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Executive Summary

Success Works was commissioned by Alzheimer’s Australia Vic (AAV) to develop new service models for the provision of responsive, best practice counselling and support for people with Alzheimer’s disease and other forms of dementia and their families and carers.

A key component of the project was to conduct action research to pilot new modes of delivering counselling and support. Four projects were implemented:

- **Online counselling**: using one-to-one text-based counselling, via the internet, in real time to provide session times when counsellors are available as an alternative to more traditional ‘face-to-face’ counselling.

- **Online services for people with younger onset dementia**: providing an online forum for people with younger onset dementia and their families and carers; and an informal ‘chat’ room including moderated discussion groups.

- **A comparison of face-to-face vs. telephone-based counselling**: providing either telephone, face-to-face or a combination of both modes of counselling.

- **Culturally and linguistically diverse (CALD) best practice counselling**: ensuring that clients from CALD communities have access to tailored and timely support services, through the establishment of sustainable relationships between AAV and the communities. (Note: this project received three year funding via a charitable trust in late 2010).

A Background Paper addressing current practices in dementia counselling was developed to inform these projects. A copy of the paper is provided at Appendix A.

The paper includes a discussion about:

- The incidence and prevalence of dementia in Victoria based on latest statistics
- The role of Cognitive, Dementia and Memory Services (CDAMS) clinics in Victoria
- The impact of dementia on carers and family members as well as those with dementia
- Some trends in the literature on how best to support people with dementia and their families and carers
- The ways in which dementia affects different population groups
- The use of technologies to provide counselling and support for people with dementia and their families.

Qualitative data was collected in three rounds for each action research project, including interviews with clients involved in the projects. An online survey was also available for clients participating in the online projects to report on the experience, however this proved to be less successful in gaining feedback.
Quantitative program data from AAV and CDAMS currently provides some limited insight into current and projected service demand. The Department of Health is developing documentation to build upon the existing CDAMS practice guidelines (2006) and the health independence programs (HIP) guidelines (2009). This work will strengthen a defined point of access to CDAMS and timely dissemination of referrals. Together with the CDAMS data collected through the Victorian Integrated Non-Admitted Health (VINAH) system, this should provide a sound basis for collaborative strategic planning between CDAMS and AAV, in terms of referral and access pathways and projected service demand.

The initial workshop for each project was held in late 2009 with the projects operating during 2010. Whilst the pilot projects each attracted a small number of clients and ran for a limited duration (around four months), project staff and clients expressed a high level of support for the online counselling and online forum in particular. The online projects and the CALD project were also described as generating a high degree of enthusiasm and energy. Team members of these projects reflected on a range of learnings they had acquired during the projects and ideas they had for the future.

Generally staff and clients experienced little trouble with the technology created to support the online projects, though they reported that having tip sheets and telephone support available, should they experience difficulty, would be useful in the future. A number of staff reported a marked increase in their level of comfort with, and knowledge of, technology.

The projects have been effective in raising awareness amongst staff involved in the projects, of the potential that new service modes provide in meeting the needs of carers and family members who are unable or unwilling to access traditional forms of counselling and support provided "face-to-face" in offices or their own homes. Each of the project teams was able to identify a cohort of carers who they felt could benefit from the new modes of service.

At the end of December 2010, the CALD project is still at an early stage of its three year timeframe. However, even at this early stage, the assertive outreach approach adopted for the CALD project is showing a way forward in engaging with potential referral points, and increasing the awareness of dementia and the support available via AAV. The project has made a very successful start in connecting with four communities and supporting them to develop plans for 2011.

The report concludes that there is enough evidence from the literature and the findings of the action research projects to integrate the new modes of counselling and support into the suite of services provided by AAV. This is in line with current Department of Health expectations in Victoria regarding the provision of responsive, integrated and flexible service provision.
The report makes nine recommendations to build upon AAV's desire to provide contemporary counselling and support services that will meet the needs of a growing and diverse client group.

Recommendation 1
- That AAV seeks discussions with funding bodies about:
  - Future resourcing needs to respond to a growing demand and to deliver a more contemporary suite of services tailored to identified needs
  - The establishment of a steering group to scope the feasibility of creating a national online community incorporating both an online forum and chatroom.

Recommendation 2
- That AAV shares their growing experience and expertise with new modes of counselling and support with referral and access partners and explore ways to strengthen referrals, particularly with CDAMS. Such joint planning should be supported by the Department of Health’s new practice guidelines and data systems.

Recommendation 3
- That AAV integrates the provision of new modes of counselling and support by:
  - Explicitly providing, and promoting the availability of, telephone counselling
  - Implementing online counselling as an ongoing option available to clients
  - Reactivating the online forum, and promoting it widely.

Recommendation 4
- That AAV considers the professional development and infrastructure needed to encourage staff to broaden their skills, confidence and experience providing telephone and online counselling such as dedicated rooms that are networked and set up with IT equipment.

Recommendation 5
- That AAV investigates collaboration with agencies also providing telephone and online counselling and support services.

Recommendation 6
- That AAV develops a future staffing profile, considering the diversity of staff and skills needed in five years and the recruitment strategies needed to attract and retain a more diverse workforce to support the provision of counselling and support through a range of service modes.
Recommendation 7

- That AAV shares the learnings from the CALD project at key points in the life of the project with AAV staff, interstate counterparts, and other referral and access points.

Recommendation 8

- That AAV commences some initial discussions with key Indigenous organisations to gauge their level of interest in working together.

Recommendation 9

- That AAV reviews data collection systems (including: recording telephone counselling services provided; and establishing base line data of services provided to CALD communities) to ensure future service planning is supported by reliable data.
1. Introduction

Success Works was commissioned to develop new service models for the provision of responsive, best practice counselling and support for people with Alzheimer’s disease and other forms of dementia and their families and carers.

The new models of service will be applicable to:

- Alzheimer’s Australia Vic’s (AAV) counselling and support services
- Alzheimer’s Australia’s other State and Territories support services
- Other service organisations working with people with Alzheimer’s disease and other forms of dementia that would benefit from the knowledge and findings of this project
- Other community services supporting people with ageing and disability issues e.g. Carers Australia, Vision Australia, Council On The Ageing etc.

The objectives of this project are to:

- Document:
  - Current service demand
  - Projected service demand
  - Current service capacity in AAV and the Cognitive Dementia and Memory Services (CDAMS), Victoria’s specialist assessment and diagnostic services
  - The benefits of early diagnosis and early support for families, including cost benefit
  - Evidence of best-practice service models.

- Undertake action research to pilot service innovations, evaluate them and refine the most effective and cost-efficient models.

- Ensure the models meet the needs of diverse groups including: people who are geographically and/or socially isolated; people from culturally and linguistically diverse (CALD) backgrounds and Aboriginal and Torres Strait Islander communities; and people who are diagnosed as ‘young’ (under 65).

- Analyse the impact of applying new models of service in terms of addressing unmet needs and increasing demand.

- Develop a report on the findings from the action research and analysis to enable their application with government and with other related services.

During 2010 AAV piloted new counselling and support service models, using an action research approach.

The main purposes of conducting the action research projects were:
To be responsive to emerging consumer needs in Victoria such as: more "daughter carers" in the workforce; and the higher incidences of younger onset dementia that emotionally impacts the younger children of people with a diagnosis of dementia at a younger age

To be person and family-centred, with the development of responsive support services to meet the needs of diverse groups including: people who are geographically and/or socially isolated; people from CALD backgrounds; and Aboriginal and Torres Strait Islander communities

To be cost-efficient, enhancing sustainability

To be priority-issue focused

To be proactive in addressing unmet needs associated with the emerging dementia epidemic.

The four action research projects were:

**Online counselling:** using one-to-one text-based counselling, via the internet, in real time to provide session times when counsellors are available, as an alternative to more traditional ‘face-to-face’ counselling.

**Online services for people with younger onset dementia:** providing an online forum for people with younger onset dementia and their families/carers; and an informal ‘chat’ room including moderated and facilitated discussion groups.

**A comparison of face-to-face vs. telephone-based counselling:** providing either telephone, face-to-face or a combination of both modes of counselling.

**CALD best practice counselling:** ensuring that clients from CALD communities have access to tailored and timely support services, through the establishment of sustainable relationships between AAV and the communities. (Note: this project received three year funding via a charitable trust in late 2010).

Chapter 2 of this report provides a summary of the Background Paper prepared to inform the action research projects. It also contains a discussion of program data collected from AAV and CDAMS.

Chapter 3 outlines the action research methodology undertaken for this project and includes a discussion of the limitations of the data collected.

The data findings for each action research project are compiled in Chapter 4, and a discussion of the key themes arising is provided in Chapter 5.

Chapter 6 provides a conclusion and recommendations for further consideration.

Appendix A contains the full version of the Background Paper. Appendix B provides a more comprehensive picture of the program data supplied by AAV. Appendices C & D provide a list of those interviewed and the interview schedules respectively. A bibliography can be found at Appendix E.
2. Background

This chapter provides a summary of the Background Paper prepared to inform the action research projects piloting new service models, and a summary of program data provided by AAV and CDAMS.

2.1 Summary of Background Paper

The Background Paper addresses current practices in dementia counselling that demonstrate merit and bear consideration for AAV. The paper includes a discussion about the incidence and prevalence of dementia in Victoria based on latest statistics; the role of CDAMS clinics in Victoria; the impact of dementia on carers and family members as well as those with dementia; some trends in the literature on how best to support people with dementia and their families; the ways in which dementia affects different population groups; and the use of technologies to provide counselling and support for people with dementia and their families.

One of the key findings is that there are very few rigorous studies and evaluations conducted on counselling specifically in the field of dementia that replicate previously successful studies and/or use randomised sampling, especially in the Australian context. The Background Paper highlights that the accumulated ‘practice wisdom’ within Alzheimer’s Australia nationally, including Victoria, is a valuable resource in the area of dementia counselling.

Incidence and prevalence

Dementia is the leading single cause of disability in older Australians (aged 65 years or older) and accounts for one in every six years ‘lost’ to disability. It is one of the fastest growing sources of major disease burden, expected to overtake coronary heart disease in its total wellbeing cost by 2023 (Access Economics 2009).

It is estimated that there are approximately 20,000 new cases of dementia in Victoria in 2009. Incidence is projected to increase by 400%, reaching 94,000 per year by 2050’ (Access Economics 2009). This is due primarily to the ‘ageing population’ phenomena and the timeframe when ‘baby boomers’ are entering the aged care system en masse.

South Australia, Tasmania, New South Wales and Victoria have the oldest population profiles in Australia and high incidence rates and prevalence of dementia, as a percentage of its population. Around 69% of Victorians with dementia, or about 45,000 people, live in

1 Note that neither Access Economics 2009 or 2010 publications provide 2020 estimates for incidence.
metropolitan areas (Access Economics 2009). In regional Victoria, the older population profile tends to mean a higher proportion of the population has dementia.

**Role of Cognitive, Dementia and Memory Services (CDAMS)**

CDAMS provide a primary entry point for people with dementia or memory loss into the service system, thus influencing AAV’s counselling and support work and the data on which service planning is based. If dementia is diagnosed as early as possible, then research shows that the person with a diagnosis and their carers and families have a greater possibility of planning for their future and of availing themselves of the help, support and treatments available.

CDAMS provides diagnosis and assessment of the psychological, medical and social difficulties associated with memory changes. It aims to provide information and advice on management and referral to other services as appropriate. CDAMS does not provide ongoing treatment, support or case management.

The following issues in relation to the current system were raised during consultations with CDAMS staff for this project:

- People with dementia are continuing to access CDAMS relatively late in the advancement of their dementia
- The introduction of a centralised point of access has meant referral pathways into CDAMS can be problematic, with people who need the service not gaining timely access, and people incorrectly placed on a CDAMS waiting list experiencing delayed access to the appropriate service/s
- There are lengthy waiting times for a CDAMS assessment (2 – 6 months) and depending on their circumstances, some people may need additional support in the meantime.

A concern expressed by CDAMS staff and others working in the dementia field is that despite increasing awareness in the community, people are still receiving their dementia diagnosis after the disease is already quite advanced. This is particularly problematic for people who have other compounding health concerns, are socially or geographically isolated and/or who have English as their second language.

CDAMS staff also noted people usually require encouragement to access supports available immediately post diagnosis and that a crisis situation later often precipitated the first contact with support services.

The consultations with CDAMS coordinators around Victoria have found resourcing issues that require the close attention of government in order to ensure that people with dementia and their families receive the services they need, and that the research agenda for dementia remains relevant.
This is supported by Access Economics research that noted the absence of additional dementia-targeted funding in the 2010-11 Federal Budget, without which services like CDAMS will be restricted in their ability to provide timely and accurate diagnoses of dementia (Access Economics 2010).

**Impact of dementia**

The ageing population is a global phenomenon that has contributed to an increase in dementia diagnoses, brought about largely through advances in science and medicine that assist people to live longer. Medical technology has also advanced the ability to diagnose dementia and other dementia-related illnesses.

Early intervention is an optimal strategy because the person with a diagnosis is likely to have their level of function preserved for a longer period and people being cared for at home ‘incur less societal cost than those who require long-term institutional placement’ (Leifer 2003). Institutional care was estimated at 2003 in the USA to be $100 billion annually (Leifer 2003) and 7 billion pounds in the UK (Knapp et al 2007).

A UK report on early intervention, *Making the Journey Brighter* (Alzheimer Scotland 2003) argues the case for the rapid development of early intervention services for people with dementia. With improved diagnosis, treatment and increased public awareness of dementia, people are being diagnosed sooner. However, their need for information, support and therapeutic intervention, and their families’ needs for information and support, are not yet being properly met.

A number of studies provide increasing evidence that there are important benefits associated with early intervention for people living with dementia, their carers and families. A range of early intervention programs demonstrate promising benefits in providing information about diagnosis and prognosis, reinforcing coping strategies, crisis prevention, advice and memory management programs. Carer wellbeing is shown to lessen the likelihood of the breakdown of home care and increase coping skills of carers and families, minimising the need for care settings and respite.

People in the early stages of dementia may not at first need to be cared for, and family members are unlikely to consider themselves in the role of ‘carer’. Their role at first may be more that of a ‘supporter’. Early support can help to reduce the risk of carer stress at later stages. There is evidence that early medical and psychosocial interventions not only improve the wellbeing of the person with dementia and their carer and family but delay the need for institutionalised care later in the illness.

