to raise awareness of dementia.

Providing the Train-the-Trainer training to an appropriate Aboriginal and Torres Strait Islander person (or people) is a priority.

The integrated database is still in an excel format and is a bit cumbersome to use, a customer relationship management system has been purchased and Alzheimer’s Australia Qld is currently scoping the most effective way set this up. The TCM database does not have the functionality needed to record and track community contacts, as it is more client-focussed.

Delivering carer’s workshops in regions are an identified need.
This project is attempting to develop a universal approach to providing culturally appropriate care to CALD communities that is flexible and can be adapted to the individual needs of the CALD community. A number of other research projects have developed a comprehensive understanding of the needs and issues that affect access to dementia services for CALD communities and to developing relationship with aged care services, multicultural organisations and CALD communities. Much less is known about the needs and issues of the mainstream service providers in managing a multicultural workforce and providing services to people with dementia from a CALD background. The project will develop a knowledge base to inform service providers of approaches to cultural competence and providing culturally appropriate care.

The second stage of the project will involve delivering a pilot training program to address the first step in achieving cultural competence in the workplace, theory-based knowledge of cultural dimensions and concepts and exploration of own cultural beliefs and attitudes, and working in partnership with selected organisations to refine the training program, identify the level of cultural competence in the organisation and identify the specific actions required to achieve cultural competence. The training program approach and resources will be piloted with selected organisations, evaluated and refined.

The final stage of the project will explore how the approach can be sustained and extended to other organisations and geographic areas.

An industry focus group will be established to provide peer review, expert advice and feedback and to monitor the quality of the project. The steering group will include: experienced and appropriate Alzheimer’s Australia WA staff, and representatives from service providers.

**PROJECT AIMS:**

Undertake literature review of cultural concepts and cultural dimensions. Undertake literature review of cultural competence and identify steps for implementation of a cultural competence in an organisation. Develop linkages internally with Alzheimer’s Australia WA, establish industry focus group and develop partnerships with appropriate local and national networks. Develop relevant resource to trial pilot training program and evaluate.

**PLANNED ACTIVITIES**

Stage1:

- Approval of workplan
- Develop job description, advertise and appoint a person to the position of Project Officer
- Scope the project
- Develop links and partnerships with relevant organisations
- Literature review and research ongoing
Stage 2:
- Focus groups and needs analysis of cultural competence in the context of providing culturally-appropriate care
- Deliver one pilot training program based on the identified design for the first step of the cultural competence program, theory based knowledge of cultural dimensions and concepts and exploration of own cultural beliefs and attitudes
- Continue to develop links and partnerships with relevant organisations

Stage 3:
- Evaluate the training program and review training material
- Consult with focus group, partnerships

Stage 4:
- Exploring possible funding submission for ongoing development of the project
- Final Report and submission to Alzheimer’s Australia National Office on the project

EXPECTED OUTCOMES
Gaps in available cultural training packages in the context of achieving cultural competence will be identified. Training program and training materials will be developed, relevant Partnerships will be formed to ensure sustainability of the project

SITUATIONAL ANALYSIS / CONTEXT
There are gaps in Australian research on the impact of culture and ethnicity on coping styles, attitudes towards dementia and dementia services and the implications for dementia service delivery models.

There are a number of CALD communities where dementia-specific information and services are limited or not culturally appropriate. Brochures and information sheets with direct translations from English into different languages are often not culturally appropriate.

Emerging communities have less capacity than larger and longer-established communities, such as the Greek and Italian communities, to meet their own needs or to attract funding to establish services. In addition, emerging communities are going through culture shock in attempting to integrate themselves in the Australian community and the strategy of attempting to educate emerging communities about dementia, when they have more immediate needs to address, must be questioned.

Alzheimer’s Australia WA has established relationships with older, more established communities but little contact with, or experience in working with newer and smaller communities and people from CALD backgrounds generally do not use Alzheimer’s Australia WA services.

Alzheimer Australia services were promoted over a period of 3 months in the languages of several emerging communities on SBS radio in a program organised by the Australian Multicultural Foundation (AMF), however the dementia helpline did not receive any calls in WA from members of the target communities during this period.

The lack of utilisation of dementia services by CALD communities is thought to reflect either a lack of awareness and/ or unwillingness to access available services from a mainstream service provider as opposed to from an ethnic/multicultural provider.

Providing culturally appropriate care requires cultural competence which is a holistic and systemic response to cultural diversity. Developing cultural competence is not an individual or one-off initiative in response to diversity; it is a
A continuous organisation-wide approach that embeds cultural considerations into all aspects of service planning, resourcing, implementation and evaluation. In this way, cultural competence is proactive rather than reactive. It requires an acknowledgement and acceptance of the fact that cultural diversity exists; is here to stay and is fluid in nature.

Cultural competency is yet to become an integral component of organisational culture. Non-government and government organisations currently lack the resources to successfully integrate cultural competency into procedural and policy practice.

**BUILDING ON**

The Alzheimer’s Australia WA Education team has delivered dementia education programs to Aged Care Workers and family carers from Chinese, Polish, Macedonian, Romanian and Italian Communities, and the *Mind Your Mind* program has been delivered to Italian and Spanish communities.

Alzheimer’s Australia WA Support Services have been involved in training Greek and Macedonian staff to run their own dementia helpline service. Training has also been extended to Rainbow Multicultural Services to enable them to operate a dementia helpline. Alzheimer’s Australia WA Support Services also supports the Italian and Greek communities to facilitate monthly carer support groups for family carers of people with dementia.

Cultural awareness training has been offered to staff at Alzheimer’s Australia WA however there is not a coordinated approach to ensure that all staff members receive training. However, the cultural awareness training was focused on awareness of other groups’ cultures, which the review of the literature has shown is an ineffective approach to achieving cultural competence in the workforce.

There are pockets of work being done by a range of organisations to improve awareness of dementia and access to services amongst CALD communities. There are initiatives in several service provider organisations to address the cultural competence of the workforce and the approach to the training programs has been amended to include the findings of the research undertaken under this project.

The Sikh Association of WA received funding through the Dementia Community Support Grant program and approached Alzheimer’s Australia WA for assistance in translating information into Indian dialects.

**RATIONALE FOR ADOPTING THIS APPROACH**

The literature review found a large number of research reports and research articles identifying the needs of various ethnic communities. This approach has been undertaken for the last 20 years and the research continues to identify the same issues.

The review also found that most approaches to culture and ethnicity and the interactions between individuals and services tend to address the question of cultural diversity and community care in terms of the clients’ special needs, while overlooking the culture(s) amongst providers. Issues of cultural diversity are often understood in terms of ‘problems’ or ‘barriers’ CALD communities face by focusing on ‘their’ unique characteristics or risk factor.

Cross-cultural conflict and misunderstanding occur because there is an interaction between people from different cultures. Service providers are not culture-free. As cultural and linguistic diversity exists within the Australian population, it is also reflected in the aged care and health care workforce. It cannot be assumed that the culture within service provider organisations is predominaely Anglo-Australian or neutral. Health and community care services are large, complex social organisations operating within cultural frameworks that may not always match those of the communities they serve.
Meeting the needs of the multicultural community must be addressed in the context of the culture of the service providers and their ability to meet the specific needs identified by the communities they work with. Rather than starting with pre-conceived ideas about how to improve access to dementia services the project is purposefully developing a clear understanding of a range of issues that affect the interaction between members of the CALD communities and mainstream service providers, such as barriers to effective cross-cultural communication and the much underestimated cross-cultural misunderstanding that occurs when people from different cultures interact.

As this project was developed in partnership with selected service providers, it has been important to be clear about the aims of the project, while allowing the details of the approach taken to develop as the project progresses.
IMPLEMENTATION

The first six months of the project, from January to June 2011, have focussed on:

- Research into cultural concepts, cultural dimensions, effectiveness of cross-cultural training and the meaning of cultural competency.
- Work with the Sikh Association of Western Australia

SCOPING THE ISSUES

This work has involved:

- A comprehensive review of literature relevant to culture, cultural concepts and cultural dimensions, including literature from other disciplines that have specific relevance to the management of a multicultural workforce, such as cultural anthropology and international management
- Identifying organisations working with different ethnic communities in Western Australia and the resources available for working with CALD communities, and
- Consultations with service providers, including a review of how organisations orient staff to work with both clients from diverse cultures and within culturally diverse workforces

Cultural awareness training does not address the pervasiveness of cultural influences on how information is processed, how people relate to others, attitudes and beliefs about dementia and dementia services. A number of issues that have implications for achieving cultural competence in service organisations, and for training for cultural competence and communication with people from CALD communities to improve the quality of service provision experienced by CALD communities have been identified. A comprehensive report on issues that influence attitudes towards dementia and the use of dementia services will be completed by mid-September.

Other identified issues include:

- The demographic profile of different cultural groups that mean that some groups are more at risk of not receiving services, for example, Estonians, Latvians, Lithuanians, Ukrainians, and Dutch communities have a majority of older members and a lack of culturally-specific support services
- Differences in awareness and acceptance of dementia in different communities, for example, African and Middle Eastern communities have low awareness and acceptance of dementia
- Differences in attitudes towards, and expectations of, dementia services and other community services. The standard of facilities in some countries of origin puts people off accessing services and there is a need to break down these attitudes
- A lack of culturally-appropriate dementia screening and diagnostic tools
- Difficulty in obtaining a diagnosis of dementia that delays referral and access to care
- Specific cultural attitudes towards the caregiving role that have important implications for how carers can best be supported, including differences in coping styles that influence the quality of life of people with dementia and carers
- Cultural factors that influence whether extended family support is accessed
- Increased social isolation of some families where one person has dementia
- Relationship problems within the family and intergenerational conflict are compounded by the diagnosis of dementia, and vice versa
- Differences in communications styles that have implications for designing dementia awareness and education programs, some cultures have very indirect communication styles and delivering the training in an Anglo-Saxon style is not effective
• Programs are most successful when the community has prioritised dementia as a community issue
• A lack of Australian studies on the efficacy of caregiver support programs for CALD groups
• The need to get better at measuring outcomes of program rather than outputs, such as the number of brochures distributed: measuring outcomes involves re-thinking what ‘success’ looks like
• Cultural implications changes over time; culture is not homogenous but varies depending on a person’s ethnic, racial, linguistic, religious, socio-economic, educational and generational status
• Cultural differences can lead to clashes in values between people from different backgrounds; this has implications for how services are provided

Service providers currently address these issues in different ways. The prevailing model in community-based care for people from a CALD background is to match the care worker to the client, for example, to match an Italian care worker with an Italian client. Cultural matching is more difficult in residential care; the current approach is for clusters in some mainstream facilities to cater for people from specific cultural backgrounds. There are culturally-specific residential care providers for larger, more established communities that work well but only cater to a limited number of cultural backgrounds.

The need to be aware of cultural influences extends to the culturally diverse workforces of mainstream service providers. One organisation has highlighted the different ways that different cultures demonstrate respect by asking questions such as: the importance of the age of the people communicating, the significance of different manners of speaking, whether to speak only when spoken to, how gestures and eye contact can express respect, and what questions might be interpreted as ‘too personal’ and therefore disrespectful.

This report will be a starting point for discussions about the next stage of the project. The WA Dementia Training and Study Centre have scheduled a full day workshop for health professionals and service providers on the issues of dementia and people from a CALD background. This will provide an opportunity to present and discuss the findings of the project and trial the pilot cultural training program.

The project advisory group consisting of representatives from service provider organisations was established in July 2011, once the research into cultural concepts, cultural competence and aspects regarding the management of a multicultural workforce was completed. The feedback was positive and the focus group validated the approach taken and the findings of the project and is keen to investigate the implementation of cultural competence in their organisations.

A pilot cultural competency training program has been developed and will be trialled with members of the advisory group.

**SUPPORTING THE SIKH ASSOCIATION**

The Sikh Association of Western Australia was funded through the Dementia Community Support Grant for a project that aimed to:

• Raise the awareness of dementia among the communities of Indian Sub-Continent
• Remove the stigma attached to dementia through community education
• Provide community support to people with dementia and their carers and families
• Identify existing promotional material that can be used by the communities of Indian Sub-Continent; and
• Promote a healthy lifestyle that has potential to reduce the risk of dementia
Alzheimer’s Australia WA assisted the Sikh Association in developing a pamphlet with translations into Punjabi, Hindi, Tamil and Gujarati. The brochure provided contact information for Alzheimer’s Australia WA and the Sikh Association and brief information under the following headings: “Worried about your memory?”, “What is dementia?”, and “Taking action early can help”.

The brochure was launched by Helen Morton, the Western Australian Mental Health Minister at a Dementia Open day held at the Sikh Temple on 17th March 2011. The Alzheimer’s Australia WA Special Access Liaison Officer spoke at the launch, and organised for a person with dementia to deliver a speech. The launch was well attended and reported in local papers.

The Sikh Association has sought further funding to continue to raise awareness of dementia and to increase the capacity of communities from the Indian sub-continent to respond to the needs of people with dementia and their families.

**CHANGES MADE DURING IMPLEMENTATION**

The direction of the project was changed as a direct result of the literature review. The review started with a look at the research reports and research articles identifying the needs of various ethnic communities. The wealth of information found on this topic raised concerns about the ability to ‘add anything new’ in this area. In addition, a pattern was identified, with most approaches to culture and ethnicity, and the interactions between individuals and services tending to address the question of cultural diversity and community care in terms of the clients’ ‘special needs’ while overlooking the culture(s) amongst providers. Issues of cultural diversity are often understood in terms of ‘problems’ or ‘barriers’ CALD communities face by focusing on ‘their’ unique characteristics or risk factor.

A deliberate choice has been made to shift the focus of the project to barriers preventing service providers from reaching a status of cultural competence and providing culturally-appropriate care that would meet the needs of the multicultural communities. As a consequence, the scoping phase of this project has been done without referencing approaches used in other state and territory Alzheimer’s Australia organisations which have traditionally focused on the clients’ special needs.

Focus groups with multicultural communities have not been conducted as planned at this stage. Focus groups held in the past have generated information about the issues but have not led to changes and a decision was made to hold-off running focus groups until a commitment could be made to following up issues raised.

**PROJECT OUTCOMES**

**OUTCOMES FOR COMMUNITIES**

Information about dementia is now available for readers of Punjabi, Hindi, Tamil and Gujarati and the Sikh association is more aware of the services available through Alzheimer’s Australia WA.