The mental health impacts for the carers and family members of people living with dementia have been well documented (Brodie and Gadling-Cole 2003; Joling et al 2008; Goldman 2001; Gutheil and Chernesky 2001); the positive benefit of offering counselling and support to reduce depression is also well documented (Nauert 2008). About 25% of the carers who were randomly selected from an Alzheimer’s disease (AD) registry had
clinical depression (Neundorfer quoted in Vitaliano 2006), and an earlier study found this figure to be as high as 70% (Hanks 1992). Other sources estimate that one in three carers has an anxiety disorder (Joling et al 2008).

Caring for a person living with dementia has also been described as a ‘dress rehearsal for bereavement because it can involve prolonged grief and bereavement is associated with several negative sequelae, including higher mortality rates’ (Vitaliano and Katon 2006). This means that carers experience the symptoms of grief at the same time as providing ongoing care for the person with dementia.

Carers with good mental health provide a better quality of care to their family member (Nauert 2008). Providing counselling for family members ‘should be considered an essential component of optimal comprehensive care’ (Nauert 2008). The implication is that the carer’s ability to cope is the factor that has the most significant impact on the health of the person living with dementia.

Comparatively, there are fewer published studies that deal specifically with the person living with dementia. Counselling services offered at AAV take the different stages of dementia into account and treat a person appropriately according to their specific set of needs. According to the Alzheimer’s disease Research Centre, people living with dementia who have reached the ‘acceptance stage’ and are reconciled to the ‘terminal nature of their dementia’ are much more able to enjoy life and adapt to the advancement of the disease (AD Research Centre n.d.). However, Aminzadeh & Byszewski (2007) and Baylor College of Medicine (2007) claim that there is an urgent need to better understand how people living with dementia experience diagnosis to assist with designing adaptive coping responses.

Impact on population groups

In the United States, research has found that African-American carers are less likely to be a partner of the person with dementia than Caucasian carers and are more likely to be an extended relative. Caucasian carers are more likely to be married, older, of higher socioeconomic status and appear more willing to pursue full-time institutional care for the care recipient than African-American carers (Haley et al 2004). Latino carers tend to be younger, less educated, have lower incomes, more likely to be unemployed than Caucasian carers and are also more often daughters than partners (Coon et al 2004). Despite limitations of socio-economic status, both Latino and African-American carers appraise their situations to be less stressful than Caucasian carers do.

The appraisal technique measures the extent to which carers appraise a particular situation or behaviour as being stressful. Coon et al (2004) argue that a number of factors can

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2 This term refers to the person with dementia who is receiving the care of a carer/caregiver and is favoured by American literature such as this by Haley et al.
impact how much situations are appraised as stressful including ethnicity, culture, social support, and past history (Coon et al 2004).

The significance of this for AAV is that interventions can be as vital and successful for people from different CALD communities, despite some differences in how they appraise their situations as carers. The nature of the support will still vary considerably according to individual need and circumstance.

There have been very few empirical studies of the incidence and prevalence or indeed experience of dementia in CALD groups in Australia and whether this mirrors the overseas experience (Cheng 2009). Access Economics was commissioned by Alzheimer’s Australia to estimate the current and projected incidence and prevalence of dementia in Australians who do not speak English at home (Access Economics 2006). They estimated that in 2005, around 12% of Australians with dementia (about one in eight) did not speak English at home.

Research into the ‘Ethnic Baby Boomer’ population in Victoria (Ethnic Communities Council of Victoria 2009) noted that the adult children of people who immigrated to Australia are in a particularly difficult position when it comes to caring for their ageing parents. These CALD groups are likely to have maintained traditional cultural expectations about being cared for in their old age by family members. The combination of ethnicity and baby boomers ‘ageing into’ aged care is likely to create an extra layer of complexity to the issue of caring for people with dementia.

Qualitative studies suggest that some CALD migrants regard dementia as part of normal ageing and may have poor knowledge about the disease and its causes. Comparing community based studies from non-English countries to an Australian study shows that dementia literacy is higher in the general Australian population. Studies that have compared CALD migrants to mainstream groups suggest that CALD groups have poorer knowledge about dementia than white or Caucasian groups.

Education, marital status, and perceptions about the helpfulness of services were significant predictors of wanting a referral and being amenable and responsive to outreach services (McCallion 2004). A key success factor was having tailored outreach workers who were able to make connections to people from within established community organisations and local service outlets. The information and referral help given by staff of the Alzheimer’s Associations resulted in a significant increase in the use of their services. While this study was limited in testing the effectiveness of their interventions, it notes importantly that within six weeks a relatively low-cost information and referral intervention resulted in significantly increased service use (McCallion 2004).

Similarly the nature and extent of dementia in Indigenous communities is largely unknown, as are: the experience and meaning of dementia for Aboriginal and Torres Strait Islander people; the causes of and risk factors for cognitive decline; and the need for and provision of dementia services.
The two known prevalence studies conducted in remote Australian communities show very high rates of dementia in relatively young populations of Indigenous people. There are proportionately high mid-life mortality rates among the number of ‘younger-old’ Indigenous people aged 45 to 64 years.

Indigenous people experience ongoing challenges finding services that are appropriate to their needs and circumstances and may have problems accessing the services that do exist. In rural and remote areas, Indigenous people need transport to services, facilities such as respite and Home and Community Care services (HACC), and staff and services capable of delivering care adapted to their language, culture and local circumstances.

The most noticeable difference in relation to service needs between Aboriginal and Torres Strait Islander and non-Indigenous clients is that far greater percentages of Aboriginal and Torres Strait Islander clients need dementia and aged care services before age 55. Aboriginal and Torres Strait Islander elders wish to be cared for in their communities where they are close to family and kin and where they can die on their land. To date, there is little known about the impact of this on families and their care arrangements.

“Many Indigenous carers and families lack understanding of what causes dementia and are fearful of the medical system. Language and cultural differences prevent many indigenous people from using early intervention services” (Broe et al 2009). The social and health profile of Aboriginal and Torres Strait Islander Australians includes many of the risk factors associated with a greater chance of developing dementia in later life than in non-Indigenous populations.

Gender as well as ethnicity has considerable bearing on the experience of dementia. Significant gender differences have been found in caring roles and experiences between men and women. For many women, “care-giving is an oppressive institution that can interfere with their sense of competence, economic independence and options for equality in adulthood” (Montgomery and Williams 2001). This suggests that it is not what is done, but who performs these tasks and in what manner that is important. Careful consideration of the care-giving context, especially the relationship between the carer and the care recipient, may lead to a better understanding of the impacts of care-giving and more effective design and targeting of support services.

People with younger onset dementia (YOD) require different types of support than those who are older, and care in a residential facility may not be appropriate. For example, people with younger onset dementia are likely to be physically able, which is particularly problematic for residential care and respite services because facilities are often designed for the physically frail or disabled. The emotional impact of ‘premature’ institutionalisation is also significant (Access Economics 2010).

In particular, maintaining someone in their home and if possible within employment are two ways in which YOD differs from other forms of dementia affecting older people. The Alzheimer’s Australia report on Exploring the Needs of Younger People with Dementia in
Australia acknowledges that the availability and frequency of ‘suitable’ activities was a problem (Alzheimer’s Australia 2007: 22). In addition, Dementia Education Online suggests that the recreational/social activities offered to people with YOD should reflect the activities they were involved with before their diagnosis (Dementia Education Online n.d).

In addition to the informational and emotional support that ought to accompany any diagnosis, people with younger onset dementia are more likely to require practical support and advice about changing their employment status, superannuation issues, or considering early retirement (Armstrong 2003).

Access Economics, quoting Alzheimer’s Australia, states that:

"Greater support is required in the community care setting to enable younger people with dementia to continue to combine work and family responsibilities. For example, children of people with younger onset dementia may be at greater risk as the family tries to cope with the condition and relationships come under stress. Support services therefore need to be available for children and teenagers to help them cope with the effect of dementia on their parent" (Access Economics 2010).

AAV identified supporting people with YOD as a priority area for their action research agenda. They are particularly interested in exploring different modes of delivering support for this group, who are generally likely to be more ‘tech savvy’ than older people, and who also require services that can adapt to and fit in with their broader range of responsibilities and obligations.

The Care Relationship

If not a partner, the carer is usually another family member. It is known that the process of providing care is emotionally, physically and financially draining (Montgomery and Williams 2001). The experiences of carers, including their stress levels, the ‘burdens’ they face (defined as the ‘cost’ of care), and the types of support they require will vary according to the nature of their relationship (Montgomery and Williams 2001).

The type of care will vary with children providing a less intimate style of care to partners, with sons distancing themselves from the care-giving role more than daughters, and more inclined to delegate some of the responsibility (Montgomery and Williams 2001). However, burden is not necessarily proportional to increases in physical disabilities. Greater stress has been noted among individuals caring for a relative with dementia than for those with physical disabilities (Levesque et al 1999). Yet others note fewer burdens for some family members caring for a loved one with dementia than for family members caring for a physically disabled person (Montgomery and Williams 2001).
Modes of counselling delivery

Counselling can be offered in a number of forms other than traditional face-to-face modes. Over the past decade or so, there has been a marked increase in a range of telephone, internet and e-health services in the fields of medicine and counselling. These services have increased dramatically over the past ten years and have been particularly successful in meeting the needs of younger age groups of clients as well as those people who are comfortable and proficient with internet-based applications such as chat rooms and online discussion groups.

Broadly, e-health includes not only technical development but also a new way of working, an attitude and a commitment for networked global thinking, to improve health care locally, regionally and worldwide by using information and communication technology (www.ahcwa.org.au/index.php?option=com_docman). For example, over the past five years or so, traditional face-to-face counselling services, such as those mainly offered by services such as Relationships Australia have expanded their range of services to offer e- and video-counselling (http://www.relationships.com.au/). There has also been a growing number of private counselling practitioners in the Australian and international market that exclusively offer internet and/or video-linked services.

It is significant that dementia-related peak bodies in the UK and USA for example, have established, run and where applicable, moderated, a suite of regular online services that are tailored to a range of support groups and provide information and counselling to families, carers and people living with dementia.

There are notes of caution around delivering internet and telephone based counselling that are discussed in the Background Paper in Appendix A.

The Background Paper concludes that there are sufficient indications in the literature to warrant action research into the use of telephone and internet technologies in providing support and counselling for people with dementia and/or their carers and family members.

A full version of the Background Paper is provided at Appendix A.

2.2 Program data summary

AAV data

A review of service data supplied by AAV provides an indicative picture of the number and range of contacts made to AAV. For the period July 2003 - June 2008:

- 69,426 contacts were made. A ‘contact’ refers to any form of communication between staff and the client group including a facsimile, telephone call, email, face-to-face, or mail where some sort of relevant exchange of information takes place
(e.g. discussion of dementia/caring). A contact records what service was provided and when. It is worth noting that visits to the website are not recorded as contacts.

- The client group with the largest percentage of recorded contacts (more than three-quarters) was ‘family’. 75% of all contacts were made to family (including the person of concern, family members and others concerned with services to the family)
- Service providers comprised 14% of all contacts which may include client related contacts (such as liaising with a person’s General Practitioner (GP) or consultation to a case manager) or non client related (such as giving talks about services or discussing general dementia issues)
- The most common primary modes of contact involved telephone usage, comprising two thirds of contacts (66%)
- The most common way for clients to come into primary contact with the service (33%) is through the Helpline (a support service provided by advisors (trained volunteers) and counsellors)
- Family contacts had the largest number of contact hours in terms of ‘direct time’ (64%), followed by service providers/professionals (17%)
- There has been a steady increase in the percentage of family contacts from 70% in 2003 to 81% in 2008
- There has been a steady decrease in the percentage of contacts involving service provider/professional from 17% in 2003 to 10% in 2008. It may be the case that service providers are making greater use of AAV’s website, and therefore ‘bypassing’ direct contact.

A look at a snapshot of client data for the period July 2007 - June 2008 indicates:

- The majority of carers were female (73%), compared with one-quarter male (24%)
- The gender distribution for ‘persons of concern’ was female (56%) and male (39%)
- Persons of concern included 3,915 persons, of which the overwhelming majority was over 70 years of age (84%)
- Female relationships to persons of concern mainly included daughters (52%), and wives/female partners (27%)
- Male relationships to persons of concern mainly included husbands/male partners (45%), followed by sons (36%)
- The majority of persons of concern were living in their own homes (85%)
- More than one half of persons of concern (57%) were living with their spouse/partner. Of these persons, one third were living with their wives/female partners, while one quarter were living with their husbands/male partners
- The majority of people (96%) and contacts (94%) did not involve an interpreter
- The majority of persons of concern had been diagnosed with dementia (79%).

A more comprehensive picture of the AAV program level data and client demographics is provided at Appendix D.
CDAMS data

In the absence of reliable and consistent data from CDAMS agencies the following data should be treated with caution and can only provide an indicative picture at best. The data is taken from three clinics: Mt Eliza, Caulfield and Bendigo for the 2007 and 2008 calendar years. This data indicates:

- A consistent increase in the number of clients across the three clinics Mt Eliza, Caulfield and Bendigo (8.2%, 34.3% and 3.6% respectively), with Caulfield having the greatest increase.
- The portion of clients referred to AAV was approximately between 15-27% for the three clinics for both 2007 and 2008.
- In 2007 27% of CDAMS clients in Caulfield had been referred and this portion decreased to 25.5% in 2008 (however, there was an increase of 27% in the actual number of clients referred due to the increase in overall CDAMS clients)
- In Bendigo 15.7% of CDAMS clients were referred to AAV in 2007, which increased to 17.6% in 2008
- In 2008 in Mt Eliza 16.5% of clients were referred to AAV. Data for 2007 was not available
- Of those clients referred to AAV from Caulfield, there was an 83.3% increase in the number of those who were Australian born for 2008 increasing from 12 in 2007 to 22 in 2008
- There was a 90% increase in 70-79 year old clients who were referred to AAV and a 30% increase in octogenarians, while those aged 69 or less saw a decrease in numbers referred
- Demographic data for Mt Eliza and Bendigo showed the breakdown of all CDAMS clients. Both regions had an increase in the number of overseas born clients (23.5% for Mt Eliza and 40.9% for Bendigo). Both also saw a slight increase in clients who were aged between 60 and 89 (10.6% for Mt Eliza and 3.2% for Bendigo). Bendigo however saw a 23.1% increase in clients younger than 60, while Mt Eliza saw a 13.3% decrease. There was also a decrease in clients 90 years and older for both areas (5% decrease for Mt Eliza and 17.6% for Bendigo).