**OUTCOMES FOR ALZHEIMER’S AUSTRALIA WA**

Knowledge of the cultural concepts, cultural dimensions, and culturally-conditioned patterns of behaviours, as well as diverse issues that influence awareness of, and attitudes towards, dementia and the use of dementia services amongst CALD communities has become more nuanced. The research report will have implications for how Alzheimer’s Australia WA approaches work with CALD communities. It will lead to a revision of current approaches to training staff to work with diverse communities and of the models used to engage with, and provide education and clinical services to, people from diverse backgrounds.
OUTCOMES FOR THE SERVICE SYSTEM

Several mainstream service providers have valued the opportunity to discuss challenges related to providing services for CALD communities, and having culturally diverse workforces, and will be trialling pilot training programs to develop cultural competence in the workforce.

Consultation with external agencies as part of the evaluation has confirmed the value of the work being done by the project. The Manager of Strategic Learning and Growth at the Brightwater Care Group is implementing a cultural competencies training program and will use indicators developed by the Alzheimer’s Australia WA project in a questionnaire being developed to assess the cultural competencies of staff to identify training needs. Contact with the Alzheimer’s Australia WA project has informed the approach being taken by the organisation and has provided a valuable sounding board.

The Clinical Training Consultant at Uniting Church Homes has requested that the Alzheimer’s Australia WA project worker deliver a training session as part of the organisation’s Dementia Link Day activities.

RESOURCES DEVELOPED OR ACQUIRED

A pamphlet with translations into Punjabi, Hindi, Tamil and Gujarati was developed in consultation with the Sikh Association of Western Australia.

WHAT HELPED OR HINDERED THE PROJECT?

PARTNERSHIPS

During the scoping phase of the project representatives from mainstream service providers have been involved in discussions of emerging issues, particularly in relation to workforce development’ to improve the appropriateness of services provided to CALD people.

The Sikh community does not have the capacity to continue working in partnership with Alzheimer’s Australia WA without additional funding; they have applied for further funding through the Dementia Community Support Grant program however, funding is generally not provided again to an earlier grant recipient. This has put on-hold discussions about training and supporting a community ‘Dementia Champion’.

The pilot training program developed by the project will be delivered in August at a workshop organised by the WA Dementia Training Study Centre.

DATA AVAILABILITY

A barrier to developing detailed understanding of the demographics of different communities is that Census data is now five years old; new demographic data from the 2011 census will not be available until June 2012.

PROJECT START DATE

The project start date has meant that at the end of June the project is six months into the 12 month project.

LESSONS LEARNT

Current approaches to improving awareness of dementia and access to services for people from diverse cultural backgrounds have not been successful in engaging with vulnerable minority communities. There is a need to ‘rethink’
approaches to working with diverse communities based on a deeper understanding of the issues that influence attitudes to dementia and the use of services rather than doing ‘more of the same’.

**LEGACY / SUSTAINABILITY**

The project has reviewed the literature about how to increase access to dementia services by developing the cultural competence of service providers.

There will be an increased focus on CALD issues across the range of Alzheimer’s Australia WA services.

The resources for increasing awareness of dementia and access to services developed for the Sikh community will continue to be available.

**FUTURE PLANS**

The next phase of the project will involve working through the implications of issues raised in the review, and work with specific communities to develop new approaches to increase awareness of dementia and access to services. Work after the report could lead to:

- Work with identified CALD communities to raise dementia awareness via education
- Working with CALD groups & service providers to assist them to build capacity to provide support for people with dementia in their communities
- Develop further the pilot training program targeted at service providers and cultural competency of their workforce
- Develop and pilot a survey & workshop to assist organisations determine their level of cultural awareness/competence and assess the pilot program
- Develop links with carer support groups from ethnic communities, and encourage the facilitators to attend the facilitation sessions with other carer support group facilitators at Alzheimer’s Australia WA
- Research carers’ coping styles and cultural differences, and incorporate findings into support and education programs
20. SOUTH AUSTRALIA - GLBTI DEMENTIA COMMUNITY PROJECT

Start date: December 2010  
Funding: $72,943 

Staffing: 8 EFT  
Staff commencement date: 17th January 2011

PROJECT DESCRIPTION

The project is strengthening existing relationships between Alzheimer’s Australia SA and GLBTI service providers to improve access to dementia information and services by:

- Consulting GLBTI communities and service providers, and ongoing research, to ensure understanding of the needs of GLBTI people with dementia or with concerns about their memory or cognitive functioning
- Creating referral pathways from GLBTI service providers to dementia services
- Reviewing information resources and community education material to ensure that they are inclusive of GLBTI people; modified resources will be trialled, evaluated and further refined
- Increasing the appropriateness of training programs and support and counselling services provided by Alzheimer’s Australia SA for GLBTI people
- Increasing the sensitivity of other dementia service providers to GLBTI needs and issues through education and professional development
- Identifying ‘GLBTI-friendly’ services
- Promoting dementia education and dementia services to GLBTI people

The project will build on the strong relationships that the project worker has with the GLBTI community and a GLBTI Dementia Advisory Group will be established to guide the project. The involvement of GLBTI organisations and individuals in the advisory group will also raise the profile of dementia in the community.

PROJECT AIMS

To improve support and education for GLBTI people living with dementia, families and carers by creating sustainable relationships between GLBTI peak bodies and Alzheimer’s Australia SA to support the development and ongoing delivery of GLBTI-friendly programs.

PLANNED ACTIVITIES

- Literature and research – ongoing
- Identify and develop relationships with key stakeholders
- Develop a SA GLBTI Dementia Advisory Group
- Focus Groups and needs analysis with the GLBTI community to determine requirements from the project
- Review existing Alzheimer’s Australia SA programs
- Restructure programs in line with needs analysis
- Increase Alzheimer’s Australia SA staff awareness of GLBTI issues and contribute to the development of professional development programs to educate service providers about the needs of GLBTI people with dementia and their carers
- Develop and disseminate promotional materials, work with Marketing team to create a GLBTI Alzheimer’s Australia SA brand and image for materials, utilise GLBTI media
- Develop a GLBTI Dementia flier and modify existing help sheets based on needs of communities
• Plan, develop, provide and evaluate GLBTI specific Dementia education modules, support and resources for GLBTI living with dementia, or caring for someone living with dementia
• Develop sustainable partnerships, and reliable referral pathways, with GLBTI peak agencies, organisations and communities

EXPECTED OUTCOMES

• Support and education for GLBTI members in regards to living with dementia and caring for someone living with dementia
• Sustainable relationships developed between GLBTI peak bodies and Alzheimer’s Australia SA to support ongoing delivery of programs
• GLBTI-friendly program development and materials

(Aims, activities and objectives adapted from project work plan, progress report and position description)

SITUATIONAL ANALYSIS / CONTEXT

Information collected by Alzheimer’s Australia SA over the last several years indicated where clients identified as GLBTI they did not remain active in services/programs for any length of time, with the major issue being fear of discrimination, lack of understanding (from others in the group) and a feeling that they ‘just didn’t fit’.

Where the dementia was related to HIV/AIDS their concerns were even greater, with comments provided that they felt as if they ‘fell between the cracks’ of specialists HIV/AIDS services and Alzheimer’s Australia services, with their unique needs (in the main, these clients are male and predominantly under 55). HIV/AIDS services are focussed on HIV/AIDS-related issues and are experiencing a decline in resources, dementia is not currently a priority for HIV/AIDS services – however, the incidence of HIV-related dementia is projected to increase.

A focus group with lesbian women in the southern metropolitan area early in 2010 further highlighted the issues of the GLBTI community in accessing services, with concerns about Alzheimer’s Australia SA branding/delivery being ‘heterosexual’-focused only – needing some link/demonstration of awareness of GLBTI issues (linked to same issues faced by CALD/ Aboriginal and Torres Strait Islander communities).

GLBTI service providers have become more aware of the ageing of their population and the impact that dementia may have in the future (and already has). Baby-boomer GLBTI posit that they have ‘fought the fight’ for identity and fear the need to become ‘closeted’ again as they age and cognitively decline. Most Gay and Lesbian specific health services are HIV/AIDS-related.

GLBTI individuals may not identify with, or connect with, GLBTI communities and services, it can therefore be difficult to access GLBTI individuals via health and community care services. In Adelaide, many gay men and lesbian women live ‘quite suburban lives’. Gay men, lesbian women, people who are bisexual, transgendered people and intersex people are diverse and have different issues. For example, amongst gay men there are a range of communities who have little in common apart from their sexuality and there is a wide difference between people who cross-dress and those who identify as transsexual.

Older, non-heterosexual men and women have experienced discrimination, rejection and sometimes abuse because of their sexuality; some have chosen not to be publically open about their sexuality. Homophobia is still prevalent and many religious organisations providing aged care services, as well as individuals working in aged care, discriminate against, and judge homosexuality. The expression of homophobia can be subtle and unintended. Even when services are ‘gay-friendly’ gay men and lesbian women may anticipate discrimination and negative judgements and therefore not access services, or be anxious about accessing services.
It is not uncommon for gay men and lesbian women to have had past heterosexual relationships – this can create difficulties as dementia advances if they remember past heterosexual relationships but do not recognise their current same-sex partner.

Gays and lesbians who do not have children can be expected to carry the burden of caring for a parent with dementia because they are perceived by other family members as being more available (this could apply equally to any children who are not parents).

The prevalence of dementia amongst people who identify as GLBTI will increase as the baby boomer generation ages and the risk of developing dementia increases.

Language is an issue – some gays and lesbians prefer to identify as queer, while others strongly object to this label, ‘gay’ is sometimes used as a non-gender specific term for homosexuality however, it is viewed by some as applying only to men and some lesbian women do not identify themselves as gays.

GLBTI dementia education and care services fit within broader issues of attitudes towards sexuality amongst aged care and dementia service providers.

**BUILDING ON**

In 2009, Alzheimer’s Australia South Australia launched the paper “Lesbians, Gay Men and Dementia” on World Alzheimer’s Day. The response to the paper was overwhelming and started the discussion around the relationship between GLBTI service providers and Alzheimer’s Australia SA. However, both organisations have lacked dedicated resources to continue this partnership.

The project will build on existing dementia education program materials including Living with Memory Loss, Carer Education and information sheets. These resources will be modified to be relevant and responsive to the needs of GLBTI people.

**RATIONALE FOR TAKING THIS APPROACH**

Building relationships of trust with GLBTI communities will help to establish referral pathways to dementia services. Modifying existing resources and Alzheimer’s Australia SA programs as deemed appropriate by these communities will make Alzheimer’s Australia SA services more GLBTI-visible and appropriate.

Older GLBTI people and people with HIV-related dementia have good reasons for not trusting that dementia service providers will be aware of, respectful towards, and able to accommodate their needs and issues. Alzheimer’s Australia SA needs to demonstrate its commitment to developing and promoting services that are inclusive and accepting in order to increase access to services for GLBTI people in the longer term.
IMPLEMENTATION

GLBTI DEMENTIA ADVISORY GROUP

A GLBTI Dementia Advisory Group has been formed and has met twice so far, the 13 people involved include a mix of GLBTI service providers, aged care and carer’s service providers and elders from GLBTI communities. Two of the members are Aboriginal people. The advisory committee provides strategic and practical advice to the project and extends the reach of the project into the networks of advisory group members. Terms of Reference for the GLBTI Dementia Advisory Group have been developed.

DEVELOPING INTERNAL RELATIONSHIPS

Relationships have developed between Alzheimer’s Australia SA staff and the project worker who has met with the following teams: Community Services Team; Access & Equity Unit (Aboriginal and Torres Strait Islander & CALD); Early Intervention Team; Dementia Link Workers and the Dementia Care Essentials Team.

Professional development to increase awareness of GLBTI and broader sexuality issues has been provided by the project worker in response to staff requests and has been well received by staff.

The project worker has also developed close links with the SA/NT Dementia Training and Study Centre (DTSC) and is working part-time for the centre.

DEVELOPING EXTERNAL RELATIONSHIPS

Articles in the Alzheimer’s Australia SA newsletter, the Carer’s SA newsletter and Blaze, a South Australian GLBTI Community Magazine, have raised the profile of the project.

The project worker has been actively contacting relevant agencies to introduce the project and this contact has led to invitations to become further involved. For example, attending an Aboriginal and Torres Strait Islander function in Murray Bridge led to a request from Murray Lodge to come and talk to them about cultural training. Agencies that have been contacted include: Aids Council of South Australia (ACSA), People Living With HIV/AIDS (SA) (PLWHA), Positive Living Centre (PLC), Adelaide Diocesan AIDS Council (ADAC/Centacare), The HIV Women’s Project, P.E.A.C.E. Multicultural HIV/AIDS & Hep C Services - Relationships Australia (SA), MOSAIC - HIV/Hep C Counselling and Treataware.

The project has also been promoted through presentations to the Northern Dementia Action Group, Executive staff at the Murray Mudge Aged Care Hostel and the Uranian Society (Older Gay Men’s Social/Cultural Group). The project worker was recently invited to give a presentation about the project at the Northern Partnership forum, a regional service provider dementia forum with around 60 services present.

Uniting Care Wesley has a brief to make their services GLBTI-inclusive, this work is starting with an Aged Care Hostel and lessons learnt in this initial example will inform the wider implementation of staff training and changes to policies and practices. The Alzheimer’s Australia SA project worker is on the steering committee for this project.

A presentation on GLBTI issues at the National Alzheimer’s Australia conference was very well attended and generated positive response from participants. The project worker made several contacts at the conference including meeting Michael Kirby who has offered to help the project.

A national email list of interested people and organisations has been developed, there are about 35 people on the list and email updates are distributed every 2 or 3 months to keep people in the loop.
SCOPING THE ISSUES

A large focus group for women has been held and a focus group for men is being organised with the assistance of Befriend, an agency that provides support to isolated GLBTI people.

Reviewing relevant literature and activities is ongoing. The Hammond Care Group in NSW has been identified as innovative service successfully addressing diversity issues. The project worker is in contact with the AIDS Council in NSW who have been funded by the Department of Aged and Community Services to develop a cultural sensitivity package.

REVIEWING AND DEVELOPING RESOURCES

The 75 National Dementia information sheets have been reviewed and four information sheets that need to be revised to be more GLBTI-friendly have been identified and the Department of Health and Ageing has been informed of the changes that are needed.