This summary provides similar trends as reported in the literature and by CDAMS representatives and AAV staff interviewed for this project. For example, the increase in overall client number for the three sample clinics is in line with observations and predictions of increasing demand.

The number of referrals to AAV as a proportion of overall client numbers for the three clinics seems low and indicates there is room for improvement in the referral pathways between CDAMS and AAV. The data on CALD status and age profile is difficult to draw conclusions from and is inconclusive as to whether this matches projections about an increasing incidence of people with younger onset dementia from CALD backgrounds.
3. Methodology

A key component of this project was to conduct action research to pilot identified service innovations. As the purpose of action research is to support and improve the management, implementation and development of projects and to contribute to a learning process, it was an ideal methodology for trialling new approaches to service delivery at AAV.

Action research follows a learning cycle of Plan, Act, Observe, Reflect:

![Action Research Cycle Diagram]

Action research supports participants to take risks. There are no mistakes – just learning. Through an early analysis of the data, key issues and potential service barriers or gaps can be identified and fed back to those responsible for the project. If required, those responsible can make changes as the learnings emerge.

AAV established four action research projects overseen by a Project Steering Committee comprising senior managers and other staff from AAV together with the consultants from Success Works. The Steering Committee’s role was to oversee the process and to ensure that the pilot projects were on track or adjusted as needed.

A Reference Group was also established, comprising a selection of staff and relevant stakeholders with an interest in the project, to provide input, advice and guidance from their respective professional organisational perspectives.

As previously discussed, a Background Paper was also prepared to inform each of the four projects.
Each action research project had a project leader (also a member of the Steering Committee) and each project was undertaken by a small number of staff members interested in and keen to take part in the project. Project staff were given sufficient time and support to undertake the project, while continuing on with their existing work. Some reduction in their day to day work demands was anticipated to account for their participation in the pilot program.

Each project commenced with a workshop involving the staff participating in the trial and reference group members. Each workshop included a summary of the relevant literature, and participants were asked to contribute their own knowledge and experiences. The final design of the pilot projects followed these initial workshops.

The initial workshops were designed to help determine:

- Selection criteria for participants
- The recruitment process for participants
- Any ethical considerations
- The process for review
- Critical questions to be answered or considered during the pilot.

Each pilot was expected to commence prior to the end of December 2009. The duration of the pilots was for a minimum of four months.

After the initial workshops (in November 2009), relevant action research data was collected on three occasions during the pilot period:

- At the beginning (December 2009) - to determine the goals of the pilot and current implementation status
- Part way through (July 2010) – to determine progress and learnings to date
- At the end (October/November 2010) – to determine progress, achievements and learnings.

Action research qualitative data was compiled from:

- Interviews with participating staff
- Interviews with project leaders
- Interviews with reference group members
- Interviews with external agencies involved with the pilot
- Interviews with participants (people with dementia, carers, family members)

Whilst quantitative data, compiled by the participating staff, was expected to include data related to the demographics below, this did not eventuate (see data limitations below):

- Age
- Gender
- Postcode
• Status (carer/person with dementia/CALD Worker)
• Relationship to person with dementia
• Type of dementia
• Ethnicity
• Language(s) spoken at home
• Date allocated
• Date service received
• Other agencies involved

A simple online survey, for clients participating in the younger onset dementia community and online counselling projects, was also developed and accessible through the AAV website. The survey asked participants some simple questions about the service mode they participated in. The survey used a 1-5 Lichert scale to assess: the degree to which participants found the pilot mode accessible; what their expectations were and whether it met these; and what they gained from participating. It also asked them some demographic questions.

As previously discussed, agency data was also collated from program level and client demographic data provided by AAV for the period July 2003 - June 2008. CDAMS data from 3 offices Mt Eliza, Caulfield and Bendigo was collected for the 2007 and 2008 calendar years.

Data limitations

Agency level data should be treated with caution. The difficulty in accessing CDAMS data was largely due to the inconsistencies between the clinics, in terms of what data they collect and how easily it could be reproduced for the purposes of this project. CDAMS coordinators also had limited availability and resourcing to contribute to this project.

Each project experienced difficulties in collecting reliable and useful demographic data about the clients participating in the trials. The telephone vs face-to-face counselling project experienced problems in staff entering information in the data log, and the online projects identified that the way participants commence with the project (ie via the AAV website link) means they do not go through the usual intake process where demographic data is collected.

The responses from clients participating in the action research projects were very limited. Only a small number of clients (11) responded to the online survey. Of those who did respond to the survey, a number provided very little, if any, information. This avenue for collecting data was less fruitful than expected. It appears some clients may have experienced difficulty in using the technology and a number indicated they were unsure about what the question was asking.
Twelve clients across all projects responded to an invitation to be interviewed about the project, all of whom were interviewed. None of the clients using the online counselling service took up the invitation to participate in an interview about the pilot.

Though small in number, interviews with clients provided useful information.
4. Findings

This chapter outlines the data findings from each action research project:

- Online counselling
- Younger onset dementia online community
- Face-to-face vs telephone counselling
- CALD

4.1 Online counselling

This pilot project team decided that online counselling would be available for all clients to opt in at their discretion. Online counselling was offered by the intake staff (who would ensure that clients had access to a computer and the literacy and cognitive ability necessary to receive counselling in this form). Clients could also register for online counselling via the AAV website, and at this point they would be allocated a counsellor and sent an email to set up a date and time for the first appointment. They then accessed the website via a password to begin the counselling session. Subsequent appointments were arranged between the counsellor and the client. The online counselling session occurred as an instant message format not as email but without requiring additional software to be purchased or downloaded by the client.

The team was interested to find out if there was a need for online counselling, how it compares with other forms of counselling, how useful it is to clients and for whom it might be suitable.

This project took some time to become operational. Delays in the project start up occurred due to changes in key staff involved, the difficulty for staff in learning how to use the technology, and the time involved in setting up the project. Initially the online counselling had a prominent place on the website's homepage but when it moved to a less prominent place, it was felt that this impacted on the uptake by clients.

At the mid way point in July 2010 the project leader indicated that she had already learnt a great deal about IT requirements. The online counselling option was on the AAV website and two clients were booked in for counselling. There was also excitement at this point that clients were accessing online counselling.

I am surprised about the good response to the pilot from people invited to access the pilot by clicking on the web link (AAV project team member)

The project ran for approximately three months. Seven clients had involvement with this project: four clients receiving counselling, one client was unable to access the technology,
one found it difficult to make an appropriate time to access online counselling and one who was interested but did not follow through. None of the seven volunteered to be interviewed for this research project.

Most interest in this mode of counselling came directly from the website. While it was also offered at the point of intake, no one took it up at this point.

Early implementation problems and a number of issues were identified by the project team including:

- Missing the screening that normally happens at the intake process, therefore demographic information is not available about clients using the service when they sign up directly through the website link
- People generally want a quick response in seeking support via an online mode but the process to receive online counselling was not quick (albeit, it was quicker than face-to-face counselling)
- Difficulty for staff in gauging the level of computer skills of the client. Counsellors did not always feel they were able to resolve the technology issues of clients

Some issues were resolved as the project continued, such as extending session times so that the link did not "time out" part way through the session.

Staff who provided counselling through this mode noted some differences from other forms of counselling including not getting the same cues from the client and it being more difficult to tell if the client is disengaging. Counsellors can feel they are wasting time while they wait for a response from the client. Online counselling was seen by the project team as a slower medium and staff expressed some frustration with this.

Online counselling was considered to be beneficial for those who are limited in their use and/or access to the telephone, and for those who are computer savvy.

There was agreement that staff should not expect online counselling to be the same as face-to-face or telephone counselling as it is a different experience.

The team identified a range of improvements that could be made if online counselling was continued by AAV including:

- Improving access by simplifying the booking-in system
- Providing a separate desk so staff are not distracted
- Clarity for staff about not expecting it to be the same as face-to-face counselling
- Speaking with other organisations providing this mode of counselling to learn from their experience
- Having a back up of telephone counselling in case there were problems with the technology
- Tip sheets for counsellors and clients.
The need for formal training to be able to deliver this form of counselling was identified: both training in what can be achieved but also in how to provide this mode of counselling. A particular skill set is required.

....both an intellectual and skill set shift is needed. Staff who were able to do this were successful in delivering this mode. (AAV project team member)

The project team expressed strong support for this form of counselling to be part of the suite of services offered. It was recognised that there had been a huge amount of learning for staff and AAV, and that it would have been good to run the pilot for longer.

4.2 Younger Onset Dementia online community

There were two aspects to this project; an online forum and a chat room. The project group decided initially that online support should only be offered to carers and family members due to the risks perceived in also opening up the pilot to people with dementia. It was also felt that the online environment would be difficult for people with dementia due to their need for familiarity, routine and visual recognition. The group finally decided to open the pilot to people with dementia but felt it was unlikely they would participate. One of the primary aims of this service initiative was for carers and family members to have contact with each other.

The group agreed the forum would be set up on a separate website with a link from the AAV website and include: "real time" discussion, with AAV staff as a moderator, at least twice a week (once during the day and once during the evening); and the ability to post and respond to "static" discussion threads. The site was moderated during the live discussions and via an alert function for the conversational threads. A list of frequently asked questions (FAQs) assisted people using the site, along with rules of the room to guide behaviour, and the opportunity to email the help desk with technical questions.

Initially the team thought that carers and family members of people currently on the Early Onset Dementia AAV database would be invited to join the site via letter. However the team felt that an expression of interest flyer advertising the pilot and asking people to log on to the page on the website was thought to be a better way to engage people. Participants could use a screen name to protect their privacy if they chose. The team was interested to find out who used the online services, how useful they found it, what they liked and did not like about it, and what other support they might require.

As with the other pilots the team struck some delays early on with staff changes, annual leave and IT issues. The project was established at the same time as a parallel project was running to upgrade the AAV website. The project generated a lot of enthusiasm, and interest from motivated staff to be involved from early on in the project.
At the mid way point in the three month trial there were 25 registrations from a mail out to 130 people and 6-8 actual users. Staff found it very rewarding that people were using the service.

A forum had been established, and six topics were posted on the forum: employment, coping, driving, services and support, medication and financial. However people generally ignored the topic headings and posted anywhere. One conversation topic was started by one user after some encouragement by AAV posting the title "well here goes...". At the mid point there were 26 posts under that original story with others also telling their story.

...the stories people told were so powerful, and frank, and very moving. (AAV project team member)

The chat room was offered twice per week; Tuesdays from 7-9pm and Thursdays from 10am-12 noon. The chat room did not run as well as expected and the uptake was minimal. No one had attended the day time chatroom session, possibly because the carers were at work. Clarity was needed around the role of moderator, as counselling was not part of the moderator role. Staff were still finding the new technology a bit daunting and were apprehensive about their role as a moderator. The team was pleased with the cost effective software and that the site looked like an AAV site. They identified that the registration process, a two-stage process, may need refinement.

Interviews were conducted with seven clients who accessed the younger onset dementia online community; six women and one man. Four were aged 46-55 years, one aged 55-65 years and two aged over 65 years. Three accessed the online forum only and three accessed both components. One client did not access the services but provided her thoughts about how she might have used the service had her circumstances been more amenable.

Clients mostly found the technology reasonably user friendly with those less familiar with this type of technology needing time to get used to it. One client who had difficulty accessing the technology emailed AAV for assistance and advised that was helpful. One client found the chat room hard to access and navigate and the times did not suit her. Another client suggested having separate written instructions sent to users to help them in getting going.

...like when you buy a new computer - a cheat sheet or something similar. (AAV client)

One client reflected that he was initially cynical about the service but was surprised how useful it was.

One client had a specific issue that he was seeking help with and thought the online service might be the best way to access this information. Another client reflected the online
The forum was good for sharing experiences and connecting with others in similar circumstances, which helped with the feeling of aloneness and increased awareness of the issues. Others found it good to hear about other people’s issues and how they deal with them. Participants gained both knowledge and confidence by using the online services, and a realisation that other people were going through the same issues but that everybody was different. The sharing aspect of the forum was also identified as beneficial - gaining information themselves but also helping others by sharing their experience and knowledge. All saw that the online forum has plenty of future potential.

The accessibility of the online forum was noted as positive for one client as she could use it at any time. Being located in rural Victoria restricts her ability to access services, and to attend meetings.

*Going to meetings can be a pain in the butt, with this distance doesn’t matter. I am able to do it in my own time.* (AAV client)

The online forum was seen as more convenient than the chat room as the session times for the chat room were problematic and did not suit one client trying to seek support through this mode.

Those who used the online services expected that more people would have used them. In particular for the chat room it may have been more beneficial if more people used it. One participant was able to get a helpful response to the issue he was seeking help with and so in this way it was of great benefit. Participants also identified the need to support a younger cohort of carers.

*The next generation are more likely to make more use of these services* (AAV client)

*Most services are for old people, and we’re not old* (AAV client)

The project group reflected that the trial did not go for long enough or reach a wide enough group. The group would love to see the online community go nation-wide, and for it to be advertised widely through community health, carers groups, and aged care groups. They reflected that other agencies would need to know about it and how to refer people to it to ensure maximum uptake.

It was also suggested that it would be valuable to offer chat room sessions with a specialist such as a doctor and offering different times and more frequent sessions. Better technology was also identified as something that would make the service better in the future.
4.3 Face-to-face vs. telephone counselling

The focus of this project was to compare the experiences of clients who receive face-to-face counselling, initial face-to-face counselling followed by telephone counselling and telephone counselling only. The project group agreed to restrict participation in the pilot to the carers and family members of people with dementia. The group was concerned about the suitability of telephone counselling for people with dementia due to their reliance on visual cues in their communication and difficulties some can have in using the telephone.

Telephone counselling and face-to-face counselling was appointment-based as per existing arrangements. The option of telephone counselling was built into the intake process and also offered to Ballarat and Bendigo clients facing delays in accessing counselling due to staffing constraints at the time. Initially it was thought that three counsellors from three metropolitan areas and three from rural areas would take part in the project, however when the project commenced it was agreed that all counsellors would take part. At the project inception stage it was identified that rooms could be quarantined for telephone counselling and that headsets would be purchased.