A GLBTI resource is being developed using a facilitated digital story telling process to tell the stories of GLBTI people and dementia. Feedback from agencies and the communities was that a visual resource would be more useful than a brochure or other printed material. A male couple, where one person has dementia and his partner is caring for him, have agreed to be involved; other people’s stories may include a lesbian who cares for her parent with dementia and a transgender person. This resource would be available as a CD ROM, online and can be used in face to face presentations. As the project start date was delayed, the final $20,000 of project funding (to June 2011) will fund the development of this resource.

Discussions have started with the SA/NT Dementia Study and Training Centre about developing a GLBTI-specific training module for medical and aged care professionals. This module would be part a bigger-picture sexuality training package being developed by SA/NT and QLD Dementia Training and Study Centres. There will be a specific advisory group for this project.

CHANGES DURING IMPLEMENTATION

This project has largely developed as initially planned. The decision to develop a CD ROM has been informed by consultations and is consistent with the original project plan. Rather than creating formal Memorandums of Understanding between Alzheimer’s Australia SA and GLBTI service providers, the project worker is identifying where the aims of Alzheimer’s Australia SA and GLBTI service providers converge, and how both organisations will benefit from working in partnership.

The level of involvement of the project worker in organisational change processes within such a short time was not anticipated and is a sign of how well the project has been accepted both with Alzheimer’s Australia SA and by external organisations.

PROJECT OUTCOMES

OUTCOMES FOR PARTICIPANTS

Staff members in a range of Alzheimer’s Australia SA services have reported that they are more open to discussing sexuality with clients and are more likely to pick up cues about sexuality. There is a greater sense of openness and clients are responding.

The visual stories resource will be specifically relevant to GLBTI people who have dementia, or are caring for someone with dementia, and will provide information about how to access available services.
The profile of dementia has been raised amongst the GLBTI people who have become involved in the project through the advisory group, participation in the focus group and responses to media articles.

**OUTCOMES FOR ALZHEIMER’S AUSTRALIA SA**

The existence of the project and the professional development provided to staff by the project worker have increased awareness of, and sensitivity to, GLBTI and sexuality issues within the organisation. Discussions about GLBTI and sexuality issues and the implications for how people work are ongoing. Some staff members have opened up about their own sexuality; a sign that they are experiencing the workplace as a safe space for being open about their sexuality.

Alzheimer’s Australia SA is seen by other dementia and aged care service providers as a valuable resource for increasing awareness of, and developing response to, issues concerning the care and support of GLBTI people with dementia. This is evidenced by the requests that the project worker has received to talk about the project at service provider forums and to be an advisor to Uniting Care Wesley as they work to make their services inclusive of GLBTI people.

It is expected that the capacity of the whole of Alzheimer’s Australia SA to respond to GLBTI people will build over time.

**OUTCOMES FOR THE SERVICE SYSTEM**

There is an increased level of awareness amongst aged care services as evidenced by requests for the project worker to speak to network meetings and to meet with individual organisations.

It is anticipated that sharing information about the work that Uniting Care is doing to develop sensitive responses to GLBTI people will support other agencies to develop GLBTI-inclusive practices.

**WHAT HAS HELPED OR HINDERED**

**PARTNERSHIPS**

The approach to developing partnerships is to develop trust by being clear and straightforward about what is wanted from the partnership, where the aims of the project fit with the interest of the partner organisation, and how the Alzheimer’s Australia SA project can assist. Developing relationships both internally and externally has involved an ongoing series of discussions, addressing issues that can be sometimes hard to talk about. There is recognition that developing awareness and more inclusive practice takes time and that for some people the project is raising difficult issues that have not been talked about before.

The project worker is employed by the GLBTI project 4 days per week and is working for the SA/NT DTSC one day per week. This relationship has benefited both the GLBTI community project and the work of the training and study centre.

It has been challenging to get dementia onto the agenda of GLBTI organisations however, these discussions are occurring in the context of issues related to ageing. The CD ROM resource telling stories of GLBTI people’s experience with dementia will support conversations within GLBTI communities about dementia as a part of conversations about ageing.

**FLEXIBILITY**

Having the capacity to respond to requests from organisations to provide information or support them in improving their responsiveness to GLBTI people has enabled the project to build partnerships that, over time, will lead to more inclusive services. Similarly, having the flexibility to respond to requests for a CD ROM resource helps to build credibility.
Having a project worker who is well known and respected within the GLBTI community has been important. The project worker’s training skills, experience in community development and in particular his sensitive, warm and non-threatening approach has enabled people to engage in what can be difficult discussions.

LESSONS LEARNT

Developing trust and increasing awareness of the issues amongst aged care and dementia service providers is an important first step in a longer process. Agencies need to make an organisational commitment to developing their capacity for providing sensitive services for GLBTI people.

Similarly, training in GLBTI issues is a first step in developing awareness; ongoing discussions with staff have shown that they develop a more nuanced understanding of practice implications over time.

Identifying common aims, rather than developing MOUs, has been a more successful approach to developing partnerships with GLBTI service providers.

Undertaking the project has generated goodwill towards Alzheimer’s Australia SA in the GLBTI community; when the project worker position was advertised there were several calls from people congratulating Alzheimer’s Australia SA for implementing a project to specifically address the needs of GLBTI people.

Employing a project worker who is known and respected within the community has been crucial for developing relationships with service providers and members of GLBTI communities.

LEGACY / SUSTAINABILITY

Creating sustainable change in the attitudes and practices of dementia service providers is a longer-term process that is important to address. Alzheimer’s Australia SA staff members are more sensitive to GLBTI issues and needs, however, this will take time to embed and further develop into a cultural norm.

Similarly, there is a higher level of awareness of GLBTI issues amongst aged care providers, but further work is needed to translate this awareness into organisational policies and practices. Relationships with GLBTI and aged care service providers have been developed, although past experience is that dedicated resources and ongoing activities are needed to sustain these relationships.

The resources developed will be a sustainable legacy of the project.

FUTURE PLANS

Future plans include:

- Continuing to increase the capacity of Alzheimer’s Australia SA staff and other organisations, there are layers of awareness and as people think more deeply about the implications of being more sensitive to GLBTI people new issues arise
- Continuing community development work and being a conduit for GLBTI people wanting to know more about dementia, and for services providers wanting to know more about GLBTI issues

If funding is available, a GLBTI dementia link worker position would enable Alzheimer’s Australia SA to work closely with GLBTI communities to create sustainable pathways to services for people with dementia, their carers and families.

The project worker will be continuing the community development work of this project on a part-time basis after June 2011 and will work with the SA/NT Dementia Training and Study Centre on a part-time basis.
The project will develop and implement a program to provide individualised cognitive training and other psycho-social interventions for people with dementia. Project participants will undergo a comprehensive assessment, a comprehensive assessment of their cognitive functioning, quality of life, depression, subjective interpretation of memory, and involvement in pleasant activities. The assessment findings will inform the development of an individualised intervention plan. Each person will meet with a facilitator on a weekly basis, and individual plans will be regularly reviewed. A flexible approach to providing the treatment program will respond to individual needs and preferences, for example, the individual sessions can be held at Alzheimer’s Australia Tas or in the participant’s home, if needed, transport to Alzheimer’s Australia Tas will be provided. If there is a significant decline in cognitive functioning, or major life changes during the project, the intervention plan will be modified to provide additional support, or change the way the treatment is delivered, for example, being flexible about times and dates or switching from group-based to individual cognitive training.

**PROJECT AIMS**

The original project aim was to establish a pilot Cognitive Rehabilitation Treatment Program for people with Mild Cognitive Impairment (MCI) or diagnosed early dementia. However, the scope of the project has been broadened to include people with mid-stage dementia.

**PLANNED ACTIVITIES**

- Adapt assessment protocols and treatment manuals from the treatment program in Greece for use in an Australian context
- Extensive literature review to identify specific activities that can be used in cognitive rehabilitation and follow-up with researchers
- Seek referrals from current programs Alzheimer’s Australia TAS programs (e.g. Living with Memory Loss, younger onset group and Active Cognitive Enhancement Program (ACE) for healthy adults and local Geriatricians
- Face to face meeting with potential participants to discuss involvement in the program
- (The project initially planned to recruit people with mild cognitive impairment or early-stage dementia however, as no referrals were received from geriatricians, participants were recruited from people who have had contact with Alzheimer’s Australia TAS counselling or support services. The eligibility was extended to include people with more advanced dementia.)
- Run 16-week program with weekly one-on-one contact and 3 group sessions. Weekly sessions of 1.5 hours, including 30 minutes using computer program designed to assist cognitive functioning.
- Run individual and group sessions, focusing on individual goals specific to the client, followed up with group computer sessions
- Conduct comprehensive neuropsychological assessment, screen for depression and measure quality of life in the first 3 weeks of the program. Neuropsychological tests of cognitive functioning cover: attention, executive function, verbal memory, visual memory, language, visual perception – visuospatial abilities and general cognitive performance tests
- Identify specific cognitive deficits for each client and develop specific activities to address these
- Develop individual plans with each person taking into account assessment findings and client-identified goals
- Individual plans are monitored and adapted as needed during weekly sessions
- Weekly follow-up meetings of facilitators to review and revise sessions if needed, and to discuss progress of each client
- Regular meetings with psychology supervisor
- Re-administer comprehensive assessment at the end of the program

**EXPECTED OUTCOMES**

- Add to the evidence base about the effectiveness of cognitive rehabilitation strategies in general, and more specifically in an Australian context
- Maintain initial levels of cognitive functioning
- Increase social engagement and well-being of participants
- Increased use of support services offered by Alzheimer’s Australia TAS and other services
- Raise the profile of Alzheimer’s Australia as an organisation that embraces current world trends in progressive and innovative dementia treatments

**SITUATIONAL ANALYSIS / CONTEXT**

This is the first program of this kind to be offered in Australia, and there is no Australian literature on the effectiveness of cognitive rehabilitation for people with dementia. Medical responses to dementia in Australia focus on pharmacological interventions to slow down the deterioration of cognitive functioning. The project is likely to be viewed with scepticism and bias because it is outside the accepted medical model.

The current project bridges the gap between cognitive training for healthy older adults and psychosocial or medical interventions currently available in Australia for people with dementia. Most people with memory concerns or a diagnosis of dementia do not have an assessment as comprehensive as the assessment that the project will provide.

Alzheimer’s Australia Tas has a positive reputation and history of innovation. This track record and strong relationships with key stakeholders, including researchers at the University of Tasmania and clinicians, will support the project in challenging established attitudes and offers possibilities for influencing treatment directions.

The availability of individualised support for people with younger onset dementia and their families is very limited. Some people with Younger Onset Dementia are reluctant to attend groups or access support provided by Alzheimer’s Australia Tas, however, once they do attend, they often keep coming and appreciate the contact with others.

While not specifically seeking to improve access to services, it is anticipated that increased use of support services may flow from participating in the program as participants become more familiar with, and feel comfortable attending Alzheimer’s Australia Tas. If the comprehensive assessment identifies physical or mental health issues, participants will be referred to appropriate services.

If increased social engagement is a client goal, the project will support participants to access social opportunities, this may involve linking participants with other services provided by Alzheimer’s Australia Tas, as well as other services and activities in the community.
BUILDING ON

Cognitive rehabilitation program developed in Greece.

The successful Active Cognitive Enhancement Program (ACE) developed in collaboration with the University of Tasmania. ACE is a cognitive training program for healthy older adults, those who do not have a diagnosis of MCI or early dementia.

RATIONALE FOR ADOPTING THIS APPROACH

There is some evidence that cognitive training can reduce the cognitive deterioration of people with dementia, and there is a need to build an Australian evidence base about the effectiveness of cognitive training and individualised psycho-social interventions in reducing cognitive decline and improving the quality of life for people with dementia.

Depression is common in people with dementia, it is often under-diagnosed in older people and this is a particular problem for older people with dementia, as symptoms of depression can be similar to symptoms of dementia. As explained in the Alzheimer’s Australia fact sheet on depression “If a person with dementia also becomes depressed, they will be struggling with two lots of difficulties. The depression will exacerbate the effects of the dementia, making it even harder for them to remember things, and making them more confused, anxious or withdrawn. It may also cause behavioural changes, such as walking around aimlessly, aggression, social withdrawal or refusal to eat.”

This project will assess participants for depression and will offer counselling and other interventions such as increased social engagement and more pleasant events that can be helpful in reducing depression. Reducing depression has the potential to reduce the cognitive impact of dementia.
IMPLEMENTATION

Designing and establishing the program

Cognitive education resources and assessment tools used in the program were selected on the basis of a review of relevant literature. A range of neuropsychological assessment materials were purchased and questionnaires selected for use in the initial and final assessment of participants’ cognitive capacities, mental health and quality of life.

A dedicated room was set up for running the program, with computers to provide group sessions in computer-based cognitive training.

To support implementation, a package of 16 session outlines was developed to support facilitators and ensure consistency, and a range of information sheets were developed for program participants.

Recruiting participants

Eight people with dementia were recruited to participate in the project. Four of the participants had younger onset dementia, six had early-stage dementia and two had mid-stage dementia. Face to face meetings were held with each participant to explain the project prior to commencing the 16-week program. Participants were recruited through Alzheimer’s Australia Tas programs.

Initial assessment and Individualised planning

The initial cognitive and psychosocial assessment took place over the first 3 weeks of the program. The program was implemented by psychologists who had the training needed to administer and interpret the test results.

Cognitive skills development tasks, tailored to match the individual client’s interests and skill levels, were developed, for example:

- training in visual scanning enabled a person who was an avid cook to reduce the number of mistakes she was making during these tasks, thus reducing increasing frustration, and reduction in time spent enjoying this activity
- categorising and grouping activities to support abstract reasoning skills
- naming tasks to improve verbal fluency and naming abilities
- discussing what had just been read in the newspaper (thus practicing memory skills, and improving orientation to day and current events)
- strategies to use in the home to improve memory, such as large calendars, diaries, family members using notes as reminders
- someone who had been used to using a computer diary now also carries a notebook to jot down things to remember to add to the computer diary, thus reducing frustration
- using ‘to do’ lists, and doing one thing at a time
- tasks based on primary interests such as gardening, football and which addressed specific cognitive deficits
- taught how to use public transport after losing driver’s license so could retain independence and community activities

Action plans were works-in-progress, over time, different goals emerged and different issues were identified and addressed.
CHANGES MADE DURING IMPLEMENTATION

The program initially planned to recruit people with early-stage dementia and mild cognitive impairment; however, a lack of referrals of people in this category resulted in opening up the program to people with more advanced dementia. Two participants had mid-stage dementia and could not take full advantage of the program due to their inability to remember what had been discussed in previous weeks and general cognitive deterioration. The focus for these clients moved to collaboration with carers and engaging the people with dementia with day club activities.