It was hoped that the provision of telephone counselling would significantly increase and that staff would embrace this way of working.

Getting this project started took longer than expected due to: staff changes and annual leave; working out the data collection and consent process; and lack of clarity about project roles. Some resistance from staff to embrace telephone counselling was also reported.

At the mid pilot stage, the project leader reported that 59 clients had agreed to participate in the project, with the majority (49) choosing face-to-face counselling. However significant issues relating to the documentation of data collection, both in timeliness and completeness were also reported, so the actual number of participants could not be verified.

Also at the mid-point of this pilot staff were indicating that telephone counselling was part of their standard practice. However they indicated that they strongly favoured face-to-face counselling and that it was difficult to find a group that telephone counselling might be good for. Even if clients may prefer this service model, counsellors might miss some important information by not seeing them at home or in person. After some discussion, staff agreed telephone counselling might be useful to people who were not available during the day time, were geographically isolated, liked the anonymity of the telephone and or had a physical limitation and were unable to come into an AAV office for counselling.

Interviews were conducted with five clients who were part of the face-to-face vs telephone counselling trial; four women and one man. One client was aged 56-65 years, two clients
were aged 66-75 years and 2 clients were aged 76-85 years. Three of these clients accessed face-to-face counselling and two accessed both telephone and face-to-face counselling.

For those accessing only face-to-face counselling, all found out about the trial through direct contact with an AAV counsellor. All three found the hours provided for counselling sufficient for their needs and that it met their expectations of confidentiality and of feeling comfortable with the counsellor.

There was plenty of time to ask questions and receive answers (AAV client)

Clients reported it was good to have someone who cared about them and to have someone to clarify the issues with, and to realise they were not alone. All felt the sessions were worth their time and effort.

Clients were referred onto other support options such as information sessions and support groups. The counselling also provided support and strategies for managing safety issues, knowledge of dementia and connection with others who are also experiencing similar issues, which were rated as very important to the clients.

Having a visit at home was good for one client as they did not have to travel. Learning about the services earlier would have assisted one client. All commented on face-to-face counselling as being a very positive experience.

The two clients who accessed both face-to-face counselling and telephone counselling found out about the counselling services after conducting their own research about what was available. One client has had telephone and face-to-face counselling interchangeably. Both clients were seeking information about: how to deal with particular behaviours; what they could expect and general information about dementia; and also an opportunity to vent concerns and anxiety with someone who was understanding and empathetic. They found the services provided met these expectations.

The clients reported feeling better supported and that the suggested strategies were helpful and successful and were impressed with the level of support from the counsellor. One client, living in rural Victoria has had support from 3 different counsellors but found each one has provided excellent support.

The project team reported difficulties in the administration of this project which they thought contributed to the low level of uptake and the low numbers of clients available for interview. The process for gaining consent from clients to participate in the action research did not work well with very few consent forms being received, so whilst the clients may have consented to receiving telephone counselling, and presumably received telephone counselling, they did not return the consent form to enable participation in the action research pilot. This resulted in a lack of data recorded in the log set up to record data
about clients involved in the pilot project and made it difficult to ascertain exactly how many people participated in the telephone component of this project.

As a result, at the end of the pilot, whilst the team thought around eleven clients were offered a choice of telephone or face-to-face counselling, it was unclear who in fact had taken up this option. The project team themselves indicated they were confused about the recording of data.

The team reflected that face-to-face counselling has benefits for the counsellor on the occasions when they do not have to visit the client at home (although most sessions are home visits); that the counsellor has more visual cues and that it was a good way to build trust before moving on to telephone counselling.

The team thought the telephone mode of counselling was influenced by geographic location and circumstances of the client.

One client was at risk of losing her job if she took any more time off work, so accessing counselling via the telephone was a great benefit.

One counsellor has provided a teleconference with family members located around Australia and telephone counselling was an excellent way of the whole family assessing the same information together, though this was noted as practical information rather than emotional support.

Telephone counselling was seen to be beneficial for those unable to leave the person they are caring for, though noting that sometimes people with dementia do not like their carers talking on the phone. The anonymity of telephone counselling was seen as positive. When using interpreters, counsellors reflected it was more effective if you can see the person. The project team thought it was best if face-to-face counselling was provided initially and then followed up with telephone counselling.

Adult female carers around 50 years of age were thought to be more used to receiving support via the telephone and comfortable with this mode of communication and are likely to be more familiar with the concept of counselling.

Professional development for staff conducting telephone counselling was identified by senior staff, such as listening for audible cues and being able to draw this out. It was also suggested there was the opportunity to learn from AAV staff currently involved in providing a telephone-based support group. It was also reported that staff may be reluctant to identify that they need additional skills.

Staff expressed a general sense of disappointment about this project. Whilst some staff indicated that they do a lot of telephone counselling none of their clients were referred to the project. Staff were seen as reluctant to set up the process for clients to participate throughout the duration of the project.
There are a range of views about the degree to which telephone counselling is already provided as part of the suite of services provided by AAV. Some staff reported they already provided telephone counselling so it was nothing new. Data collected regarding counselling could be tweaked to more clearly reflect the degree to which telephone counselling is already taking place. This may be an area to consider in the future to gain further insight into AAV’s practice and provision of telephone counselling.

4.4 CALD

At the initial workshop for this pilot, three possible pilots involving people from culturally and linguistically diverse communities (CALD) were identified via a consultation with a small group of staff: working with a CALD organisation that has an existing relationship with AAV; working with a migrant resource centre providing culturally appropriate care to a number of communities within a local area; or working on an existing project in the Loddon Mallee region. The project group also identified the need to develop cultural competence within AAV. However, there were divergent views about the appropriateness of each of these, leading to a decision by the reference group, to rethink the approach.

The commencement of the CALD project therefore stalled, and AAV decided to apply to a charitable trust for funding for a three year project. This funding submission was successful and the three year project commenced in October 2010. The aim of the project is to ensure that clients from CALD communities have access to tailored and timely support services, through the establishment of sustainable relationships between AAV and the communities.

At the end of December 2010 the project is still in its early phases, though important learnings are already emerging and significant progress has been made.

In the first year of the project, AAV is working with four established communities: Chinese, Arabic, Greek and Filipino communities. At the time of writing, the team had made contact with key community leaders and agencies for each community, who have all reported that they see dementia as an emerging issue, have been pleased to have contact with AAV, and have expressed interest in working in partnership with AAV.

The team has made direct contact with Arabic, Chinese and Greek key welfare agencies and with community leaders in the Filipino community.

Initial priorities for each community have been identified: for the Greek community - to increase the usage of the Helpline; for the Chinese community - to incorporate a dementia awareness program into their established music group for people with dementia and their carers; for the Filipino community - to run a program about memory loss and dementia; and for the Arabic community - to run information and awareness sessions for Arabic communities.
Across all four communities there is also a priority to continue to receive professional development from AAV for all staff; up-skilling their existing volunteers and increasing their knowledge and uptake of services, particularly the National Dementia Helpline.

Each community is discussing how they will go about using AAV services and programs. All are at different stages and there is great diversity within communities. For example, in the Arabic communities dementia is an emerging issue of which they are just becoming aware.

In 2011 each of the four communities will have an “output plan” identifying a range of actions to increase awareness about dementia and developing activities to support their priority areas. It is expected that this will increase their knowledge of services available from AAV and will also increase AAV’s capacity to better respond to their support needs. AAV will look to collect base line data in 2011 to document increased usage of services.

Over the three year life of the project AAV will increase the number of communities they are working with to around twelve by the end of the project.

The team identified that one of the keys to establishing good links with organisations to-date has been the skill of the key project worker who is an experienced CALD worker, and is well known and well respected. Her experience provides her with the understanding about how to make the initial contact and who to contact.

**It’s about knowing who the right people are - not necessarily starting with the CEO. (AAV project team member)**

The project worker has also utilised a range of community networks to develop the project and establish trust in the partnership approach. It is estimated that 80% of initial contacts were made through these networks - such as the network connected to the Community Partnership Program.

The project team has identified that agencies need to see there are benefits for them in connecting with AAV. The importance of maintaining positive relationships, maintaining a presence in the networks, using a strengths-based approach, and being aware that most agencies do not have full time staff and have limited resources has contributed to the successful start of the project. A useful way to connect to agencies has been to be available to talk with communities and have information available for distribution at information afternoon teas or awareness days.

This assertive outreach model appears to be a successful way to establish relationships and engagement with the issues.

AAV has already identified some areas in which they can improve access for CALD community members such as:

- Investigate options for the more seamless use of interpreters on Helpline
• Information for volunteers around language groups (not interpreting). An introduction is scheduled for the volunteers’ first meeting of 2011.

• Promoting the AAV volunteer program in communities - targeting ten community languages.

• Translating brochures about the support services available into the four identified community languages to compliment information currently available about dementia.

The project team is also learning that existing AAV programs may not suit community needs and that AAV may need to develop new programs rather than adapt existing programs so that they are more meaningful to communities. They also wish to engage those who do not yet have a diagnosis but have the symptoms of dementia - reaching people earlier. Training with key community leaders planned for 2011 will aim to assist in the design of programs.

The project team identified that the energy and enthusiasm for project has been important to its early success and now it is a challenge for AAV to make sure the project does not all sit with the key project worker. The team is considering how to assist AAV staff to continue to embrace the project, including ideas such as creating opportunities to partner with the project worker in visiting agencies, making presentations and to link in with regional offices.

...just having a discussion in a staff meeting won't embed the project. (AAV project team member)

The presence of other counsellors at agencies was noted as a way of building trust as agencies need to identify with a key person. The team noted that some AAV counsellors are already beginning to participate and build their confidence in working with CALD communities.

The project team also reflected that the project raises issues for future recruitment of staff at AAV including identifying the skill set needed to work in this area, and how to increase capacity and capability over time.

4.5 Summary

In summary, around 83 carers had involvement across the three projects: telephone vs face-to-face counselling, online counselling, and the younger onset dementia online forums (around 40 of these also accessing more traditional face-to-face counselling). For reasons largely due to data collection and consent processes, not all of these people agreed to be contacted or ended up receiving the services through the pilot action research projects.
Each of the projects experienced delays in commencement; starting projects in January was particularly problematic due to the number of staff taking annual leave, and was compounded with changes in project staff. The impact of delays and slow start up of projects overall was thought, by team members, to impact on the level of enthusiasm of staff. On the other hand, it was thought to have a positive impact in that the idea of new ways of working was continually reinforced and that once the projects were ready to go it was no surprise.

The online projects and the CALD project were the ones spoken about most enthusiastically and are the ones that were described as generating reinforcing energy. Team members of these projects also reflected on a range of learnings they had acquired during the process and ideas they had for the future.
5. Discussion of key themes

This chapter outlines the key themes arising from an analysis of the data:

- Impact of new modes of counselling and support
- Referral and access pathways
- Suitability
- Building capability

5.1 Impact of new modes of counselling and support

Senior staff reflected that whilst the pilots were quite simple concepts they were harder to implement than expected. Project leaders commented that fitting in projects with other work expectations was difficult. Initially it was thought that having additional resourcing in the form of back up counselling would be sufficient to support the implementation of the projects, however at the end of the project, staff reflected that what was most needed was project management skills.

Whilst the project teams largely talked about feeling supported by the agency and having a good level of enthusiasm for the project, the exception is the face-to-face vs telephone counselling project. This project faced resistance from staff, confusion about roles and data collection and disappointment from the project team. On a positive note though, during the course of the project this project team shifted its thinking about the potential benefit of telephone counselling for carers and the ability to meet the needs of carers currently not being met.

The projects have also increased the knowledge and comfort level with technology of some staff, and demonstrated that new modes of counselling and support will be used by some carers and may meet their needs in the way that traditional forms of support cannot.

Staff involved in the online modes expressed disappointment that the projects did not continue for longer indicating that they saw merit in providing services in new ways and feeling very encouraged when clients accessed them.

5.2 Referral and access pathways

AAV data provided for this project indicates that from 2003-08 there was a steady decrease in percentage of contacts from service providers/professionals from 17% in 2003 to 10% in 2008. This suggests there is room to increase the activity and exchange between professional groups to raise awareness about the types and modes of service available at AAV. It is noted that AAV’s Education Services Department works directly with professionals as a primary target group. In addition, as mentioned previously, greater use
of the website by professionals might impact on the ‘visibility’ of interactions between AAV and this group of stakeholders.

Stronger referral links provided to clients and pathways between CDAMS and AAV could also improve the timeliness of support including for those waiting for assessment. According to the Department of Health, health services are required to “have a defined point of access so that clients have access to a health service in a timely and seamless way” (personal communication from DoH). The CDAMS discussion in 2.1 and Appendix A suggest this is not always successful.

Improving early access to support, even before diagnosis, has been identified by a number of researchers as a critical issue for service systems to contend with. This has been confirmed by the AAV action research projects.

Many of the clients interviewed for this project indicated they found their way to the pilots via their own research, often internet based, or through their AAV counsellor. A number reflected it would have been good to have known about such services earlier.

Participating in the pilots also provided clients with a mechanism for accessing further support either within AAV or provided by others. It also provided them with connections to other people in similar circumstances and this confirmed the expectation, supported by the literature, regarding the nature of peer-based support. Again, many identified the need to access support at an early stage.

Modes of counselling such as the online forum which are simpler to access and do not require an intake process can be readily and quickly accessed, with a degree of anonymity. They also have the potential to be advertised more widely than just through the AAV website.

The assertive outreach approach adopted for the CALD project also shows a way forward in engaging with potential referral partners, and increasing the awareness of dementia and the support available via AAV. As this project continues it may provide further insight about engaging other agencies that can be adopted beyond a focus on CALD communities.

**5.3 Suitability of mode**

While small in scale and short in duration, the action research projects provide useful data about which carers the new modes of counselling might best suit. They also confirm a need for counselling and support to be provided in a range of modes. As none of the participants in the pilots were people with dementia, this project is unable to comment on the suitability of the new modes for people with dementia. People with dementia were invited to participate in the YOD forum, however this invitation was not taken up. Success Works notes that people with dementia do participate in forums elsewhere, for example the UK Alzheimer’s Society online forum, indicating that more investigation is necessary to find out why they did not participate in the YOD online forum pilot. The Steering
Committee for this project has expressed their disappointment regarding the lack of involvement by people with dementia, as much of the impetus for the pilots was to expand the range of service provided to this group of people. The lack of participation by people with dementia may be due to small numbers of participants more generally across the pilots; it might be that the mode was not perceived as suitable; or it may be that reluctance by some staff to promote alternative modes also prevented people with dementia from participating. It is suggested that AAV do further research into why this may or may not be the case.