The planned use of group computer sessions did not occur for a number of reasons: it was difficult to find a time that suited all participants; some participants had no familiarity with computers and did not want to learn; finally, the chosen computer-based cognitive development program was too difficult for the participants.

Instead of using computer-based cognitive training programs, activities to enhance cognitive abilities were developed for each individual. The activities addressed identified cognitive deficits and were based on the participant’s interests and aspirations, such as cooking, gardening or painting. It took longer than anticipated to develop the program because of the need to develop additional cognitive skills training exercises.

PROJECT OUTCOMES

OUTCOMES FOR PARTICIPANTS

All participants demonstrated improvements in the Geriatric Depression Score, except for one, although this participant’s ratings were still considered to be within the subclinical, ‘normal’ level. Those with the highest depression scores at the start of the program showed the biggest improvements.

Quality of life was also enhanced for most participants, with the biggest improvement for a participant with an initially low quality of life score. While three participants’ quality of life scores were reduced, the reductions were only small: two with only 3% decline and the third with a 11.5% decline.

The number of ‘pleasant events’ increased for all but one participant and again, the biggest increases were amongst people with the lowest scores at the start.

Of the participants who completed the Rivermead Behavioural Memory Test, three showed improvements and four had small decreases in their scores. One person was not able to complete this test.

All participants had increases in their subjective ratings of how they felt about their memory. Similarly, all participants except two had increased their use of memory strategies and a decrease in memory mistakes made. One of the individuals who reported more mistakes had a very low score for mistakes prior to the commencement of the program.

Two clients had home help organised after their needs were identified during the program, and another client was provided with support for their partner to obtain a Carer’s allowance from Centrelink.

Webster packs were introduced to one participant due to the finding during the course of the program that he was not taking his medication as directed. This client also mistakenly thought he had early-onset Alzheimer’s Disease and as a result of this conversation his seizure-related dementia and prognosis was clarified.

Three of the clients were attending an Alzheimer’s Australia Tas day club (either the ‘Creative Well’ or the younger onset group) when the program commenced, at the end of the program seven of the eight participants were attending the day club programs. Social support was also increased for one participant after they were introduced to another Alzheimer’s Australia Tas client.
Simple psychoeducation made a big difference for many participants. Explaining the implications of a diagnosis and understanding their particular cognitive deficits lead to changes in attitude. Greater understanding of their condition, practical strategies (e.g. use of external memory aides) to address deficits and counselling resulted in a willingness to participate in activities that had been given up after the initial diagnosis. For most clients, there was also an emphasis on addressing the emotional consequences of their memory impairment, particularly given that anxiety and depression are common in people with memory difficulties.

There were clear improvements in quality of life as a result of being involved in the program; it is more difficult to draw conclusions about the impact of the program on cognitive functioning and the extent to which clients would have deteriorated, or in some cases improved, over the 16-week time period, in the absence of the program.

**OUTCOMES FOR ALZHEIMER’S AUSTRALIA TAS**

The staff members who run the program are members of the counselling team and the whole team was kept up-to-date with the progress of participants involved in the program as it was being implemented. The counselling team, who also answer all helpline calls, have become aware of the importance of individual counselling, further assessment and personalised planning after a diagnosis and have been offering counselling appointments to newly diagnosed people who contact the helpline.

In order to manage the increased demand on counselling staff, aspects of the program are being adapted, the assessment is being conducted over two, rather than three, sessions and counselling is being offered on a more flexible schedule, for example fortnightly rather than weekly, and is tapered off as needs reduce.

Visiting people at home gives staff a different understanding about what’s happening at home compared to asking clients about their home situation in an office interview.

Alzheimer’s Australia Tas is a partner with the University of Tasmania in an application for funding through the Australian Research Council to further research the role of psychosocial and cognitive rehabilitation for people with early and mid-stage dementia. If successful, this larger research program will further explore the impact of cognitive skill development, will look into the model being used in Greece to build evidence about the benefits of psychosocial approaches to treatment. This is building on previous work done in partnership with Tas Uni to develop a cognitive skills development program for healthy people.

**OUTCOMES FOR THE SERVICE SYSTEM**

An important finding has been that when people are diagnosed with cognitive deficits they are often not thoroughly and holistically assessed. Misunderstanding about a diagnosis, or a lack of education about the implications of a diagnosis of dementia or cognitive impairment, can lead to depression and a sense of hopelessness that results in people giving up activities that they are still capable of enjoying. The program facilitators have liaised with GPs as needed regarding individual participants. They are also writing to GPs to inform them about the outcomes of the project and the availability of Alzheimer’s Australia Tas services.

The program is being promoted to geriatricians and other community organisations so that they are aware that Alzheimer’s Australia Tas offers comprehensive assessments and individualised responses to address cognitive deficits and to improve the mental health and quality of life of people with dementia. It is anticipated that over time there will be more referrals to the program, and that referrals will occur at the time of diagnosis.

The need for more education and support for carers, and the importance of continuing to review support needs has been identified.
BROADER APPLICATION

This model could be adapted for use by other dementia service providers. The lessons learnt about the importance of individual counselling and education following a diagnosis is relevant to a range of service providers.

The facilitators hope that other organisations will be inspired to establish similar treatment centres throughout the country if an Australian evidence base demonstrating the effectiveness of this approach is developed.

RESOURCES DEVELOPED OR ACQUIRED

- Weekly session outlines developed to guide the implementation of the project
- Screening tool developed for the program
- Neuro-psych and psycho social tests acquired will be available for use after the project
- Cognitive education computer program acquired
- Individually tailored cognitive skills training exercises

Information sheets were developed specifically for use with program participants cover:

- Cognitive Rehabilitation Overview
- Feelings and adjusting to change
- Relaxation
  - Breathing
  - Progressive Relaxation
  - Mindfulness
  - Visualisation – Colours
  - Visualisation – Peaceful Place
- Managing Memory Loss
- Keeping Involved & Active
- Looking after yourself – health
- Memory Training

WHAT HELPED OR HINDERED THE PROJECT?

PARTNERSHIPS

Alzheimer’s Australia Tas has built on a collaboration with the University of Tasmania developed during joint work on the Active Cognitive Enhancement (ACE) program for healthy people.

Although links had been established with the Greek Treatment Centre who were willing to share their resources, it was difficult to maintain contact with staff in Greece during the implementation of the project.

The lack of referrals from geriatricians was disappointing and unexpected as Alzheimer’s Australia Tas has established relationships with geriatricians.
STAFF

The skills and experience of the Alzheimer’s Australia Tas psychologists was crucial in the development of this program. As well as having the skills to conduct the comprehensive psych-social assessments, the psychologists had counselling skills and were able to link participants into community services and Alzheimer’s Australia Tas services as required.

FLEXIBILITY

Having the flexibility to make adaptations during the development and implementation of the project was important in ensuring successful implementation. Adaptations were made to the way participants were recruited, the level of cognitive impairment of participants, and the structure of the program; having individual sessions rather than group cognitive training sessions, and developing individualised cognitive training exercises rather than using the computer-based exercises.

LESSONS LEARNT

Recruiting participants through health providers was challenging. The project initially intended to work with people with mild cognitive impairment or with early-stage dementia however, given the lack of referrals from geriatricians, the scope was broadened and people with more advanced dementia were enrolled in the project. Participants with moderate levels of impairment remained in the program for the 16-week period and demonstrated improvements in their mental health and quality of life however; people with advanced dementia were not able to benefit from being involved in the program. While the project worked successfully with participants with early-stage dementia, offering counselling and cognitive training activities was not successful for people with more advanced dementia.

Where people had more advanced cognitive impairment, the program staff focussed more on the needs and concerns of carers. Educating carers about the impact of their partner’s cognitive impairments reduced the carer’s levels of frustration, which indirectly benefited the person with dementia. Organising additional support such as day programs or home help supported the carers to better look after themselves.

Individual counselling was important for participants as it gave them an opportunity to talk about their experience and discuss anxiety or depression without having to be concerned that they were further burdening their carers.

Visiting people in their home provided a clearer picture of how well people were managing. It takes time for some carers to open up about needing some help and support, keeping in touch and developing a relationship with the carers over time contributed to a greater acceptance of community services.

LEGACY AND SUSTAINABILITY

Individual clients have learnt about their cognitive abilities and deficits and will continue using strategies developed in the program. Carers will continue to benefit from the community services that have been put in place to increase the level of ongoing support.

Alzheimer’s Australia TAS has developed materials, documented and built up experience in how to conduct comprehensive assessments and provide cognitive rehabilitation. A new psychologist is being trained to administer the cognitive tests so that Alzheimer’s Australia Tas can continue to provide the program. Without a psychologist on staff, the neuropsychology assessments could not be done, however, Alzheimer’s Australia Tas could continue to provide individual counselling and ‘pleasant events’ if a psychologist was not available.

The initial set up, developing the program and the cognitive skills development tasks were time consuming for staff, now that these resources have been developed ongoing costs are reduced.
The original project recipients will continue in the program, receiving counselling and cognitive skills development, but there will be more flexibility about the frequency and duration of sessions.

Introduce the program as a resource that can be offered as follow-up to the ‘Living with Memory Loss’ course. The program reinforces the messages about how to live with memory loss and offers strategies that can be used to reduce further deterioration. A major role of the counsellor running the program is to provide further education to both the person with dementia and their carer about the individual’s cognitive abilities, how cognitive changes influence behaviour and how changes can be managed.

Providing information to geriatricians and GPs about what the program offers will hopefully lead to more referrals of the patients for ongoing support.

Alzheimer’s Australia Tas will be an industry partner in the University of Tasmania Australian Research Council research project that will further explore the use of counselling and cognitive rehabilitation exercises for people with dementia if research funding is granted.
22. AUSTRALIAN CAPITAL TERRITORY - YOUNGER ONSET DEMENTIA

Start date: 1\textsuperscript{st} December 2010  
Funding: $33,938

**Staffing:** Two existing staff members have extended their hours, and other roles have been re-organised to allow them to work on the project. At times, additional staff members are involved in specific activities.

### PROJECT DESCRIPTION

A consumer focus group at the start of the project identified a range of issues for people with YOD, their carers and families. A primary focus of this project was to directly respond to these issues by offering age-appropriate group activities that are enjoyed by the person with dementia, and provide respite for carers. The project has also provided social activities for couples and families as a way of reducing social isolation, supporting carers, and involving the children of people with YOD who often have limited awareness of, and contact with, support services.

In addition Alzheimer’s Australia ACT has worked to improve access to age-appropriate day care and residential respite and to improve the appropriateness of mainstream services by increasing awareness of the needs of people with YOD amongst other service providers.

### PROJECT AIMS

To provide:

- Community-based respite that is innovative, flexible and responsive to the needs of younger people with dementia, their families and carers
- Re-engaging relationships of younger people with dementia, their families, carers and communities, and in particular, the children of people with younger onset dementia

### PLANNED ACTIVITIES

- Focus group session for people with YOD and their carers and families to identify issues and unmet needs
- Explore opportunities to develop partnerships with service providers who provide residential services and day programs for people with YOD
- Explore opportunities for increase funding to provide in and out-of-home respite for people with YOD through existing Alzheimer’s Australia ACT programs
- Promote the special needs of people with YOD through interagency forums and network meetings
- Explore opportunities for funding to develop resources to support the children of people with YOD
- Explore the need to develop training programs specifically for diversional therapists working with people with YOD in residential care and day programs
- Respite for people with YOD which is inclusive of their families and carers
  - Establish small group activities that are beneficial to the person with YOD and provide respite for carers
  - Provide 3 opportunities for dinner for 10 couples who are living with YOD
  - Provide 2 opportunities of respite, by way of a group outing, for the children of people with YOD
  - Provide 2 opportunities for the whole family to have a social outing, such as a cruise on Lake Burley Griffin in the ACT
EXPECTED OUTCOMES

- Increased awareness and engagement to reduce social isolation
- Highlighted need for age-appropriate respite for people living with YOD, their families and carers
- Reduced indicators of ill-being that impact on family and carers of people with YOD
- Establish a model of age-appropriate respite for people with YOD

(Project aims, activities and outcomes from project plan and progress report)

SITUATIONAL ANALYSIS / CONTEXT

The Access Economics report on the prevalence of dementia has predicted increasing numbers of younger people (under 65) with dementia. The Alzheimer’s Australia ACT National Dementia Helpline has reported increasing enquiries about services available for people with YOD and the Alzheimer’s Australia ACT Respite Links program has experienced increased demand for in and out-of-home respite care for people with YOD.

There are no day programs or residential care services that specifically cater for people with YOD. The need for age-appropriate in-home respite, day programs and residential respite care for younger people with dementia, their families and carers has been identified by Alzheimer’s Australia ACT. Some younger people are using a day program to give their carers a break. The feedback to Alzheimer’s Australia ACT staff is that although the facilities are of a high standard, younger people with dementia dislike going there because it is set up for much older people, younger people feel that they do not fit in.

Existing residential respite options are not appropriate for younger people; it is often distressing for the person with dementia and their carer when inspecting respite facilities to find that it is set up for frail aged residents. In some cases, people chose to go without much needed residential respite because the existing facilities are inadequate to the needs of younger people with dementia.

The Alzheimer’s Australia ACT has used its Respite Links service to provide one-on-one support and could provide access to a broader range of mainstream activities which enabled people to continue being engaged in community activities such as using the library, going to church, seeing a movie, but the resources available to provide this level of support is limited.

Alzheimer’s Australia ACT was in danger of becoming a default day centre as people with YOD were staying at the Alzheimer’s Australia ACT offices after attending shorter programs when carers needed longer respite hours. This was inappropriate as the offices are not set up to provide this type of care and the practice had to be stopped.