Telephone and online services have obvious benefits for clients in rural and or isolated areas. Geography was frequently mentioned, by staff and clients, as a reason that more traditional forms of counselling can have limited appeal, particularly for some clients.

Life stage is also an important factor in matching the best mode of service to client need. As described in the Background Paper an increasing number of younger people are entering the system. They are more likely to be familiar with searching the internet for all sort of information in their day to day lives and are likely to also seek out information via the internet in time of crisis, and expect quick access and response. They are more likely than an older generation to have experienced some form of counselling and be more willing to seek out support.

AAV snapshot data for 2007-08 indicates that 73% of carers contacting AAV were female, and that of the female relationship to the person of concern 52% were daughters. The Background Paper indicates that carers are also more likely to be employed so meeting demands of caring with employment means they need to access support at a time more convenient to them. This is likely to be after hours or in short bursts. Online modes of support can provide support where face-to-face or in-home support is unable to meet their needs.

Whilst project staff discussed the need to make sure the clients have choice in the type of service they receive, having a better feel for who might suit different modes of counselling and streamlining intake processes, may enable AAV to more appropriately tailor services to client need at an earlier point.

The projects have been effective in raising awareness amongst staff involved in the projects, of the potential that new service modes provide in meeting the needs of carers who are unable or unwilling to access traditional forms of counselling and support provided face to face in offices or their own homes. Each of the project teams was able to identify a cohort of carers whom they felt could benefit from the new modes of service.
5.4 Building capability

This project has demonstrated the growing need for a more diverse workforce at AAV and for ongoing professional development. Professional development to increase capability in the following areas was identified:

- Project management skills - to support the implementation of new projects and initiatives
- Telephone counselling skills - the level of expertise and comfort with telephone counselling is unclear from this project and one requiring further examination
- New technology skills - increasing the comfort level and uptake of using new technologies such as online chat rooms and online counselling.

Collaboration and exchange with other services providing similar modes of counselling and support may also increase the confidence of staff in these new modes.

Project staff also identified a range of infrastructure needs that could encourage staff to broaden their skills and confidence providing telephone and online counselling such as dedicated rooms that are networked and set up with IT equipment. Support from IT savvy staff, pairing up with someone familiar with the technology or communities (in the case of the CALD project), and being given the time to ‘give it a go’ were also suggested as ways of building staff confidence.

5.5 Summary

To summarise, the project found that of the four pilots, the younger onset dementia community generated the most enthusiasm and had the greatest uptake. Themes emerging from this experience and the other three pilots included:

- Unexpected difficulties and delays in implementation (which did not derail the projects but delayed their start up). This has the dual impact of testing the enthusiasm of staff and embedding an understanding about the need to trial more contemporary modes of counselling and support amongst staff
- In spite of good relationships between AAV and the CDAMS, referral take up is relatively low and this is an area where improvements would have a positive impact on uptake of AAV support services. This would be supported by work currently being undertaken within DoH – new practice guidelines, and data systems.
- Different modes of counselling are suitable for different clients depending on their needs and circumstances. The pilot projects have added to this understanding, though not substantially
- The need for professional development or targeted recruitment to improve staff capability in project management skills and technical skills is apparent.
6. Conclusion and recommendations

6.1 Conclusion

Dementia is the leading single cause of disability in older Australians (aged 65 years or older) and accounts for one in every six years ‘lost’ to disability. It is one of the fastest growing sources of major disease burden, expected to overtake coronary heart disease in its total wellbeing cost by 2023 (Access Economics 2009).

Approximately 65,669 people in Victoria have dementia (Access Economics 2010). This estimate is projected to increase to 98,300 by 2020 which is equivalent to an increase of around 33% over the period 2010-2050 (Access Economics 2010).

The projected increase in demand means that the system that supports people with dementia, and their carers and family members, needs to be well informed and responsive to this growing and changing demand. This includes: providing clear, early assessment and referral pathways; and being receptive to the particular circumstances of clients including life stage, cultural identity, and geographic location.

There is sufficient data to conclude that each of the projects demonstrates a viable new mode of counselling and support that could be added to the suite of services provided by AAV. A number of improvements were identified that would support the implementation and integration of these modes.

Enthusiasm, energy and support stand out as the key components that generated a level of interest in the online services. The inclusion of these new modes as ongoing services will need to harness and embed this enthusiasm to maintain support from staff.

Clients did access the new modes and a number reported the benefit they received from accessing them. Telling was the disappointment expressed by those involved in the online services that the projects concluded and the expressed wish that the online community be resurrected in some form.

For projects dependant on technology, in general most clients found the technology user-friendly. However, the lack of familiarity from both staff and clients with the technology suggests that tools and training would assist in improving the comfort level with, and capability of, the technology. This is likely to lead to increased take up by clients as would opening up the forum, advertising it widely and having it run continuously.

Tools such as tip sheets for telephone/email support have also been identified as helpful. Most people found once they got going it became easier and suggested providing assistance at the earliest point. An IT savvy staff person to champion or assist staff, or a
lead user model (where one staff person is a key contact for others) could raise the capability and comfort with technology.

With the increase in the number of people with younger onset dementia it is likely that those seeking support will continue to be more used to finding information online and AAV will need to keep up with client demand for services to be provided this way.

It is likely that as more younger people seek counselling and support services from AAV they are likely to want timely services, particularly when provided online. Improvements to the intake system for online counselling and a different way of providing the chat room could also make these services quicker, and easier, to access.

The projects also raise the issue of future distribution of service delivery. Services such as online counselling and online chat forums can be delivered from a single site and do not require a regional base. However technology that provides up-to-date information with local supports and referral agencies is critical in delivering services in this way. Counselling skills may not be a prerequisite for staff managing the implementation of the online forum and chat room.

This project found it difficult to estimate the level and degree to which counselling and support is already provided via telephone. There were conflicting views given during the life of the project, and data on this mode of service provision was not collected. Staff indicated that professional development in telephone counselling, and better infrastructure may encourage staff to be more comfortable with providing support in this way. The growing cohort of female carers aged in their 50's are likely to be familiar with, and benefit from, support provided in this way.

As none of the projects included people with dementia, this report is unable to comment on the suitability of the new modes for people with dementia. In a similar vein, none of the projects were developed with the specific needs of Aboriginal and Torres Strait Islander people in mind, and as far as is known no Aboriginal and Torres Strait Islander people accessed the pilot projects.

The CALD project's use of an assertive outreach model to engage agencies and community leaders shows promise. It will be important for AAV to embed this project into the organisation in order to learn along the way and to build the capacity and confidence of staff so that increased numbers of CALD community members access AAV services and/or become part of the volunteer base delivering services (eg advisors on the Helpline).

There is an opportunity for AAV to share what they have learnt from this project with key referral agencies. Sharing the knowledge about the new modes of counselling might be of benefit to carers and family members who are currently unable or unwilling to tap into existing support services, and may encourage earlier referrals.

Linkages and partnerships with other agencies providing telephone and online counselling might support and further develop capability in embedding new modes of support.
In conclusion, this report finds that there is enough evidence from the literature and the findings of the action research projects to integrate the new modes of counselling and support into the suite of services provided by AAV.

6.2 Recommendations

Based on the findings of this report the following recommendations are made to support AAV’s desire to provide contemporary counselling and support services that will meet the needs of a growing and diverse client group.

Recommendation 1
- That AAV seeks discussions with funding bodies about:
  - Future resourcing needs to respond to a growing demand and to deliver a more contemporary suite of services tailored to identified needs
  - The establishment of a project to scope the feasibility of creating a national online community incorporating both an online forum and chatroom.

Recommendation 2
- That AAV shares its growing experience and expertise with new modes of counselling and support with referral and access partners and explore ways to strengthen referrals particularly with CDAMS. Such joint planning should be supported by the DoH’s new practice guidelines, and data systems.

Recommendation 3
- That AAV integrates the provision of new modes of counselling and support by:
  - Explicitly providing, and promoting the availability of, telephone counselling
  - Implementing online counselling as an ongoing option available to clients
  - Reactivating the online forum, and promoting it widely.

Recommendation 4
- That AAV considers the professional development and infrastructure needed to encourage staff to broaden their skills, confidence and experience providing telephone and online counselling, such as dedicated rooms that are networked and set up with IT equipment.

Recommendation 5
- That AAV investigates collaboration with agencies also providing telephone and online counselling and support services.
Recommendation 6

- That AAV develops a future staffing profile, considering the diversity of staff and skills needed in five years and the recruitment strategies needed to attract and retain a more diverse workforce to support the provision of counselling and support through a range of modes.

Recommendation 7

- That AAV shares the learnings from the CALD project at key points in the life of the project with AAV staff, interstate counterparts, and other referral and access points.

Recommendation 8

- That AAV commences some initial discussions with key Indigenous organisations to gauge their level of interest in working together.

Recommendation 9

- That AAV reviews data collection systems (including recording telephone counselling services provided and establishing base line data of services provided to CALD communities) to ensure future service planning is supported by reliable data.
Appendix A: Background Paper

The purpose of this Background Paper is to inform AAV about current practices for consideration in developing and implementing the action research projects on delivering counselling and support for people with dementia and their carers through different modalities.

The Background Paper includes the following:

- Glossary and abbreviations
- Executive Summary
- Chapter 1: Introduction
- Chapter 2: Data and Demand
- Chapter 3: CDAMS: Referral Pathways and Service Delivery
- Chapter 4: The Dementia Agenda
- Chapter 5: Population Groups
- Chapter 6: Modes of Counselling Delivery
- Chapter 7: Conclusion

A bibliography can be found at Appendix E.
Glossary and abbreviations

**Alzheimer’s Disease.** Alzheimer’s disease (AD) is a condition which attacks the brain resulting in impaired memory, thinking and behaviour. Abnormal material builds up as “tangles” in the centre of brain cells, and “plaques” outside brain cells. These disrupt messages within the brain, damaging connections between brain cells. AD is progressive and as it affects each area of the brain, certain functions or abilities are lost. Memory of recent events is usually the first to be affected, but as the disease progresses, long-term memory is also lost. The disease also affects many of the brain’s other functions and consequently many other aspects of behaviour, language and daily functioning are affected. It is not known what causes Alzheimer’s disease and there is no cure.

AD is the most common form of dementia accounting for between 50% and 70% of all cases (Alzheimer’s Australia Vic Help Sheet).

**Alzheimer’s Australia Vic.** Alzheimer’s Australia Vic is the peak body representing the interests of people affected by dementia in Victoria.

**CALD—Culturally and Linguistically Diverse.** The Australian Bureau of Statistics (ABS) defines cultural and linguistic diversity (CALD) by three variables:

- Country of birth (COB)
- Language other than English (LOTE) spoken at home
- English language proficiency.

Because CALD is a combination of factors, it is acknowledged that there is no one definition of CALD and the following description is used:

‘In the Australian context, individuals from a CALD background are those who identify as having a specific cultural or linguistic affiliation by virtue of their place of birth, ancestry, ethnic origin, religion, preferred language, language(s) spoken at home, or because of their parents’ identification on a similar basis.’ (Department of Human Services Multicultural Strategy Unit, 2002).

**Carers and Caregivers.** Both terms refer to persons providing direct support to people living with dementia. The preferred American usage is caregiver whilst the preferred Australian usage is carer and is used throughout this review.

**Cognitive Dementia and Memory Services (CDAMS).** CDAMS was developed by the Victorian Government in recognition of the need to provide a specialist multidisciplinary diagnostic, referral and educational service for people experiencing memory loss, or changes to their thinking, and for those who care about them (http://www.health.vic.gov.au/subacute/cdams.htm). In most instances CDAMS
representatives will now define their service as a diagnostic service only (based on consultations with CDAMS representatives for this project).

**Cognitive Behavioural Therapy (CBT).** CBT is a psycho-therapeutic approach that aims to influence dysfunctional emotions, behaviours and cognitions through a goal-oriented, systematic procedure. [http://en.wikipedia.org/wiki/Cognitive_behavioral_therapy](http://en.wikipedia.org/wiki/Cognitive_behavioral_therapy) There is empirical evidence that CBT is effective for the treatment of a variety of problems, including mood, anxiety, personality, eating, substance abuse, and psychotic disorders. Treatment is often brief, and time-limited. CBT is used in individual therapy as well as group settings, and the techniques are often adapted for self-help applications. Some CBT therapies are more orientated towards predominantly cognitive interventions, while others are more behaviourally orientated.

**Counselling:** professional activities that utilise an interpersonal relationship to enable people to develop self understanding and to make changes in their lives (Psychotherapy and Counselling Association of Australia 2008).

**Dementia.** Dementia describes a syndrome associated with a range of diseases which are characterised by the impairment of brain functions, including language, memory, perception, personality and cognitive skills. Dementia is not a single specific disease. It affects people differently, and the impact on their carers and families also varies. Dementia is not a natural part of ageing, although most people with dementia are older. After the age of 65, the likelihood of living with dementia doubles every five years and it affects 24% of those aged 85 and over (Henderson & Jorm 1998).

**Dementia, Stages of.** Progression of dementia may depend on many factors: the type of dementia, the age of onset, the presence of other illnesses, the level of support and care available. Each person's course will be unique, and what happens to one will not necessarily happen to another. Doctors traditionally divide up the stages of dementia into three - mild moderate and severe - and the categories overlap considerably. There are no reliable criteria that allow a person with a diagnosis to be placed in a category with precision. One possible description of the three stages is:

- **Mild**—the person can live independently for the most part, with adequate personal hygiene and relatively intact judgment, but social activities and employment are both significantly impaired.

- **Moderate**—formal employment is no longer possible and independent living is fraught with hazard to the extent that supervision is required.

- **Severe**—there is severe impairment of daily activities and continual supervision is needed.

For the purpose of providing support services to people with dementia, their families friends and carers a more useful terminology is early, middle and late stages.

People with early stage dementia are people of any age who are in the beginning phase of dementia (mild effects as above).
People with younger onset dementia (YOD) are people of a younger age (usually considered to be less than 65 years) who can be at any stage of dementia (early, middle, late). Confusion can arise if younger onset dementia is referred to as early onset dementia. (See Dementia, younger onset, below).

### Dementia with Lewy bodies (DLB)

Lewy bodies are abnormal brain cells found in all parts of an affected person's brain, the hallmark of this type of dementia. DLB can be quite common (10% of all dementia), and has sub-types such as Diffuse Lewy Body Disease, Cortical Lewy Body Disease, Lewy Body Dementia, Senile Dementia Of Lewy Type, and Lewy Body Variant of Alzheimer’s disease. DLB is similar to AD with ongoing loss of memory, language and reasoning, and often the presence of AD-type senile plaques although seldom with significant neurofibrillary tangles. DLB, however, progresses much more rapidly than AD and frontal lobe and visuo-spatial impairments usually occur earlier. Other features that differentiate DLB from AD include: motor traits of Parkinsonism, visual hallucinations, systematised delusions, REM disturbance, marked daily fluctuations, and falls and syncopal episodes (sudden loss of blood pressure resulting in fainting). In some families, DLB can be inherited.

### Dementia, Younger Onset

Younger onset dementia is onset before the age of 65. It is relatively rare with estimates of 53 in 100,000 people aged 45-64 having dementia; however there are considerable rises in incidence occurring in Australia (Access Economics 2005). The most common causes of younger onset dementia are AD (usually the rarer dominantly inherited type), Vascular Dementia (VaD – see below) alcohol-related dementia and Huntington’s disease. Diagnosing dementia for people under 65 is more complex than for older people.

### Dementia, Vascular (VaD)

VaD accounts for a further 20-30% of cases of dementia. These people appear to develop dementia from a narrowing of the arteries supplying the brain. The lack of blood can lead to many small areas of damage to the brain, each too small to be noticeable as a ‘stroke’ but collectively devastating in their effect. VaD is itself divided into sub-types:

- arteriosclerotic – reduced oxygen supply to the brain (chronic ischaemia);
- acute onset – following strokes;
- multi-infarct dementia – gradual onset following a number of mini-strokes (transient ischaemic attacks) in the outer brain (cortical areas);
- subcortical or Binswanger’s disease – demyelination (loss of the covering sheath of nerve fibres) affecting multiple sites in the deep white matter of the brain; and
- mixed cortical and subcortical VaD.

Intervention. There are three distinct components of intervention used in this review. The first is support: this aspect refers to services offered by AAV that includes National Dementia Helpline, Telephone Outreach Program, Telesupport, Living With Memory Loss Programs.

The second type of intervention is counselling. Counselling offered at AAV uses an eclectic range of approaches to suit the particular needs of the individual, couple or family. The purpose of counselling is to identify strategies for managing and living with dementia, help people plan for the future, deal with the emotional sequelae of living with dementia, resolve conflicts within families, help obtain an appropriate service or practical assistance.

Mild Cognitive Impairment (MCI): MCI is generally defined as significant memory loss without the loss of other cognitive functions. People with MCI have more memory problems than would be expected from someone at a similar age. Recent studies indicate that people with MCI are more likely to develop dementia, especially AD (Alzheimer's Australia Vic Helpsheet).
Executive Summary

Alzheimer’s Australia Vic (AAV) is developing new service models for provision of responsive, best practice counselling and support for people with dementia, and their families and carers. These new models are part of an Action Research project, Establishment of a Best Practice Counselling Service Model for People with Dementia, Their Families and Carers Project.

This Background Paper addresses best practice in dementia counselling to inform this project on current practices that demonstrate merit and bear consideration for AAV. This review provides the background and rationale for the following four models that will be trialled using an Action Research framework. These models are:

**Internet-based counselling**: using one-to-one text-based counselling in real time to provide session times when counsellors are available as an alternative to more traditional ‘face-to-face’ counselling.

**Comparative study of face-to-face vs. telephone-based counselling**: counsellors in the experimental group will provide either telephone, face-to-face or a combination of both modes of counselling.

**Online services for younger onset dementia**: to provide an online forum for people with dementia and their families/carers to include informal ‘chat’ as well as moderated and facilitated discussion groups.

**CALD project**: to ensure that clients from CALD communities have access to tailored and timely support services, through the establishment of sustainable relationships between AAV and the communities. (Note: this project received three year funding via a charitable trust in late 2010).

The main purposes of conducting this Action Research are to be:

- responsive to emerging consumer needs in Victoria such as: more "daughter carers" in the workforce; and the higher incidences of younger onset dementia that emotionally impacts the younger children of people diagnosed with dementia at a younger age
- person and family-centred, with the development of responsive support services to meet the needs of diverse groups including people who are geographically and/or socially isolated, people from cultural and linguistically diverse (CALD) backgrounds and Aboriginal and Torres Strait Islander communities
- cost-efficient, enhancing sustainability
- priority-issue focused and
- pro-active in addressing unmet needs associated with the emerging dementia epidemic.
One of the key findings is that there are very few rigorous studies and evaluations conducted on counselling specifically in the field of dementia that replicate previously successful studies and/or use randomised sampling, especially in the context of Australia. Therefore, this paper highlights that the accumulated ‘practice wisdom’ within Alzheimer’s Australia organisations nationally, including Victoria, is a valuable resource in the area of counselling for dementia that is specific to the Victorian context.

More often, findings are limited in their applicability, if ‘gold standards’ of clinical rigour were to be applied to these publications. It is likely therefore that promising approaches and innovations occupy the corridors of ‘grey literature’ and that there is much collective wisdom contained within service organisations that deal directly with people living with dementia, their carers and families.
Introduction

This Background Paper begins with a discussion about the incidence and prevalence of dementia in Victoria based on Access Economics data released in 2010. Their report identifies dementia as one of the fastest growing chronic illnesses in Victoria.

Chapter 3 examines the issues affecting service delivery for people with dementia and their families principally through the operations of the CDAMS, and the impact these systemic issues have on AAV’s work.

The impact of dementia on carers and family members as well as those with dementia is the focus of Chapter 4, as well as the need for and benefits of early intervention and some trends in the literature on how best to support people with dementia and their families.

The ways in which dementia affects different population groups including men, women, people from CALD or Indigenous backgrounds and those affected by Younger Onset Dementia (YOD) are discussed in Chapter 5.

Chapter 6 examines the use of technologies like telephone and internet to provide counselling and support for people with dementia and their families as well as discussing existing group programs such as AAV’s Living With Memory Loss program. Literature shows that under the right conditions these can be as effective as face-to-face modalities for delivering counselling.

Chapter 7 concludes that despite what some might describe as a ‘paucity’ of literature on how best to support people with dementia and their carers, there is sufficient evidence to confirm that AAV’s action research agenda adequately reflects the range of issues currently dominating the dementia field and can add value by helping to identify which modes of support are best suited for which carers and care-recipients.
Data and demand

Dementia Overview and Victorian Projections

Dementia is the leading single cause of disability in older Australians (aged 65 years or older) and accounts for one in every six years ‘lost’ to disability. It is one of the fastest growing sources of major disease burden, expected to overtake coronary heart disease in its total wellbeing cost by 2023 (Access Economics 2009).

It is estimated that there are approximately 20,000 new cases of dementia in Victoria in 2009. Incidence is projected to increase by 400%, reaching 94,000 per year by 2050³ (Access Economics 2009). This is due primarily to the ‘ageing population’ phenomena and ‘baby boomers’ beginning to enter the aged care system en masse.

Approximately 65,669 people in Victoria have dementia (Access Economics 2010). This estimate is projected to increase to 98,300 by 2020 which is equivalent to an increase of around 33% over the period 2010 -2050 (Access Economics 2010).

Along with South Australia, Tasmania and New South Wales, Victoria has the oldest population profile in Australia and high incidence rates and prevalence burden of dementia, as a percentage of its populations. Around 69% of Victorians with dementia or about 45,000 people live in metropolitan areas (Access Economics 2009). In regional Victoria, the older population profile tends to mean a higher proportion of the population has dementia.

The Southern Metropolitan region ranked the highest for dementia prevalence and incidence out of the eight Department of Health regions, with around 16,000 prevalent cases of dementia and 4,800 new cases, according to Access Economics (2010). Over the next ten years, dementia incidence and prevalence will increase at a faster rate in metropolitan regions in Victoria than non-metropolitan regions. By 2020, the North and West Metropolitan Region is expected to rank first in both dementia prevalence and incidence (Access Economics 2005).

For the non-metropolitan regions, by 2020 Barwon South West is projected to have the largest share of people with dementia (7.9% of the Victorian total) followed in descending order by Loddon Mallee, Hume, Gippsland and Grampians (Access Economics 2005).

These findings underline the critical importance of early intervention and counselling in order to make the advances necessary to minimise the challenges of living with and caring for someone with dementia. This will lead to a better quality of life for Victorians and make significant savings in the future cost burden of dementia.

³ Note that neither Access Economics 2009 or 2010 publications provide 2020 estimates for incidence.
CDAMS: Referral pathways and service delivery

Cognitive Dementia and Memory Services (CDAMS)

The Cognitive, Dementia and Memory Service (CDAMS) was developed by the Victorian Government in recognition of the need to provide a specialist multidisciplinary diagnostic, referral and educational service for people experiencing memory loss and their families. Early intervention and prevention, in terms of information and education, has been posited as a way to reduce the burden on the health system and the people directly affected by the disease – patients, carers and their families. CDAMS provides diagnosis and assessment of the psychological, medical and social difficulties associated with memory changes. It aims to provide information and advice on management and referral to other services as appropriate. CDAMS does not provide ongoing treatment, support or case management.

The purpose of discussing CDAMS here is that they provide a primary entry point for people with dementia or memory loss into the service system, thus influencing AAV’s counselling and support work and the data on which they base their service planning.

A CDAMS assessment involves medical and allied health consultations. This may include an initial home visit followed by medical and neuropsychological assessment in the clinic. A family meeting is held at the completion of all assessments to discuss the results and recommendations. Interpreters can be arranged where English is not the first language of the person to be assessed or their family. The CDAMS multidisciplinary team may comprise a combination of:

- Geriatrician
- Neurologist
- Psychiatrist
- Neuropsychologist
- Occupational Therapist
- Social Worker
- Community Nurse
- Referral / Eligibility Criteria

It is possible that a consequence of having CDAMS in Victoria is a heightened awareness of dementia issues in Victoria than other states. Victoria has the second highest incidence of dementia in the country - approximately 66,000 people currently, expected to increase to 246,000 people by 2050⁴ (Access Economics 2010). This clearly raises questions about strain on the service system, referral pathways and the impact of this on people with

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⁴ Note that 2020 projections are not provided by Access Economics for this measure.
dementia and their families. Therefore AAV and the broader service system are proactively planning to meet this future demand.

Some of the issues that have been raised in consultations with CDAMS representatives include:

- Access
- Assessment
- Waiting lists
- Who is CDAMS most appropriate for?
- Referral pathways

These will be discussed in more detail in the following section with consideration given to how they influence AAV’s work and their proposed action research agenda.

**Access**

Most CDAMS now receive referrals via a central point of access – in most cases a hospital administered centralised intake that refers to other subacute ambulatory care services (SACS) funded services as well as to CDAMS. Prior to the introduction of a central point of access, CDAMS staff directly prioritised referrals according to their direct assessment of the urgency. It reportedly can take 6 months in order to train a CDAMS worker in how to effectively identify a suitable referral, and how to assess a client’s immediate needs.

The centralised intake has changed the degree of control CDAMS staff have over the quality and flow of their referrals. CDAMS staff have reported through these consultations that there are two main problems impacting on their service delivery:

- Inappropriate referrals: These are people whose need for CDAMS has been incorrectly assessed and they have been put on a waiting list for CDAMS while their ‘real’ need for another service is not being met.
- CDAMS coordinators are also concerned that people who truly need the service CDAMS provides are being inappropriately directed elsewhere, and opportunities for early intervention or early diagnosis are being lost.

The central access point is causing CDAMS to ‘re-triage’ referrals even after the centralised intake has done an initial triage, due to incorrect decision-making by non-specialist personnel. This is ‘double-handling’ that diverts CDAMS resources away from their primary task. This in turn impacts upon the potential for early diagnosis and intervention.

**Assessment**

Currently, most CDAMS use the same process of a home-based assessment for the client, followed by an appointment being made for their full medical assessment. This is followed up by a case conference, where the client and their family meet with the specialists to receive their diagnosis and discuss follow up support options. The outcomes of the
feedback session are written up as a case plan, complete with the contact details of other support services that are recommended, including AAV, and a copy is sent to the client and/or their carer and to their GP.

Staff consulted during this action research project advised that the service a client receives at CDAMS is of a high quality. However issues remain around timely access (i.e. referral) to CDAMS as discussed above and then the length of the waiting list at some CDAMS. This may put clients at risk, particularly where their dementia is already quite advanced, and they or their carer may be facing other health issues and/or social issues. This defeats the purpose of early diagnosis, and early intervention in terms of support services and prescription of appropriate medications.

Waiting lists

Waiting lists for the medical assessment at CDAMS can be lengthy, varying from 6 weeks to 6 months, and this brings with it its own set of concerns. Where possible, and where the CDAMS staff have had an opportunity to prioritise their own waiting list, they can put other supports in place to assist people while they are waiting for their medical assessment. Services such as the Aged Care Assessment Service (ACAS) can organise urgent support when needed.

CDAMS coordinators express concern that if all eligible people were to gain appropriate referrals to CDAMS or private specialists in a ‘timely’ fashion, early enough in the disease so they may potentially slow its progress and maintain some quality of life (perhaps through access to appropriate medication), the service system may not be able to cope with this demand. Each CDAMS clinic has different means of prioritising and managing its waiting list. For example, some services currently only accepts referrals for people with a MMSE (Mini Mental State Examination) score of at least 18, as medications and interventions are considered most effective in the early stages of dementia – thereby maximising the expertise and available specialist resources of the clinic. People in the more advanced stage of dementia are not assessed for a formal diagnosis, which may have implications in terms of the referral pathways to other services in the support service system.

Inconsistent processes result in inconsistent experiences for patients depending on where they live. It also makes it difficult to assess accurate levels of demand for CDAMS from region to region, depending on how eligibility is defined.

Who is CDAMS most appropriate for?