The project is working to address the recommendations from the Communiqué from the Younger Onset Dementia Summit 2009:

*Increased awareness to reduce stigma and social isolation*

- A greater emphasis on supporting people living with YOD, their families, carers and their communities
- A funding stream be established to provide innovative approaches for age-appropriate respite in partnership with people with YOD, their family, carers and their communities

*Provide access to appropriate services*

- A targeted strategy be implemented to improve the range and quality of in-home and out-of-home services available for people with YOD, their families and carers.
- Relationship re-engagement programs be developed as part of a suite of options for people with YOD
- Programs be established to support carers to ensure that their health and wellbeing needs are met
• Services be established to meet the social, emotional and psychological needs of children of people with YOD

• People with YOD be eligible for services that are established prior to the age of 65 to ensure continuity of care

**BUILDING ON**

Alzheimer’s Australia ACT has established relationships with people with YOD who are represented on the Alzheimer’s Australia ACT consumer advisory group. The project has built on the success of providing individualised support offered to people with YOD by the Alzheimer’s Australia ACT Respite Links program.

The Alzheimer’s Australia ACT has been working to address the lack of respite options for people with YOD for some time and has a clear vision of establishing a centre that could provide day programs and residential respite specifically for people with YOD. The facility could be set up as a Centre of Excellence and Resource Centre targeting people with YOD. Alzheimer’s Australia ACT staff could rotate through the house to be a resource for care staff.

Alzheimer’s Australia ACT has also explored the option of setting aside one day a week specifically for younger people with dementia at an existing respite service. The intention was to both provide respite and social engagement for families by supporting the people with YOD to prepare a meal that could be shared with carers and families at the end of the day. However, the high level of demand for the existing respite service precluded the option of allocating a day specifically for people with YOD.

Alzheimer’s Australia ACT has the expertise to provide specialist training to service providers on YOD and difficult behaviours.

**RATIONALE**

Providing appropriate respite options for younger people with dementia is important; if it is enjoyed by the person with dementia, it becomes a welcome activity and carers get a break. If the respite option is inappropriate, it is distressing for both the person with dementia and their carer, and is less likely to be utilised. Carers need respite to maintain their wellbeing, if they do not get a break from a demanding caring role their capacity to continue caring long term can be diminished. Appropriate respite is also important for the person with dementia who may be concerned about being a burden on the carer. The lack of all-day respite means that some carers of people with YOD have to take extended leave without pay, long service leave or retire early.

The individualised support provided by the Respite Links program is ideal because it enables the person with dementia to continue with enjoyable activities and maintain a level of community involvement. However, it is not financially viable for Alzheimer’s Australia ACT to provide individualised, one-on-one support to an increasing number of people with YOD.

The current project is therefore exploring options for providing appropriate and enjoyable group activities for people with YOD as a way of providing respite. The group activities also provide opportunities for people with YOD to meet and develop relationships that can lead to ongoing mutual support for the people with dementia and their carers. Feedback from people with YOD and their carers is that they are seeking respite from social isolation in addition to, or in some cases rather than, time apart as respite from their caring responsibilities.

Children often do not identify themselves as having a carer role and are unaware of the services and support available to them, many people with YOD have children who are in their teens or early adulthood. Family-focused activities such as a cruise on Lake Burley Griffith are a way of informally making contact with the children of people with YOD. Alzheimer’s Australia ACT counsellors will attend and specifically target these young adults with an enjoyable activity, provide information about dementia and raise awareness of the services available for children.
IMPLEMENTATION

Alzheimer’s Australia ACT held a focus group of consumers of people with younger onset dementia (YOD), their families and carers to obtain feedback in relation to the need for services and appropriate activities for younger people with dementia, their carer’s and families.

The following issues were identified by the focus group of people with YOD, their families and carers in the ACT:

- The need to keep people with YOD active is more important in some ways for carers than getting ‘technical’ support and information from health/medical professionals
- Stimulation and social engagement is important for people with YOD
- Different generation therefore different physical/psychosocial needs
- Critical lack of YOD-specific in-home respite, day programs and residential respite care
- Difficulties for people who are still working and caring for a person with YOD
- Respite does not have to mean separation. A break together is of value in reducing carer burnout
- Support for the carer is very important in reducing the burden of care
- It is ‘always with you’ - the carer cannot get away from it – no opportunity for a break which can impact on the carer’s health
- Impacts on the whole family
- People don’t know how to engage with people with YOD
- Opportunities for going out with friends decreases
- Circle of friends diminishes
- Meeting others in similar circumstances is of great value in reducing isolation
- Sharing experiences was important
- Suggestion to partner with other organisations to provide services appropriate for people with YOD i.e. Parkinson’s Society

ACTIVITY GROUPS

In response to the expressed needs of people with YOD, two groups were established to provide respite for carers and enjoyable activities, social interaction and exercise for younger people with dementia. Transport is provided to pick people up and drop them off at home after the group, the groups are:

- A younger women’s social group that meets for coffee for two hours each week, 3 or 4 women usually attend
- A weekly mixed-gender walking group that goes to new places

SOCIAL EVENTS

Social events were held to provide a way of providing respite for couples and families. The social events were organised by Alzheimer’s Australia ACT at no cost for people with dementia and their families, travel to and from the events was offered if required.

There has been one dinner for couples and three family events; two cruises on Lake Burley Griffith and a luncheon in the Botanic gardens. The luncheon was primarily organised for the children of people with YOD although some of the parents also attended.
INDIVIDUALISED RESPONSES

The project has extended the support available to young people with dementia through the Respite Links program to assist them to access mainstream activities and services that are of particular interest to the individual.

TRAINING PACKAGE FOR DIVERSIONAL THERAPISTS

Work has started on developing a training package for divisional therapists who work with people with YOD. Literature is being reviewed and the external organisations and staff who would be offered training are being identified. Some agencies are reluctant to engage with people with YOD, for example a men’s shed wanted an Alzheimer’s Australia ACT staff member to be present with the client. Over time they have realised that the attendance of an Alzheimer’s Australia ACT staff member is not required.

WORK TOWARDS ESTABLISHING A YOD-SPECIFIC RESIDENTIAL RESpite SERVICE

Alzheimer’s Australia ACT is continuing to follow-up with Uniting Care the main agency interested in developing residential respite options for people with YOD however, staff changes at Uniting Care have delayed discussions. Alzheimer’s Australia ACT is playing a lobbying, coordinating role in working towards the development of respite options as they are unable to commit ongoing resources to running such a service.

There have been substantial changes to funding arrangements for the Home and Community Care (HACC) program that have also impeded discussions about developing residential respite options. HACC packages for people under 65 years are now funded by the states and, as a consequence, the administration of HACC for people under 65 in the ACT has moved to NSW and is now managed from the Sydney office. It is anticipated that the implications of changes in funding arrangements will be unclear for 12 months.

CHANGES MADE DURING IMPLEMENTATION

The interest of the children of people with YOD in being more involved in Alzheimer’s Australia ACT activities was not anticipated at the start of the project. As a result of the high level of interest a resource package for children is being developed in consultation with the children. Some of the adult children have also volunteered to be involved in fund-raising activities such as the Sydney Marathon which will raise the profile of Alzheimer’s Australia ACT and YOD, and provide additional resources. Alzheimer’s Australia ACT has offered two interested adult children free registration at the Dementia Co-operative Research Centres national conference.

There had been fewer social activities for couples by the end of June than originally planned (one dinner instead of three) and one less social activity for children than planned although ongoing contact with some of the children has been established as described above.

PROJECT OUTCOMES

OUTCOMES FOR PARTICIPANTS

Additional people with YOD are linked into activities; at the start of 2011, Alzheimer’s Australia ACT was working with 17 people with YOD, (plus carers); at June, an additional 5 couples, where one partner had YOD, have participated in the Living with Memory Loss program. People who attend the Living with Memory Loss program are invited to join activities for people with YOD. The walking group was attracting eight people at the start of 2011 and two additional men with YOD have since joined the group.
The walking and coffee groups provide peer support and a pleasant activity for people with YOD and give carers a break. People with YOD discuss their experiences of dementia with others who are in the same situation. One example of the practical support offered by the groups involved a woman who had concerns about remembering family member’s names at an upcoming family function; the coffee group supported her by suggesting that she develop a visual memory aid (a booklet with photos and names) and during coffee meetings the group coached her in recalling the names of family members.

An interview with a couple where the woman has dementia and her husband has given up work to care for her verified the importance of these activities for both the person with dementia and the carer. For the woman with dementia, the weekly group activities have allowed her to maintain independent interests, to get support from peers going through similar experiences and importantly to know that her husband is getting a break. The carer values the few hours of respite that the groups provide, as this gives him time to maintain his own interests and to have a break from the caring role. He expressed the view that without the support of the activity groups and social activities provided by Alzheimer’s Australia ACT many carers would not be able to maintain their caring role over the long term and there would be a higher demand on residential care services.

**FAMILY RE-ENGAGEMENT**

The family events have been important vehicles for supporting families to reconnect. Adult children feel comfortable in an environment where the behaviour of the person with YOD is understood and accepted; they can relax while having time out with their parents.

For some families, communication between adult children and parents has opened up, children are more aware of the impact of dementia and parents are more open about what they are experiencing. The boxed article written by the partner of a man with YOD describes the impact of the family activities on her family.

**Box 1: The Impact of family activities from a Carer’s perspective**

*Article written by the partner of a younger man with dementia for the Alzheimer’s Australia ACT newsletter, reprinted with permission*

In my case, it is my partner Chris who was diagnosed with Alzheimer’s disease, three and half years ago when aged 56. He had difficulty telling his children (aged 24, 20, 18 at the time) about his illness as he wanted to spare his children this devastating news. So to some extent he minimised the implications and its potential impact. He didn’t want them to worry and even though he was scared for himself he was very scared for them and wanted to protect them as he felt a father should. I gave them some handouts but we didn’t discuss their content in detail or if they had read them.

As a result I don’t think the children had any real idea of how this disease affects the sufferer on a daily basis. Often when the children came around there would be conversations about the past, growing up and other lovely things but no conversation about how he was going or the impact of the disease.

It was hard to know what support the children needed, they are after all adults and we could not just send them to counselling. In addition with Chris and I dealing with this disease relentlessly we did not have the energy or resources to support the children unaided and remained unsure how to approach the subject without upsetting everyone.

We have now attended three functions, two dinners and a lunch and have found these social functions wonderful. The children were able to mix with other people and their families that have younger onset dementia in a safe and relaxed environment with staff from the ACT Office on hand. We also had a lot of fun and laughs at these functions.

Both Chris and I have seen a change in the attitude of the children. They appear to have come to a greater understanding of the disease and have been generally been more supportive of their dad and of myself. They appreciate the time spent with him and are quick to assist their dad. They want to help and know that this is important to both of us. We all feel that we can talk more openly and honestly about the disease. This has to be a good thing.
OUTCOMES FOR ALZHEIMER’S AUSTRALIA ACT

Alzheimer’s Australia ACT educators, counsellors, support staff and dementia liaison officers have all been involved with the project and are more aware of the needs of both people with YOD and their carers and families.

Eight adult children of people with YOD came to the luncheon and 3 came forward seeking more involvement, they are interested in developing a resource pack for children of people with YOD and have formed an informal committee of interest. This group are developing a survey to ask what would be useful in a package for children.

Two of the children are assisting with fundraising and publicising YOD by entering the Sydney marathon.

OUTCOMES FOR THE SERVICE SYSTEM

Mainstream services that have engaged with people with YOD with the support of Alzheimer’s Australia ACT have more awareness of the capacity of people with YOD and associated issues.

RESOURCES DEVELOPED OR ACQUIRED

Work has started on developing training for diversional therapists and a resource package for the children of people with YOD.

WHAT HELPED OR HINDERED THE PROJECT?

PARTNERSHIPS

As discussed the staff changes at Uniting Care have meant that discussions about developing YOD specific respite services have been on hold. However, Alzheimer’s Australia ACT will continue working with Uniting Care towards developing appropriate respite.

The project has generated new partnerships between Alzheimer’s Australia ACT and the adult children of people with YOD.

FLEXIBILITY

The project has enabled staff to respond flexibly to the individual needs of people with YOD and to follow up on interest expressed by the adult children of people with YOD to be more involved in the work of Alzheimer’s Australia ACT.

STAFF

Extending the hours of existing staff has meant that the project has drawn on the expertise of existing staff who already had established relationships with people with YOD. Not needing to recruit and train staff enabled the project to commence as soon as funding was available. Alzheimer’s Australia ACT staff members have extended their hours and have been flexible in their working hours in order to be available at social activities on weekends.

LESSONS LEARNT

A more flexible appreciation of respite is needed. The idea of respite as separation needs to be reviewed, in some cases couples are looking for activities the can do together - respite from social isolation rather than respite from the caring role is most important for some couples. Increasing social engagement reduces the caring burden and carer stress.
levels. People realise that they are not in this alone, especially children.

Having established relationships with parents made it easier to engage children of people with YOD; Alzheimer’s Australia ACT had credibility because of links with parents. Engagement was also enhanced by organising activities that were enjoyable and added to the quality of life of the person with dementia and the family. This approach was considered more successful in educating children about dementia than information sessions would have been.

The success of the family social activities in helping families to reconnect is a model that could be adopted by other agencies and Alzheimer’s Australia organisations in other states and territories working with people with YOD.

LEGACY / SUSTAINABILITY

The increased awareness of the needs of children and conceptualising respite as being broader than giving carers a break, through either day activities or residential care, will have a lasting legacy within Alzheimer’s Australia ACT.

Some of the YOD activities that have established through this project may be able to be continued in the short term but recurrent funding is needed to providing ongoing activities specifically for people with YOD and their families and carers. Without ongoing funding more people with YOD would not get access to appropriate services, they would ‘fall through the gaps’.

Once developed, the resource package for children and the training for diversional therapists will be sustainable outcomes. Education can continue to be provided using these resources after the life of the project. Alzheimer’s Australia ACT is also exploring the possibility of linking the diversional therapist training with existing TAFE training courses.

FUTURE PLANS

In the next 12 months the project intends to:

- Develop the resource package for adult children of people with YOD
- Develop and provide training for diversional therapists (staff in external agencies who may have clients with YOD)
- Continue the existing activity groups
- Explore the possibility of establishing an activity group specifically for younger men with dementia to meet the needs of the growing number of men
- Continue to provide social activities for couples and families
- Continue to support people with YOD to access mainstream services
- Continue discussions about establishing an age-appropriate residential respite option
The Northern Territory risk-reduction project targets Aboriginal people and focuses on raising awareness of dementia and how to reduce risks.

Two different education sessions are provided. The first session “What is Dementia”, introduces dementia with the aid of the “Looking out for Dementia” DVD, a resource developed specifically to increase awareness of dementia in Aboriginal communities. The DVD features Aboriginal people and is available in English and 3 Aboriginal languages. An Aboriginal language version is played if participants are from that area, however, if a mixed group, or if from an area that speaks a different language, the English language version is played. The DVD is followed by an interactive discussion and participants are encouraged to discuss dementia and ask questions.

The second session provides information on how to reduce risks using the Mind your Mind education resource and spatial puzzles and visual illusions. This session is very interactive and the puzzles and illusions are very popular.

The sessions are provided to low-security prisoners in Darwin and Alice Springs and to people in Aboriginal drug and alcohol rehabilitation programs in Darwin, Katherine and Alice Springs. A total of 36 sessions were planned. Attendance at the education sessions is voluntary for people in correction facilities and is usually expected for people engaged in drug and alcohol rehabilitation. The sessions are usually held with groups of between eight and 15 people.

There is often considerable negotiation involved in organising the sessions and Alzheimer’s Australia NT staff always need to follow-up and confirm planned sessions. While sessions are scheduled in advance, the project needs to be flexible if there is a need to change dates or venues.

Dementia information and risk-reduction information will be provided to people who have been identified as having a lifestyle which has significant dementia risks. For example: high drug and or alcohol intake; involvement with violence and possible head injury; generally poor education; poor diet; and neglected health checks. The target group will already be involved in some form of rehabilitation or education program through a rehabilitation or correctional facility. It is expected that a high percentage of these people will be Indigenous.

Deliver basic dementia information and risk-reduction strategies to people engaged in drug and alcohol rehabilitation programs in Darwin, Alice Springs and Katherine and to people detained in correctional facilities in Darwin and Alice Springs.

Develop a timetable to allow visits to all participating facilities every three or six months.

Deliver clear, culturally appropriate, information about dementia, its causes and effects on the person with dementia, their family and community at sessions.
EXPECTED OUTCOMES

- Increased awareness about what dementia is and how a healthy lifestyle may contribute to a reduced risk of developing dementia in “at risk” groups.
- Increased understanding about how head injury and drug and alcohol abuse can contribute to an increased risk of developing dementia.
- Increased flow of information about dementia to remote communities in the NT

(Aims, activities and outcomes from project plan)

SITUATIONAL ANALYSIS / CONTEXT

Indigenous communities in the NT

- There is a high prevalence, and low awareness, of dementia amongst Aboriginal people
- There are many Aboriginal languages (approx. 150) used in the Northern Territory. Aboriginal people often understand other Aboriginal languages even though they may not be fluent in using the language. Many people can understand one of a small number of Aboriginal languages
- Low levels of English literacy means that currently available written material is of limited value
- Complexity of Aboriginal cultural practices means that it is easy to inadvertently get something wrong or to shame participants
- 82% of prisoners in the NT are Indigenous and many have links with remote communities

Service system

- Culturally appropriate resources have been developed for raising awareness in aboriginal communities
- The geographic spread and remoteness of many Indigenous communities limits the reach of Alzheimer’s Australia NT’s community education
- There is a high turnover of staff in correctional facilities and drug and alcohol rehabilitation services in the NT. There is a high level of support for the project amongst senior staff and staff on the ground in correctional and rehabilitation services but, as a consequence of staff changes, a lot of follow-up is needed to maintain relationships
- Partnerships are based on relationships between individuals; tend not to develop MOUs or other written agreements. There is a culture of working in partnership because of the relatively small number of organisations
- The project relies on staff in correctional facilities to provide a venue and to promote the education sessions and encourage prisoners to participate

BUILDING ON

This project is building on previous projects that delivered community education to people taking part in drug and alcohol rehabilitation programs and people in correctional institutions. Dementia Community Grants (rounds 1 & 2) provided funding to introduce education sessions in Drug and Alcohol rehabilitation services in Darwin, Alice Springs and Katherine and at Correctional centres in Darwin and Alice Springs.

Agencies where education sessions had been provided valued the sessions and requested that they continue; they have supported Alzheimer’s Australia NT in seeking funds to enable the education sessions to continue.
The project utilises the following resources:

- Looking out for Dementia DVD
- The Alzheimer’s Australia *Mind Your Mind* resource
- 3 dimensional puzzles and visual illusions that are used by other Alzheimer’s Australia NT services

### RATIONALE

There is an urgent need to create awareness of dementia given the low level of knowledge about dementia and the high prevalence of dementia in Aboriginal communities.

People in prison and drug and alcohol rehabilitation services are likely to be more at risk of dementia because of behaviours such as smoking, excessive drinking, violence, and poor diet.

The Northern Territory covers a large geographic area with many small remote Aboriginal communities. Alzheimer’s Australia NT does not have the resources to provide community education in remote communities. Providing information to people in correctional centres and residential drug and alcohol services has been an effective way of reaching people who are at increased risk of developing dementia and who would otherwise be hard to engage.

The presenters work to make the education session relaxed and fun and experience has shown that people attending the sessions are receptive to the information provided and welcome the change in routine.

Reducing the burden of dementia longer term involves minimising risk, recognising signs and symptoms, and getting an early diagnosis so that medication can delay progression. A first step in increasing access to services and reducing risks is to increase awareness of dementia and known risk factors.
IMPLEMENTATION

A new staff member has been recruited to the education team and experienced members of the education team have delivered the presentations at Correctional services and drug and alcohol rehabilitation services.

The table below shows the sessions that have been delivered during the duration of the project.

<table>
<thead>
<tr>
<th>Location</th>
<th>Number of sessions</th>
<th>% of target met</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAAPS Darwin</td>
<td>4</td>
<td>50</td>
</tr>
<tr>
<td>Foundation of Rehabilitation with Aboriginal Alcohol Related Difficulties (FORWAARD) Darwin</td>
<td>6</td>
<td>300</td>
</tr>
<tr>
<td>VENNDALE Katherine Region</td>
<td>4</td>
<td>100</td>
</tr>
<tr>
<td>Darwin Correctional Services</td>
<td>8</td>
<td>100</td>
</tr>
<tr>
<td>Alice Springs Correctional Services</td>
<td>4</td>
<td>100</td>
</tr>
<tr>
<td>Central Australian Alcohol Program Unit (CAAPU) Alice Springs</td>
<td>4</td>
<td>100</td>
</tr>
<tr>
<td>Drug and Alcohol Services Association (DASA) Alice Springs</td>
<td>4</td>
<td>100</td>
</tr>
</tbody>
</table>

CHANGES DURING IMPLEMENTATION

The only changes have been that more sessions than initially planned were delivered at FORWAARD and fewer sessions were delivered at CAAPS. The reduced number of sessions at CAAPS is a consequence of difficulties in getting CAAPS to commit to specific session times. Alzheimer’s Australia NT educators have been available to provide the training and continue to follow up with CAAPS.

OUTCOMES

FOR PARTICIPANTS

On average, there are 7 or 8 participants in each education sessions with opportunities for discussion and questions during the sessions. Alzheimer’s Australia NT staff report that some participants approach them after the presentations to make specific enquires about their own signs or risk level, or about the behaviour of community members. Participants are given information about how to access the service system.

Managers at both Venndale in Katherine and CAAPS in Darwin confirmed that clients are attentive and find the sessions engaging. The interactive puzzles are particularly useful in stimulating interest and involvement.

Alzheimer’s Australia NT, and the rehabilitation services consulted as part of the evaluation, anticipate that this approach will increase awareness of dementia in Aboriginal communities in the Northern Territory. Clients at rehabilitation services generally have a 3 month stay before returning to their different communities with more awareness of the risk factors and the symptoms of dementia.

FOR ALZHEIMER’S AUSTRALIA NT

The education sessions extends the work of Alzheimer’s Australia NT in providing professional education to Indigenous aged care staff and supports continuing contact with the Aboriginal drug and alcohol rehabilitation services and the corrections services.
Alzheimer’s Australia NT was invited to have a stall at an expo day organised by Berimah prison for everyone in low security. Alzheimer’s Australia NT was one of a range of service providers who set up stalls. There was a high level of interest in the Alzheimer’s Australia NT display, with a constant flow of people taking away information and stopping to talk about dementia. The expo was also an opportunity to network with other service providers and increase awareness of the resources offered by Alzheimer’s Australia NT.

**FOR THE SERVICE SYSTEM**

FORWAARD in Darwin has requested that Alzheimer’s Australia NT provide the two education sessions every three months so that the sessions are embedded in their rehabilitation program and all clients learn about dementia and the importance of a healthy lifestyle.

**WHAT HAS HELPED OR HINDERED**

**PARTNERSHIPS**

The project depends on the co-operation of partner agencies that provide a training space and promote the sessions to participants. Cultural sensitivity is essential for developing and maintaining partnerships. Personal relationships need to be developed to support working in partnership, once a good relationship has developed and the organisation has experience of the sessions being provided, word spreads that what’s being provided is worthwhile. The project is maintaining partnerships with the following agencies:

Correctional services:
- Darwin Correctional Centre
- Alice Springs Correctional Centre

Drug and alcohol rehabilitation services:
- CAAPS - Darwin
- FORWAARD - Darwin
- VENNDALE - Katherine
- Drug and Alcohol Services Association (DASA) - Alice Springs
- Central Australian Alcohol Program Unit (CAAPU) - Alice Springs

Organising sessions is far more time consuming than delivering the education sessions; patience and persistence are needed.

**FLEXIBILITY**

It is important that the educators be flexible in making, and changing arrangements for the sessions. For example, in one case a session had been organised at a correctional facility however, when the educators arrived they discovered that the facility had not promoted the session as agreed, however, the teacher of a different class had cancelled and the Alzheimer’s Australia NT educators stepped in and delivered a dementia education session.
STAFF

The project has been implemented by existing Alzheimer’s Australia NT education staff and an additional staff member has been recruited to the education team.

The project staff team are experienced in providing professional training to Aboriginal aged care staff, both in Darwin and in Aboriginal communities. The educators appreciate the complexity of Aboriginal cultures and the importance of being respectful, friendly and approachable.

Having the right attitude - being respectful, is viewed as more important than having experience in dementia education. If new staff have the right attitude they can learn about dementia and be trained to provide community education, being able to develop a rapport with people in the classes is essential.

LESSONS LEARNT

Building rapport with participants at the start of sessions is paramount, it is extremely important to build up a relationship first before delivering education. This involves being friendly and actively encouraging interactions – talking ‘with’ rather than ‘at’ participants.

Trainers break the ice by asking where participants are from, they have often been to the communities that participants come from and can talk about having visited the community. This experience of remote communities helps in building rapport with participants.

Delivery needs to be culturally sensitive, for example, dress is really important and women’s legs need to be covered. The experience of Alzheimer’s Australia NT educators is that the gender of the trainer is not important provided attitudes are respectful.

Understanding Indigenous culture is an ongoing process, as educators learn more, they appreciate how complex the culture is and how they can inadvertently offend or shame without realising it. However, it is not expected that an outsider will have a deep understanding of culture and people are very forgiving if the outsider has the right attitude and is open to learning.

It is important to be aware that English may be a second or third language. Presenters need to be respectful and patient and to learn to wait when there is a delayed response; a natural response is to try to help by offering more information, or saying the same thing in a different way, but this often is not helpful when the person is having to translate what’s been said into their first language, and then translate their response back into English.

While the DVD is a useful prompt for discussion it is important to follow up the information provided by the DVD to ensure that it has been understood and to address questions arising. Including interactive activities such as spatial puzzles and visual illusions heightens engagement.

Partnerships with organisations start with personal relationships, it is important to be flexible and responsive to the need for last minute changes. Making arrangements with organisations is more time consuming than providing the sessions.

Experience gained in other education roles (training aged care and health workers) has developed the skills of staff in working with Aboriginal people and experience gained in implementing the current project informs other training and education programs.
LEGACY / SUSTAINABILITY

The people who have participated in the sessions have some awareness of dementia it is anticipated that over time awareness will spread in communities.

Awareness of Alzheimer’s Australia NT and dementia has increased amongst correctional centres and Aboriginal drug and alcohol rehabilitation services. Some services may utilise the resources to provide information about dementia. However, there are risks associated with this approach if the resources are used without opportunities to discuss and respond to issues arising. The evaluation of the “Looking out for Dementia” DVD highlighted the importance of having people with dementia expertise available to answer questions and clarify any misinterpretations of the information provided.

A resource modelled on ‘Looking out for Dementia’ could be developed with, and for, different CALD communities in different languages.

Providing education to people at high risk by developing partnerships with Correctional centres and Drug and alcohol rehabilitation services could be applicable nationally and particularly in WA and Qld where there are remote Aboriginal communities and a large geographic area to cover.

FUTURE PLANS

There is an ongoing need for education for people in corrections and drug and alcohol rehabilitation services as there is a regular turnover of clients and agencies value the sessions provided by Alzheimer’s Australia NT. Additional funding will enable the sessions to continue to be provided.

Alzheimer’s Australia NT is exploring the possibility of training Aboriginal Health Workers to deliver the education sessions. A few Aboriginal Health Workers would need to be trained as some Aboriginal workers would not be welcomed by some communities, matching the presenter to the community background of session participants would be important. As Alzheimer’s Australia NT would only be able to offer a limited number of hours of work to trained presenters, it may be most feasible to train existing staff of Aboriginal Health Services.

There is potential to collaborate with Aboriginal drug and alcohol services to integrate dementia into a multi-disciplinary approach to reduce risks of dementia and other chronic diseases.

Alzheimer’s Australia NT would like to build on existing relationships, and develop new relationships, with remote communities so that education sessions and follow up can be offered directly to the community members. Work with remote communities requires a commitment to ongoing contact to build relationships, reinforce information and review how messages about dementia have been understood. Alzheimer’s Australia NT provides training for aged care staff in Aboriginal communities and demand exists for community education to be provided alongside the professional training. Initiating community education projects directly with communities would require more resources and a longer time span.