CDAMS coordinators were asked via this consultation for their views on the changing ‘face’ of dementia. Their observations were that people are presenting younger and with a more complex set of health needs than used to be the case. Anecdotally they report that many people with dementia, in some parts of Victoria more than others, have other forms of chronic illness, which impacts on their ability to access support for their dementia. The
The ethnic profile of people with dementia is also changing. Access Economics (2009) estimated that by 2020 there would be a 22% increase in the number of CALD people with dementia in Victoria to approximately 16,000. Therefore it is likely regional variations in the statistics for dementia, depending on where CALD communities are most populous, can be expected.

A concern expressed by CDAMS staff and others working in the dementia field, is that despite increasing awareness in the community, people are still receiving their dementia diagnosis after the disease is already quite advanced. This is particularly problematic for people who have other compounding health concerns, are socially or geographically isolated and/or who have English as their second language.

**Referral pathways**

Many factors can impact on the speed and efficiency with which someone gains access to CDAMS. Referral pathways vary from region to region and the strength of local referral networks impacts on how ‘streamlined’ the process is for the client. How aware GPs are of CDAMS and/or dementia issues in general, and people’s capacity to access private specialists for a diagnostic service (CDAMS being the only public health diagnostic service in Victoria) both vary.

CDAMS often delivers distressing news when they give someone a diagnosis of dementia, and that person may experience complex emotions and may be under considerable stress. This means that their ability to absorb information about follow up supports, or even the types of support services they are likely to need, may be impaired. CDAMS provide newly diagnosed people (who are all at varying stages in the progression of their dementia) with information about support services. However most CDAMS representatives noted people often require support and encouragement to access these services, immediately post diagnosis, and CDAMS ability to provide this ‘linking’ function is restricted by their funding arrangements and workload.

Although dated, the review of CDAMS undertaken by the Australian Institute for Primary Care in 2003 also found a need for revising and increasing resource allocations. They estimated that at its current service delivery rate, CDAMS was only seeing approximately a quarter of eligible clients (Australian Institute for Primary Care 2003). The consultation with CDAMS coordinators confirmed some of the difficulty of accurately determining and measuring unmet demand. The Victorian Integrated Non-admitted Health minimum data set which collates CDAMS data measures the number of contacts with clients, not the actual number of clients, which is problematic as one single client can have multiple contacts and therefore be ‘counted’ multiple times in the data. The review acknowledged that the data collection methods limited the ability of CDAMS and its funders to make decisions based on client data.
Summary

To summarise, CDAMS provide a diagnostic service and have been integral in raising awareness of dementia among the medical profession and the public. All CDAMS staff consulted noted under-resourcing of services in terms of current (and future) demand, and restrictions on access to specialist staff and resources state-wide. This has necessitated developing both lengthy waiting lists for diagnosis, and varying priority of access guidelines responsive to local and regional circumstances. Centralised intake has changed the degree of control CDAMS staff have over the quality and flow of their referrals.

CDAMS is a diagnostic service, which also recognises the benefits of early intervention in terms of counselling and support for people with dementia, their family and carers. CDAMS staff noted people usually require encouragement to access supports available immediately post diagnosis and that a crisis situation later often precipitated the first contact.

In all, the consultations with CDAMS coordinators around Victoria have found resourcing issues that require the close attention of government in order to ensure that people with dementia and their families receive the services they need, and that the research agenda for dementia remains relevant.

This is supported by Access Economics research that noted the absence of additional dementia-targeted funding in the 2010-11 Federal Budget, without which services like CDAMS will be restricted in their ability to provide timely and accurate diagnoses of dementia (Access Economics 2010).
The Dementia Agenda

Trends in Dementia Care

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person’s functioning. It is a broad term used to describe a loss of memory, intellect, rationality, social skills and what would be considered normal emotional reactions (AAV 2005). Alzheimer's disease (AD) is the most common form of dementia that affects the cerebral cortex of the brain, mostly in older or middle-aged people. It is progressive and as it affects each area of the brain, certain functions or abilities are lost. Memory of recent events is usually the first to be affected, but as the disease progresses, long-term memory is also lost. The disease also affects many of the brain’s other functions and consequently many other aspects of behaviour, language and daily functioning are affected. It is not known what causes AD and there is no cure.

The ageing population is a global phenomenon that has contributed to an increase in dementia diagnoses, brought about largely through advances in science and medicine that allow people to live longer. Medical technology has also advanced the ability to diagnose dementia and other dementia-related illnesses.

Other demographic factors that may draw attention to dementia care in Victoria include: “Lower birth-rates (meaning that there will be fewer adult children to share the responsibilities for parent care); and more women being in the workforce will reduce the number of people readily available to serve as the source of unpaid carers” (Montgomery and Williams 2001).

Benefits of early intervention

Late diagnosis of dementia is an alarming and growing trend internationally as well as in Australia (Access Economics 2005). If dementia is diagnosed as early as possible, then research shows that the person with a diagnosis and their carers and families have a greater possibility of planning for their future or of availing themselves of the help, support and treatments available. Contrary to social misconceptions, there is much that can be done to help people living with dementia and their carers at an early stage (National Institute for Health and Clinical Excellence and Social Care Institute for Excellence 2006) and this is a message that AAV endorses.

A number of studies provide increasing evidence that there are important benefits associated with early intervention for people living with dementia, their carers and families. A range of early intervention programs demonstrate promising benefits in providing information about diagnosis and prognosis, reinforcing coping strategies, crisis prevention, advice and memory management programs. Carer wellbeing is shown to lessen the
likelihood of the breakdown of home care and increase coping skills of carers and families, minimising the need for care settings and respite.

Early intervention is an optimal strategy because the person with a diagnosis is likely to have their level of function preserved for a longer period and people being cared for at home ‘incur less societal cost than those who require long-term institutional placement’ (Leifer 2003). Institutional care was estimated at 2003 in the USA to be $100 billion annually (Leifer 2003) and 7 billion pounds in the UK (Knapp et al 2007).

As the need for services for people with dementia grows and the benefits of early intervention become clear, attention has been directed to understanding which factors may improve access to services for people with early-stage dementia (Pratt 2006). Using data generated from interviews with key professionals, Pratt (2006) identified issues relating to access to services for people with early-stage dementia. To improve access to services, Pratt (2006) suggests that it is vital to move beyond addressing individual factors relating to access, and to consider the impact of the framework for service delivery and the relationships that influence contact with services. Essentially this means that the systemic context within which services are delivered, how they interact with other agencies and the way in which this ‘system’ interacts with an individual, are as important factors in an individual’s ability to access a service as the characteristics of the individual themselves.

The clinical case for early diagnosis and intervention

In terms of service provision, current UK diagnosis and intervention systems estimate that less than a half of people with dementia have a formal diagnosis made, or make contact with specialist services, at any time in their illness (National Audit Office, 2007). Such diagnosis and contact are likely to occur late in the illness and in crisis situations when the opportunities for harm prevention are limited. Anecdotal evidence from AAV supports this trend of late presentation.

Some systemic issues, such as a reluctance in primary care to be directly involved in diagnosing dementia limit opportunities for early detection. Primary care physicians arguably have a key role in evaluating early signs of dementia, initiating treatment and directing people towards relevant community services (Leifer 2003). From Leifer’s study, there is a noted tendency for physicians to dismiss memory issues. The current focus of specialist mental health services for older people is on the severe and complex end of the spectrum, leaving early diagnosis and intervention in the UK situation, largely unaddressed (Leifer 2003).

In a meta-analysis of psychosocial interventions for carers of people with dementia, Brodaty et al. (2003) reported on seven studies which included care-home placement as an outcome. Five of these studies reported delays in institutionalisation for the intervention

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5 Reasons for reluctance include therapeutic nihilism; risk avoidance; concerns about competency; and resources (Illiffe et al., 2006).
group of between 53 and 329 days and a further study identified a statistically significant
decrease in permanent placement.

A brief program of carer support and counselling at diagnosis has been demonstrated to
reduce care-home placement by 28%, with a median delay to placement of 557 days
compared with those not receiving the intervention (Mittleman et al., 2006). Reductions of
6%, even in more severe cases with a highly active intervention in the control group, have
been reported for case management (Challis et al., 2002). Therefore, the service
structures to provide early diagnosis and intervention for people with dementia and family
carers are increasingly understood but have not been adequately reflected in policy to
date (Department of Health 2005). One of the reasons for this is a lack of data on the
possible costs and benefits of investment.

A UK report on early intervention, Making the Journey Brighter (Alzheimer Scotland 2003)
argues the case for the rapid development of early intervention services for people with
dementia. With improved diagnosis, treatment and increased public awareness of
dementia, people are being diagnosed sooner. However, the person’s need for
information, support and therapeutic intervention, and their families’ needs for information
and support, are not yet being properly met.

The key findings from Making the Journey Brighter suggest the overall need for an array of
dementia services in conjunction with a strong commitment of government. People with
early stage dementia and their families have a range of needs, including: diagnosis,
assessment and treatment; information; and practical, emotional, social and financial
support; and these needs must be met in order for them to maintain a good quality of life.

People in the early stages of dementia may not at first need to be cared for, and family
members are unlikely to consider themselves in the role of ‘carer’. Their role at first may
be more that of a ‘supporter’. Early support can help to reduce the risk of carer stress at
later stages. There is evidence that early medical and psychosocial interventions not only
improve the well-being of the person with dementia and their carer and family but delay
the need for long-stay care later in the illness.

Among the key early interventions specified by Alzheimer Scotland are: counselling and
other forms of emotional support for both the person with dementia and his or her family
and carers; support groups for people with dementia; carer support groups and carer
education. Other important areas that are listed include:

- accurate and timely diagnosis and assessment
- appropriate medical interventions, both for cognitive symptoms and for other
  conditions
- accurate information in a form that is helpful, including: the name and nature of the
  illness; its possible symptoms and other effects and how to cope; treatment options;
  legal issues and making arrangements for the future; services and financial issues
• rehabilitative approaches such as memory training and compensatory memory strategies and aids
• advocacy to assist people with early dementia speaking up for themselves and support them in decision-making and one-to-one support by paid staff or befrielers
• aids and adaptations to help to maintain independence (Alzheimer Scotland 2003).

Caring and Carers

The mental health impacts for the carers and family members of people living with dementia have been well documented (Brodie and Gadling-Cole 2003; Joling et al 2008; Goldman 2001; Gutheil and Chernesky 2001); the positive benefit of offering counselling and support to reduce depression is also well documented (Nauert 2008). About 25% of the carers who were randomly selected from an AD registry had clinical depression (Neundorfer quoted in Vitaliano 2006), and an earlier study found this figure to be as high as 70% (Hanks 1992). Other sources estimate that one in three carers has an anxiety disorder (Joling et al 2008).

The World Health Organisation places depression as the single leading disease in terms of years lost to disability (Mausbach et al 2007: 637). Research has also found that carers are more likely to suffer from chronic illness, such as diabetes, arthritis, ulcers and anaemia largely brought on by stress and neglecting their health in the process of caring for the person with dementia (Mausbach et al 2007: 637). Carers have been described as a shadow workforce—‘untrained, under-supported, unseen, unpaid’ (Alzheimer Society of Ontario 2008).

Caring for a person living with dementia has also been described as a ‘dress rehearsal for bereavement because it can involve prolonged grief and bereavement is associated with several negative sequelae, including higher mortality rates’ (Vitaliano and Katon 2006). This means that carers experience the symptoms of grief at the same time as providing ongoing care for the person with dementia.

While stress, depression and poor physical health are common to most carers, the intensity of these vary according to a number of factors, including the relationship between the person with a diagnosis of dementia and the carer, their socio-economic position, levels of family support, ethnicity and social networks. The carer’s ‘emotional acceptance’ of their situation will also influence the type of support they require at any given time. The person’s condition will also be a determining factor (Coon et al 2004). The most common concerns of carers relate to:

• the cause of the disease
• heredity
• the person with dementia’s physical appearance
• a desire for contact with other interested persons, and
a wish to contribute to education and research (Hayter 1982 in Coon et al 2004).

Managing behavioural problems associated with dementia has also been identified as a source of carer stress about which information may be requested (Coon et al 2004). Early intervention in terms of information and education for the carers and the person living with dementia soon after diagnosis may help to prepare them for the challenges they will face.

People with a diagnosis can be actively involved in developing a care plan and planning for the future stages of dementia. By the middle stages, the cognitive misfiring and in some cases, extreme behaviours (when these occur) can become more pronounced. Research has found that the most difficult behaviours of some people living with dementia include wandering, resistiveness, aggression and noisiness (Opie et al 1999). During this time, the carer is likely to need more active support in dealing with the daily challenges of caring, the difficult behaviours and their grief over the loss of the relationship.

Carers are likely to feel lonely, guilty and depressed. The level of mutuality (that is, the degree of benefit or pleasure they still derive from the relationship) they experience will vary. The way carers relate to the person with dementia will also vary depending on many variables discussed in the following chapter, such as carer-person with dementia relationship, gender and ethnicity.

A counsellor can provide support across the lifespan of the illness, from pre-diagnosis to death. The issues associated with each stage of the disease can vary:

- Receiving a diagnosis: in most other cases (there are some exceptions such as an Acquired Brain Injury), a person with a disability retains their mental faculties while faced with physical impairment, which can lighten the load emotionally for the carer; in other words the ‘essence’ of the relationship remains intact.
- Adapting to the demands of the caring role: in many cases the life changes that come with this will be significant, including increased physical responsibilities for caring for a dependent or semi-dependent person, increasing use of medical and other support services and changes in employment, social life and other relationships.
- Grief, loss and mourning: in the case of the death of the person with dementia, the carer experiences the loss while no longer experiencing the familiar stress and responsibility of being a carer. In caring for a person with dementia, the carer experiences grief, loss, mourning, stress and responsibility simultaneously.

Research at the University of Indianapolis with dementia carers has found that they identify the process of ‘letting go’ of their loved one as their biggest barrier (University of Indianapolis 2008). This transition is described as ‘anticipatory grief’ (Ibid), anticipating the loss of a loved one. In the case of dementia, this loss is a slow and inevitable process. ‘Ambiguous loss’ is the feeling that comes from interacting with a person with dementia who is physically alive but seems to have lost some of their personality (Ibid). Within this
context, issues connected to the practicalities of caring become entwined by the emotional stress suffered by the carer.