If resources permitted, Alzheimer’s Australia NT would like to work with Aboriginal people to extend the range of resources available; creating culturally appropriate pamphlets in Aboriginal languages, producing DVDs featuring Indigenous people in a wider range of languages and using radio and TV to get messages out in language would be valuable. An aged care co-ordinator from East Arnhem shire has suggested filming some of the role plays currently used in certificate 3 training, in language, for use in community education.
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Alzheimer’s Australia has recently introduced a new national data collection program that all states and territories are using to report on services provided through the National Dementia Support Program (NDSP).

The reporting on services provided through the National Dementia Helpline, Counselling and Support and Education and Training includes data on Aboriginal and Torres Strait Islanders, CALD, Homeless, Rural & Remote, and YOD.

**NATIONAL DEMENTIA HELPLINE CONTACTS**

The number of telephone calls to the National Dementia Helpline and internet inquiries from Aboriginal and Torres Strait Islanders, CALD, Homeless, Rural & Remote, and YOD individuals, as well as whether contact is with people with dementia, carers and families of people with dementia, people with memory concerns, people at ‘known’ heightened risk of developing dementia, or the general public, is recorded.

**COUNSELLING AND SUPPORT SERVICES PROVIDED**

This dataset identifies the number of Aboriginal and Torres Strait Islanders, CALD, Homeless, Rural & Remote, or YOD participants who have:

- attended group counselling sessions and the average number of people per group
- attended one-on-one counselling sessions and the average number of counselling services provided per person
- been referred for counselling

The Counselling and support services data also reports on whether counselling has been provided to people with dementia, carers or family members, or people with early-stage dementia and carers or family members of people with early-stage dementia. However, this data is not cross tabulated with the data on Aboriginal and Torres Strait Islanders, CALD, Homeless, Rural & Remote, or YOD.

This dataset also provides information about the involvement of Aboriginal and Torres Strait Islanders, CALD, Homeless, Rural & Remote people and those with YOD in activities such as social groups, leisure activities, carer support groups, group presentations about dementia and the number of referrals and contacts made to other services. In addition, there is the capacity to describe work done to specifically target specific needs groups. The first report using this new data management system provides useful information but does not yet include details of activities and work with specific groups from all states and territories.

The report on support programs also provides Aboriginal and Torres Strait Islander, CALD Homeless, Rural & Remote, and YOD data about:

- referrals received for early intervention support
- *Living with Memory Loss* programs delivered and the number of participants who attended
- other early intervention programs offered and participants attending
- the number of ongoing support sessions and groups provided and the number of participants who accessed ongoing support groups for people with dementia; and
- on-going counselling and other non-NDSP services.

Numbers of Aboriginal and Torres Strait Islander, CALD, Homeless, Rural and Remote and YOD visitors to Dementia Memory and Community Centres (DMCCs), and participants in activities are provided.
States and territories can also comment on program development and awareness raising activities, the identification of any significant or key additional information needs of the target groups and activities proposed to address these needs, opportunities identified to increase the efficiency and effectiveness of the activities and an assessment of what the Alzheimer’s Australia National Office could do to support national implementation.

**INFORMATION AND TRAINING PROVIDED**

**Information provided**

The information and training database enables reporting for the specific target groups on:

- The number of key community information and awareness events/activities, including (where possible) estimated number of participants
- Major activities and work in relation to Dementia Awareness Week, including media coverage
- Any additional national resources developed (including the library) or planned, how need was identified, and how appropriateness and accuracy of information is ensured
- An overview of resource distribution/availability, identifying the most requested and least requested resources.

**Accredited training provided**

A breakdown of data on specific target groups is included in reports on accredited training provided. Information is provided on:

- the number and type of training courses delivered
- the type of participants - whether people with dementia, carers or family members, Health & Aged Care Professionals, Staff of Service Providers or Community Care Staff
- feedback received on education and training activities; and
- additional or specific education and training gaps/needs identified

The data on Aboriginal and Torres Strait Islander, CALD, Homeless, Rural & Remote, and YOD is not cross tabulated with the type of participant data.

**Non accredited training provided**

Data on specific target groups is also included in reports on the number and type of non-accredited training courses delivered. Data is provided on the number of courses, number of participants and type of participants for:

- non-accredited training for workers
- Family Carers courses
- Community Education courses (including DMCC courses); and
- other activities, including DMCC workshops

The data on Aboriginal and Torres Strait Islander, CALD, Homeless, Rural & Remote, and YOD is not cross tabulated with the type of participant data.
APPENDIX 2 - SUMMARY OF PREVALENCE DATA, RESEARCH, ISSUES AND CURRENT ACTIVITIES FOR ABORIGINAL AND TORRES STRAIT ISLANDERS, CALD, GLBTI AND YOD

ABORIGINAL & TORRES STRAIT ISLANDERS

PREVALENCE OF DEMENTIA AMONGST INDIGENOUS COMMUNITIES

There have been few studies on the prevalence of dementia among indigenous communities in Australia. Smith et al (2008) found the prevalence of dementia among Indigenous Australians (45+ years) in the Kimberley to be 12.4%. This is nearly five times higher than the rate of 2.6% in the general Australian population (Alzheimer’s Australia 2007). It is not known if this rate is the same for Aboriginal and Torres Strait Islander populations in cities and country and towns (Broe et al 2009).

RESEARCH

There is insufficient information about how big the problem of dementia is among Aboriginal and Torres Strait Islander people and what types of dementia affect different people in diverse communities across the country (Broe et al 2009). Runge et al (2009: 38) explain that, “With little data or research available, we are currently uncertain of the extent or ‘shape’ of Indigenous aged care issues including dementia care”. What the research does caution us to be aware of is that the social and health profile of Indigenous Australians show many of the risks associated with a greater chance of developing dementia in later life in non-Indigenous populations (Pollitt 1997; Alzheimer’s Australia 2007; Access Economics 2009a; Broe et al 2009).

Research among rural and remote communities in WA and NT showed that Indigenous males seem to be more affected by dementia than Indigenous females. It also indicates that Indigenous people get dementia at an earlier age (before 55 years) than other Australians (Kingston 2006; Broe et al 2009). While two thirds of Indigenous people live in rural and regional environments, more research is needed into the prevalence of dementia among urban Indigenous Australians (Alzheimer’s Australia 2007).

ISSUES

Very few Aboriginal and Torres Strait Islander people with dementia access mainstream government community programs in comparison to the rest of the population and, as a result, the awareness of dementia and related issues, such as use of early intervention services, is low among Aboriginal and Torres Strait Islander community members (Broe et al 2009: 1). There are many reasons for this:

- Garvey et al (2011) investigated understandings of dementia amongst Indigenous Australians and reported a poor level of understanding of dementia amongst Aboriginal and Torres Strait Islander people and common misconceptions of dementia (this applies to all Australians). This research recommended that culturally appropriate awareness campaigns and education be provided to improve the level of understanding of dementia in Indigenous communities.
- In rural and remote areas, individuals with dementia and caregivers in the community experience ongoing challenges of availability and access to dementia care support services (Pollitt 1997; Broe et al 2009; Centre for Remote Health 2010).
- In urban areas, “many Indigenous people have problems accessing services because they are socially isolated and have personal and health problems affecting their ability to use services” (Broe et al 2009: 2).
- While dementia is perceived and experienced in many different ways, e.g., cognitive impairment in old age is often perceived as normal ‘tiredness’ or ‘childishness’ associated with old age or in extreme cases as ‘madness’ (Pollitt 1997), it is often not recognised as a medical condition and many Indigenous carers and
families are fearful of the medical system (Broe et al 2009). Yet Broe et al (2009: 3) point out that, “communities become very distressed and often call for help when the person with dementia breaks cultural taboos and norms”.

Furthermore, among those who do access services, there are linguistic and cultural barriers to becoming well informed (Centre for Remote Health 2010). Indigenous Australians remain heterogeneous in cultures, languages and histories, reinforcing the need for different models of information exchange about dementia and for offering support to families and carers (Centre for Remote Health 2010). They need staff and services capable of delivering culturally-appropriate health services and care adapted to their language, culture and local circumstances (Broe et al 2009; Centre for Remote Health 2010). There is a need for training in cultural safety, cultural competence and cross-cultural communication at every level of the health service (Nguyen 2008; Davis and Smith 2009; Centre for Remote Health 2010). Solutions to the problem of dementia also need to take account of holistic approaches to wellness including the important elements of family, community and land (Buti 1996; Hampshire et al. 2005; Broe et al 2009). For example, for those who have lived in communities it may be important to have care such that they can continue to be near or in their land and kinship group (Access Economics 2009a: vi).

**CURRENT ACTIVITIES**

- The Kimberley Indigenous Cognitive Assessment (KICA) Tool was validated to assess cognitive status among older Indigenous people of the Kimberley in Western Australia (LoGuidice et al 2005). Its use has also been validated in the Northern Territory, and Marsh et al (2006) recommend that the KICA tool be used in other remote and regional areas such as Northern Queensland and the Pilbara. An equivalent tool for urban Aboriginals is also under development (Runge et al 2009)
- One of the programs which will be using KICA assessment is the mobile Adult Health checks, which aim to reduce barriers in accessing health and social services (Alzheimer’s Australia 2010b)
- The Australian Government has funded, through Alzheimer’s Australia, the development of a Dementia Learning Resource for Aboriginal and Torres Strait Islander Communities in order to increase the awareness and understanding of dementia among Indigenous people (Alzheimer’s Australia 2007)
- Alzheimer’s Australia is developing an on-line interactive learning tool for Aboriginal and Torres Strait Islander Health Workers (Alzheimer’s Australia 2010b)
- A set of resources called “Looking out for Dementia” has been developed by Alzheimer’s Australia NT, in consultation with ATSI key stakeholders, to inform Indigenous people living in remote communities of Northern Territory about dementia (Alzheimer’s Australia 2010b)
- National Aboriginal Torres Strait Islander Dementia Advisory Group has continued work on four priority areas including: community awareness and risk reduction; workforce training; research; and development of partnerships and collaborations (Department of Health and Ageing 2010).
**PREVALENCE OF DEMENTIA AMONGST CALD COMMUNITIES**

**Table 5: Projections of dementia prevalence (people)**

<table>
<thead>
<tr>
<th></th>
<th>2010 Total</th>
<th>CALD</th>
<th>CALD % of all people with dementia</th>
<th>2050 Total</th>
<th>CALD</th>
<th>CALD as % of all people with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td>87,961</td>
<td>12,926</td>
<td>14.7</td>
<td>341,414</td>
<td>46,427</td>
<td>13.6</td>
</tr>
<tr>
<td>VIC</td>
<td>65,844</td>
<td>12,623</td>
<td>19.2</td>
<td>275,237</td>
<td>39,752</td>
<td>14.4</td>
</tr>
<tr>
<td>QLD</td>
<td>46,888</td>
<td>3,191</td>
<td>6.8</td>
<td>258,316</td>
<td>13,538</td>
<td>5.2</td>
</tr>
<tr>
<td>SA</td>
<td>23,102</td>
<td>3,035</td>
<td>13.1</td>
<td>80,774</td>
<td>6,499</td>
<td>8.0</td>
</tr>
<tr>
<td>WA</td>
<td>23,023</td>
<td>2,850</td>
<td>12.4</td>
<td>125,292</td>
<td>10,254</td>
<td>8.2</td>
</tr>
<tr>
<td>TAS</td>
<td>6,569</td>
<td>245</td>
<td>3.7</td>
<td>26,278</td>
<td>464</td>
<td>1.8</td>
</tr>
<tr>
<td>NT</td>
<td>791</td>
<td>208</td>
<td>26.3</td>
<td>6,371</td>
<td>1,086</td>
<td>17.0</td>
</tr>
<tr>
<td>ACT</td>
<td>3,111</td>
<td>476</td>
<td>15.3</td>
<td>17,008</td>
<td>1,563</td>
<td>9.2</td>
</tr>
<tr>
<td>AUST</td>
<td>257,275</td>
<td>35,549</td>
<td>13.8</td>
<td>1,130,691</td>
<td>119,582</td>
<td>10.6</td>
</tr>
</tbody>
</table>

Source: Access Economics (2009a)

**RESEARCH**

People from CALD backgrounds constitute a significant proportion of the older Australian population and they are ageing rapidly. Victoria has the highest proportion of CALD communities (Alzheimer’s Australia Vic 2008).

Cheng and other researchers (2009) have identified the gaps in knowledge on dementia in persons from CALD backgrounds and have made suggestions about future research directions, such as the need for conducting a longitudinal prevalence and incidence study of dementia in CALD people in Australia, and also examine the types of dementia and service use. This should also include an investigation of risks factors associated with dementia and the specific care needs required (Access Economics 2009a).

For a CALD person with dementia and their carer, it may be important to have resources available in their own language, and in their own home, that are culturally appropriate (Access Economics 2009a: vi).

**ISSUES**

While different issues affect different individuals and different communities in regards to dementia, there are some common issues identified by members and workers of CALD communities. These include:

- Lack of knowledge about dementia, its causes and its symptoms (Alzheimer’s Australia Victoria 2008)

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2 The 2009 Dementia prevalence projections were revised down by Access Economics in a later report in 2010.
Late diagnosis of dementia often at crisis point, due to lack of knowledge about the early symptoms of dementia, where to go for help or being ashamed of being labelled (Alzheimer’s Australia Victoria 2008)

Variations in perceptions of dementia: an illness, a normal part of ageing, a mental illness or having no meaning at all in some communities (Alzheimer’s Australia Victoria 2008). Differences in perceptions regarding dementia have implications for recognising those with dementia and developing and implementing formal care within the community and in residential care facilities. For example, individuals and their carers from CALD backgrounds have less information about formal community services, lower utilisation rates of community services and lower access to respite care (Schofield et al 1998; Ward et al 2005; Thomas et al 2007)

Stigma associated with dementia resulting in people being marginalised and isolated from their communities and sometimes from family members (Alzheimer’s Australia Victoria 2008)

Communication problems caused by low literacy levels in English language as well as in their own language. With the onset of dementia they may lose what English skills they have and revert to their native language (Lewis and Kirchener 1996; Department of Human Services 2004; Alzheimer’s Australia Victoria 2008; Runge et al 2009). This phenomenon complicates the provision of appropriate services and highlights that service provision be tailored so that care can be provided by multi-lingual carers (Access Economics 2009a)

Lack of knowledge or acceptance of the service system. People from CALD communities are often unfamiliar with dementia services and aged care services in general and how to access them. This is often due to language barriers, lack of culturally appropriate services or strong preconceived ideas of the type of services that are available (Alzheimer’s Australia Victoria 2008). For example, some ethnic groups are strongly opposed to putting family members into residential care, preferring community care instead (Australian Institute of Health and Welfare 2007a; Australian Institute of Health and Welfare 2007b; Alzheimer’s Australia ACT 2010). Also Access Economics (2009b) found that residential aged care (RAC) facilities that can accommodate diverse cultural backgrounds and recreational needs on an individual basis were highly valued by informal carers.

Misconception that most people from CALD communities are cared for by family members which is not always the case (Alzheimer’s Australia Victoria 2008).

CURRENT ACTIVITIES

New National Resources developed for specific CALD communities involving the expansion of translated resources into languages with smaller ethnic populations, including Lao and Romanian communities (Department of Health and Aging 2010: 20).

Alzheimer’s Australia Vic provided service access with: Russian Jewish community information day, signing of an Accord with Victorian Multicultural Committee and three CALD organisations, tour of Alzheimer’s Australia Vic services for Spanish-speaking seniors, a post-Ramadan ‘rest to remember’ dementia awareness raising even, Alzheimer’s Australia Vic services tour for Filipino Advisory Council for Elders, Romanian ‘Tastes to Remember’ event. (Department of Health and Aging 2010: 20).

Vietnamese seniors tour of Alzheimer’s Australia Vic services, Assyrian and Arabic-speaking seniors tour of Alzheimer’s Australia Vic services, Eastern region Chinese Social Club visit, Finland Tastes to Remember event. (Department of Health and Aging 2010: 20).

The National Cross Cultural Dementia Network (NCCDN) has focused on five priority areas: improving advocacy and empowering consumers; ensuring better quality dementia care for people from CALD backgrounds; increasing awareness and understanding of dementia across cultures; identify effective strategies for preventing and delaying the onset of dementia; and develop a strong, dynamic, unified Network (Department of Health and Aging 2010: 21-22).

NCCDN members support local state Dementia Community Grant program, namely SA, Victoria and NSW. They also encourage CALD consumers to participate in the Alzheimer’s Australia consumer groups and provide feedback on CALD issues (Department of Health and Ageing 2010: 21).

NSW NCCDN representative and NCCDN Secretariat are part of the research team for the project being conducted by the University of Queensland and South West Sydney Area Health Service, Family care-giving
for culturally and linguistically diverse (CALD) people living with dementia, the focus being on CALD family care-giving with dementia for Arabic, Chinese, Italian and Spanish speaking communities living in South West Sydney. (Department of Health and Aging 2010: 22).

- Additional languages have been added to the range of translated Help Sheets, the NCCDN through the SA office, assisted in the translation of the Latvian help sheets. (Department of Health and Aging 2010: 22).

**GAY LESBIAN BISEXUAL TRANSGENDERED & INTERSEX**

**PREVALENCE OF DEMENTIA AMONGST GLBTI PEOPLE**

Access Economics (2010) estimates an increase in the total number of people with dementia in Australia from 256,500 (2010) to 981,000 (2050). Assuming that 8%\(^3\) of people with dementia may be non-heterosexual the number of gay, lesbian, bisexual, transgender, intersex people with dementia could increase from 20,520 in 2010 to 78,480 people in 2050.

**RESEARCH**

- There are very few in-depth studies on GLBTI people and dementia in Australia: significantly, a paper was conducted by Birch in 2009 for Alzheimer’s Australia and researchers Barrett (2008; 2010) and Leonard (2002; 2008) have produced a number of important studies on GLBTI Victorians.
- 46% of GLBTI people in Australia live alone, as compared to 23% of the general population (Kirby 2009).
- 20% of HIV positive people will develop HAD (HIV Associated Dementia) also known as ADC (AIDS Dementia Complex) (eMedicinehealth 2011).

**ISSUES**

- GLBTI Australians have specific needs that arise from their experiences of social marginalization and discrimination. For example, a recent survey of prejudice-motivated violence against GLBTI Victorians concluded that GLBTI people are subject to much higher levels of harassment and abuse than the general population and that the threat of such violence is part of GLBTI people’s everyday lives (Leonard et al 2008). The effects of this discrimination include poorer health outcomes (Leonard 2002), reduced social participation and community engagement (Gray and Leonard 2009) and GLBTI people avoiding or delaying seeking care because of actual or perceived prejudice on the part of health care providers and institutions (Leonard et al 2008).
- Although lesbians and gay men face many of the same challenges around dementia as heterosexuals they may also face additional challenges such as social isolation, relationship recognition and steering through a complicated legislative environment (Birch 2009; Alzheimer’s Australia 2010a).
- Significantly, many lesbians and gay men who are now facing a dementia diagnosis became adults at a time when social and legal discrimination was prevalent. As a consequence, the invasion of privacy that community services and residential care may involve can create a fear of coming out to services providers and may lead to anxiety and depression (Barrett et al 2009; Birch 2009; Alzheimer’s Australia 2010a).
- ‘Family’ can be a concept fraught with complex emotions for lesbians and gay men of any age. Who is regarded as family can vary greatly depending on the personal situation and experience of each individual. Lesbians and gay men may refer to their ‘family of origin’ which may or may not be a part of their everyday lives, and their ‘family of choice’ which may include a same-sex partner and/or members of the lesbian and

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3 This is a midway estimate between the 2%–15%, range in the percentage of the Australian population that identified as non-heterosexual found by Smith et al (2003).
gay community (Birch 2009: 14). This complexity leads to issues around assumed roles and responsibilities of the different people that make up a ‘family’.

- Issues for service providers and care workers to be aware of include: the sensitivity around collecting information about a person’s everyday life and support systems so as to attempt to provide quality care services; accepting support via community care may mean independence and personal privacy is threatened; aged care information may be based on an assumption that all people who use the service will be heterosexual; there may be potential issues of acceptance of lesbians and gay men by their fellow residents in aged care facilities; there are difficulties relating to sexuality faced by lesbians and gay men living in residential aged care facilities; there are special issues for transgender people with dementia as well as late-stage care issues (Barrett et al 2009; Birch 2009).

- Barrett (2010) explains that some older GLBTI people need staff to understand that the grief and loss involved in having a same-sex partner with dementia is no less than that experienced by heterosexual couples. Sexual and cultural expression is important for the mental health of older GLBTI people. A positive response to the disclosure of sex/gender identity can result in GLBTI seniors feeling understood, valued and safe.

**CURRENT ACTIVITIES**

- A new Queensland study, led by Mark Hughes and Sue Kentlyn, is looking at the diversity of the care networks of lesbian and gay people aged 60 and over, and how care providers respond to this person’s sexual identity. The research involves interviews with the older lesbian or gay person, as well as their paid and unpaid carers (Hughes 2009).

- New research leading to a public information program and new resources on gay men, lesbians and dementia (Department of Health and Ageing 2010: 21).

**YOUNGER ONSET DEMENTIA**

**PREVALENCE OF YOUNGER ONSET DEMENTIA**

Access Economics (2010) estimates that YOD affects approximately 16,000 people in Australia today, which is approximately 6.2% of the total population with dementia. The total number of people is predicted to increase to 26,938 in 2050.

**RESEARCH**

People with YOD have been researched to a greater degree than other special population groups (Runge et al 2009). YOD comes in many forms. Each type of dementia has its own signature of symptoms, signs and findings on investigation, and is caused by a specific type of pathology in the brain. A breakdown of the main causes of YOD is as follows: Alzheimer’s disease, Vascular dementia, Frontotemporal dementia, Dementia with Lewy bodies and Other (Hodges et al 2009: 5). Alzheimer’s disease remains the most common form of dementia even in adults under the age of 65 years and accounts for around 30% of all cases of YOD (Hodges et al 2009: 5). Frontotemporal dementia is the second most common degenerative disease causing dementia in younger adults. The age of onset is typically in the 50s or 60s but can be as young as 30 (Hodges et al 2009: 6).

**ISSUES**

- Timely and accurate diagnosis is particularly problematic for younger people because there is low awareness of YOD among health professionals, limited access to specialist diagnostic service and a lack of awareness of the availability of genetic testing (Access Economics 2010). In many instances, accurate diagnosis can take several years because symptoms are often attributed to other conditions, such as stress or depression (Runge et al 2009; Access Economics 2010). Also, younger people are less likely to be referred
to a psychogeriatrician more familiar with the symptoms, and more likely to be referred to a neurologist (Ferran et al. 1996; Luscombe et al. 1997).

- While many of the needs of younger people with dementia are similar to those of older people, there are significant differences primarily because of the life stage at the onset of dementia. For example, YOD is likely to impose greater financial stress because the person is often in employment, and the onset of dementia may result in a demotion, early (unplanned) retirement, or sale or failure of a business. This can generate a large emotional and financial burden from needing to leave employment unexpectedly (especially if that person is still supporting a family), or the need for a spouse to leave employment in order to provide care. Furthermore, people with YOD require access to dementia specific legal advice and specialist financial advice for future planning that is in line with their future health and personal care instructions. (Access Economics 2010: 36)

- Main issues for people with YOD and their carers include: challenging behaviours, activities of daily living, sexuality, employment, driving and common drug treatments (Hodges et al 2009).

- Caring for someone with a YOD can be very challenging and stressful. Carers experience psychological problems, financial worries, loss of employment and family conflict, and their children are affected. Also carers use support services, but express some dissatisfaction with the appropriateness and availability of such services (Luscombe et al 1998; Runge et al 2009). Due to being more generally active, mobile and physically capable, a younger person is more demanding than caring for an older person (Hodges et al 2009). The act of caring for someone with YOD can lead to a change in relationships and carers may feel a sense of resentment that comes with the responsibility of looking after someone (Hodges et al 2009).

- The provision of age-appropriate care and support is an important issue for people with YOD. With a low prevalence among people under 65 years of age, dementia services are structured to support the needs of older clients. Once a diagnosis has occurred, it is hard to obtain appropriate care, as dementia support packages are tailored towards the elderly and do not account for young people who are physically active (Ferran et al. 1996; Luscombe et al. 1997; Hodges et al 2009; Runge et al 2009). Entering high-level aged care at a young age is also demoralising for both the person with dementia and their family. In 2008, COAG agreed that responsibility for this group should be included under a new National Disability Agreement (Access Economics 2010).

- Greater support is required in the community care setting to enable younger people with dementia to continue to combine work and family responsibilities (Access Economics 2010).

- There is a significant risk of younger people with dementia being shifted between disability and aged care services. When disability services are no longer able to meet a younger person’s needs due to the progression of dementia, the person and their family carers are required to navigate a second unfamiliar system (Access Economics 2010).

- The progression of dementia in younger people can be quite rapid. The challenge is to develop a smooth and seamless service. One option might be to remove age limits for access to aged care services for those with dementia, and to ensure the services received are appropriate. (Access Economics 2010: 37)

**CURRENT ACTIVITIES**

- A variety of media tools have been used to promote awareness of people with YOD and their needs. Consumers have been key players in television current affair programs which have highlighted the issues (Department of Health and Aging 2010).

- Much of Alzheimer’s Australia’s energy has recently been directed to understanding the decisions taken by COAG on disability services and the consequences for people with YOD (Alzheimer’s Australia 2010a).

- The quarterly newsletter HOPE provides a forum and information base for consumers and health professionals with an interest in YOD. A national list of service providers who are funded to provide YOD specific services has been drawn up as a baseline for measuring future increases to service provision. This is to be reviewed annually, and is distributed in HOPE (Alzheimer’s Australia 2010a).
Discussion on the accuracy of statistics concerning YOD in Australia. The most recent Access Economics report (2010) estimates are based only on UK figures, and is approximate in that it does not capture those with YOD who go undiagnosed or misdiagnosed (Department of Health and Ageing 2010).

NDSP funding, supplemented by a donation, has resulted in the development of several initiatives in Victoria: YOD Reference Group, people with YOD and their carers meet regularly to identify issues, discuss needs and advise on service development; Linking Lives project, producing Tip Sheets specifically for younger people with dementia to supplement the tip sheets available nationally, and is now focused on a ‘key worker’ pilot model that is testing the effectiveness of individually-based support; this model responds to the need for more individualised support arising from the diverse range of dementias that occur in younger people and each person’s different circumstances; and Hospital services enhancement, a partnership has been developed between Alzheimer’s Australia Vic counselling services and the Royal Melbourne Hospital (RMH), including Registrar rotations through Alzheimer’s Australia Vic and counsellors attending RMH clinics to provide support following a diagnosis (Department of Health and Ageing 2010: 21). The current Victorian YOD project included in this evaluation is extending this work.
APPENDIX 3 – STAKEHOLDERS CONSULTED

QLD SPECIAL NEEDS ACCESS PROJECT
David Cass - 60 and better, Cooktown

SA GLBTI COMMUNITY PROJECT
Paul Stone - Befriend
Anna – Aged and Community Care Association

WA CALD PROJECT
Therese De Luce – Manager, Strategic Learning & Growth, Brightwater Care Group (Inc)
Marie Redman – Clinical Training Consultant, Uniting Church Homes

NSW TWEED SECTOR DEVELOPMENT
Suzanne Raabe, - Tweed Valley GP Network
Atosha Clancy and Angela Ryan – Tweed Valley Dementia Outreach Service

NSW CALD / ABORIGINAL AND TORRES STRAIT ISLANDER
Project did not provide contact details for staff at ethno specific partner agencies

NT RISK-REDUCTION ABORIGINAL AND TORRES STRAIT ISLANDER PROJECT
Colleen Clive Griffin – Education manager, Venndale Drug and Alcohol Rehabilitation Service, Katherine
Pamela – Services manager, CAAPS Darwin

VIC ABORIGINAL AND TORRES STRAIT ISLANDER
Harry Douglas, Planned Activity Group Coordinator, Aboriginal Community Elder Service

VIC CALD
Nicky Tsolakis - Aged Migrant Connections Project Officer, North East Multicultural Association, Wangaratta

VIC YOD
Mandy Lovell - Director of the Lovell Foundation and wife of person with YOD

ACT YOD
Two consumers, a couple where the wife has YOD and her husband is her carer