Current Trends in Counselling

A key theme emerging from the literature is that a short course of intensive counselling followed by ongoing support has beneficial and sustained effects in reducing symptoms of depression among carers of people living with dementia (see, for example, The Commonwealth Fund 2009). As Ory (1999) quoted in Doyle et al 2009, states, compared to other carers, dementia carers spend significantly more hours per week providing care, and report more severe impacts in relation to:

- employment complications
- caregiver strain
- mental and physical health problems
- decreased time for leisure and other family members
- family conflict.

These findings suggest a need to tailor interventions to the unique challenges faced by dementia carers (Ory in Doyle et al 2009). To date, counselling interventions have done this by targeting the specific needs of carers. When ‘support services such as respite have been offered with little attention to the specific care-giving context, these supports have failed to make a significant impact on carer outcomes’ (The Commonwealth Fund 2009).

Carers with good mental health provide a better quality of care to their family member (Nauert 2008). Providing counselling for family members ‘should be considered an essential component of optimal comprehensive care’ (Nauert 2008). The implication is that the carer’s ability to cope is the factor that has the most significant impact on the health of the person living with dementia.

Comparatively, there are fewer published studies that deal specifically with the person living with dementia. Counselling services offered at AAV take the different stages of dementia into account and treat a person appropriately according to their specific set of needs. According to the Alzheimer’s disease Research Centre, people living with dementia who have reached the ‘acceptance stage’ and are reconciled to the ‘terminal nature of their dementia’ are much more able to enjoy life and adapt to the advancement of the disease (AD Research Centre n.d.). However, Aminzadeh & Byszewski (2007) and Baylor College of Medicine (2007) claim that there is an urgent need to better understand how people living with dementia experience diagnosis to assist with designing adaptive coping responses.

Where people living with dementia present for counselling in the early stages, there are positive outcomes noted in a number of studies (Kasl-Godley 2000; Zarit, Femia 2004). Subjects with Mild Cognitive Impairment (MCI) who enrolled in a psychosocial program showed significant improvements in terms of mental health and general wellbeing. Kasl-
Godley (2000) examined six psychosocial interventions for people living with dementia and found that these interventions appeared helpful for understanding intrapsychic concerns. In particular, support groups and CBT assisted with early stage dementia to build coping strategies and reduce stress.

Other therapies such as reminiscence and life review provided mild-to-moderate staged individuals with interpersonal connections and some improvement in mental health and wellbeing. Zarit and Femia (2004) evaluated a memory club for early-stage people living with dementia where the couple (carer and person with a diagnosis) then the group (couples of carers and persons with a diagnosis) discuss issues in supportive settings and share experiences. Participants rated these groups positively as they provided a context to discuss issues with a supportive group and peers in similar circumstances.

There continues to be an alarming international trend in relation to late presentation of people living with dementia and their carers, nationally and internationally (Moniz-Cook 1998; Alzheimer Scotland 2003). This trend is replicated in Australia across rural, regional and metropolitan regions with CALD, Indigenous groups and people living alone all experiencing higher rates of late presentation.

The review of meta-analyses of interventions with carers of people with dementia conducted by Doyle et al (2009), noted that analyses are rarely conclusive in their findings regarding the effectiveness of particular interventions. This means that while it is ‘known’ that support for carers of people with dementia is crucial for supporting the care arrangement and the carer’s own wellbeing (as some of the above sources will attest) it is still difficult to determine which type of interventions are best suited to which carers. Some of the specific needs of these different population groups are discussed in the following chapter.
Population groups

Every person with dementia and their family members experience the disease differently, and this is often related to their social setting, cultural status, socio-economic status or gender. This chapter examines some of these needs as they present for different population groups, particularly CALD and Indigenous people who have been identified as priority target groups for AAV’s action research. (Note: A decision has been made to pursue a CALD pilot project at a later date although the supporting research remains in this Background Paper.)

CALD Populations

International Overview

Research in the USA has uncovered some important differences between the characteristics and experiences of Latino and African-American carers, compared to Caucasian carers, which offer potentially transferrable insights for the Australian context (Haley et al 2004). In general, non-Caucasian carers experience their role differently to Caucasian carers because of cultural concepts of family and responsibility, socio-economic status and religion.

Research has found that African-American carers are less likely to be a partner than Caucasian carers and are more likely to be an extended relative. Caucasian carers are more likely to be married, older, of higher socioeconomic status and appear more willing to pursue full-time institutional care for the care recipient6 than African-American carers (Haley et al 2004). Latino carers tend to be younger, less educated, have lower incomes, more likely to be unemployed than Caucasian carers and are also more often daughters than partners (Coon et al 2004).

Caucasian carers had lower life satisfaction than African-American carers, and Caucasian carers’ life satisfaction declined over time while African-American carers remained more stable (Haley et al 2004). While ‘63% of Hispanic carers in contrast to 29% of African-American carers reported a negative change in their health over a six-month period’ (Coon et al 2004), Caucasian carers had higher levels of anxiety, and in general, perceive situations to be more bothersome than both African-American carers (Haley et al) and Latino carers (Coon et al 2004). As a general trend, caring takes a greater personal toll on Caucasian carers than African-American carers, but Cox (1995, in Brodie and Gadling-Cole 2003) found that lack of informal supports for African-American carers in the US increased their stress.

6 This term refers to the person with dementia who is receiving the care of a carer/caregiver and is favoured by American literature such as this by Haley et al.
In assessing the emotional costs of caring—the burden or stress it creates—researchers often use the appraisal technique, which measures the extent to which carers appraise a particular situation or behaviour as being stressful. Coon et al (2004) argue that a number of factors can impact how much situations are appraised as stressful including ethnicity, culture, social support, and past history (Coon et al 2004).

A growing body of research found evidence that religion can reap both physical and mental health benefits for diverse groups of people (Haley et al 2004). Latino carers identify religion as a key coping strategy for helping them manage their caring role (Coon et al 2004). Latinos were also less inclined to talk about their situations, share private feelings, or obtain professional help than Caucasian carers (Coon et al 2004). Latino carers described their care recipients as having more self-care impairments and behaviour problems than Caucasians, and they reported spending more hours taking care of their care recipient per day than Caucasian carers. Despite this, ‘Latino carers appraised behavioural problems as less stressful and care-giving to be a significantly more positive experience than Caucasian carers’ (Coon et al 2004).

There are cultural factors that can both extenuate and mitigate stress and burden for carers. Latino carers do not readily endorse feelings of burden (Coon et al 2004). Moreover, help seeking to alleviate burden would be incongruent with strong cultural traditions that dictate that Latinos must put the needs of their family members before their own (Coon et al 2004). Coon et al (2004) offer several explanations for this situation that apply to CALD communities in Australia as well as elsewhere:

- Carers may lack the financial resources to access formal care services
- Latino carers that are not fluent in English may find the service delivery system difficult to navigate
- Immigrant families may face additional barriers due to their immigrant status that impedes formal care access
- Latinos may believe that seeking assistance with caring implies they are ‘burdened’ (Coon et al 2004).

It is contradictory that while Latino carers were providing care for more hours per day, had lower education and income, and their relatives had more behavioural problems, they report being less bothered by this and claim to receive greater advantages from their caring role than Caucasian carers do. Although it is difficult to generalise based on only two studies, it could be that non-Caucasian carers feel a greater sense of ‘personal mastery’? over their situation, and less disruption to the rhythm of their family life than is the case for Caucasian carers.

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7 Personal mastery is a feeling of being in control and can attenuate some of the depressive symptoms experienced by carers (Mausbach et al 2007: 639). When personal mastery increases, there is a decrease in depressive symptoms and feelings of overload (Mausbach et al 2007: 639). Carers who feel under control are more likely to ‘engage in active attempts to deal with stressors (i.e. problem focused
As with all cultural groups, Latino carers are not a homogenous group. There are differences between levels of less ‘acculturated’ Latino carers (i.e. less blended with the Western culture in the USA) who experience greater levels of burden and anxiety as a result of their caring. It may be the case that acculturated Latino carers are better able to draw on the resources available to them in the community to assist them with their caring role yet retain the cultural factors that provide them with greater satisfaction.

As stated, there is an absence of research on CALD populations’ experience of dementia in Australia, however it is likely that they would experience similar issues to CALD communities elsewhere; particularly limited understandings, or experience, of services in Australia; financial, systemic or language barriers that prevent them from accessing appropriate services; different cultural understandings of the caring role, which may ‘clash’ with socio-cultural understandings of the caring role in Australia. In addition, it is important to remember that CALD communities must always be active partners in designing their own services, as no ‘community’ is a homogenous group, and all caring scenarios will be unique.

**CALD populations in Australia**

There have been very few empirical studies of the incidence and prevalence or indeed experience of dementia in CALD groups in Australia (Cheng 2009). Access Economics were commissioned by Alzheimer’s Australia to estimate the current and projected incidence and prevalence of dementia in Australians who do not speak English at home (Access Economics 2006). They estimated that in 2005, around 12% of Australians with dementia (about one in eight) did not speak English at home.

Research into the ‘Ethnic Baby Boomer’ population in Victoria (Ethnic Communities Council of Victoria – ECCV - 2009) noted that the adult children of people who immigrated to Australia are in a particularly difficult position when it comes to caring for their ageing parents. These CALD groups are likely to have maintained traditional cultural expectations about being cared for in their old age by family members. The ECCV (2009) suggests ways service providers can consider the issues that relate to these cultural groups including:

Developing a broad public awareness campaign targeting all members of the Baby Boomer generation to highlight the key issues for consideration in terms of caring for the ageing parents

Resourcing CALD aged cared agencies to develop secondary culturally-appropriate material and resources that target the CALD Baby Boomers

coping) such as strategising, seeking social support or gathering additional information’ (2007: 641). Personal mastery has been associated with reduced morbidity and depression in carers (Mausbach et al 2007: 638) therefore counselling/intervention models that can build on this are directly relevant to dementia.
Resourcing migrant and multicultural community organisations to facilitate culturally-appropriate family information sessions that encourage all family members to be involved in deciding the most desirable aged care solution for their frail and elderly (ECCV 2009).

The combination of ethnicity and baby boomers ‘ageing into’ aged care is likely to create an extra layer of complexity to the issue of caring for people with dementia.

One study that recruited 107 Italian Australians (age range 58 to 92 years) through community support groups found there was a low level of knowledge about the nature of dementia (Kinsella et al., 2006). AAV conducted thirty-five focus groups involving 383 participants in total from twelve CALD groups. Their study found that common to CALD groups was:

- a lack of knowledge of dementia, its symptoms and causes
- stigma resulting in people being marginalised and isolated
- late diagnosis often at crisis point (Berisic and Nesvadba 2008).

In sum, qualitative studies suggest that some CALD migrants regard dementia as part of normal ageing and may have poor knowledge about the disease and its causes. Comparing community based studies from non-English countries to an Australian study shows that dementia literacy is higher in the general Australian population. Studies that have compared CALD migrants to mainstream groups suggest that CALD groups have poorer knowledge than Caucasian groups.

The Dementia Collaborative Research Centres are working towards filling this gap in the literature by conducting a population-based telephone survey of people from Italian, Greek and Chinese backgrounds and third generation Australians. Information on the dementia literacy in other CALD groups is still needed.

Cheng et al (2009) provide a summary of key recommendations for future research in the CALD dementia sector. Among six areas that are relevant to this AAV research are:

1. Community knowledge: Identify, develop and evaluate model/s to improve dementia literacy in the community.
2. Carers: Identify, develop and evaluate model/s of education to improve dementia knowledge of family and carers in a community context.
3. Service delivery: Outline pathways and barriers to care including GPs, hospitals, community services, Aged Care Assessment Services and residential care.
4. Screening and Assessment: Develop and evaluate a valid comprehensive set of CALD appropriate dementia assessment tools including assessment of function and carer burden. The RUDAS [an assessment tool] needs further validation in different settings and dissemination strategies developed.
5. Staff and training: Establish quality evidence on the effect of the cultural competency of care workers on outcomes for persons with dementia and develop and evaluate dementia training (including training for workers from CALD backgrounds) based on this evidence.

6. Minority CALD: Examine the impact of refugee and refugee-like experiences on dementia prevalence and symptoms.

Working with CALD and Indigenous people with dementia and their carers and families has been identified by AAV as an area requiring action research.

**Supporting CALD people**

Some of the more successful dementia programs reviewed include outreach that is tailored to specific CALD populations. One standout example in the USA is the El Portal Latino Alzheimer’s Project - a dementia-specific outreach and services program targeting Latino carers in the Los Angeles County area (Aranda, Villa et al 2003). The project is an example of an inter-organisational community-based collaborative developed to provide an array of coordinated, ethnic-sensitive services to Latino dementia-affected adults and their families and carers.

An evaluation of the service showed promising results in reducing barriers to care and increasing the use of dementia services. Culturally specific outreach and service delivery strategies were identified as ways to overcome barriers to accessing and using dementia care and counselling services by CALD communities.

As dementia proliferates, the role of family carers is becoming increasingly important however many people lack the knowledge and skill necessary to provide optimal caring (Cohen and Dilworth-Anderson 2007). This information gap is noted by Cohen and Dilworth-Anderson (2007) as prevalent among minority groups and those living in poor, rural, and medically under-resourced areas. Their project used a community-partnered ‘Train the Trainer’ model to introduce a culturally sensitive intervention to a diverse group of carers in 12 counties throughout North Carolina.

Key community members in each county were trained to conduct three 2-hr sessions for carers. Sessions targeted dementia knowledge, caring skills, and resource-accessing strategies. Pre- and post-tests were administered at each session. A total of 286 African American (52%), White (31%), and Native American (17%) carers participated in the intervention with an average age of 56 years. Most participants were female (86%), married (57%), employed at least part-time (54%), and in good health (82%) and had at least a high school education (88%).

Results show that test scores increased significantly following the intervention, particularly for Caucasian and Native Americans (Cohen and Dilworth-Anderson 2007). These findings support the efficacy of a ‘train the trainer’ intervention. It highlights the importance of developing culturally sensitive programs to effectively address the informational needs of carers of people with dementia. Results from this intervention have
implications for designing future experimental interventions for carers in diverse populations and would apply to the Victorian context.

McCallion (2004) evaluated the impact of an American information and referral intervention designed to help family carers of people living with dementia obtain needed health and human services. Over 608 carers of community-residing people living with dementia were surveyed about their need for and use of community services. Of the 608 carers, 203 agreed to be referred to a staff member of an Alzheimer’s Association chapter for help finding needed health and community services. This study provided a unique opportunity to explore ways to increase carers’ exposure to information about formal services and to investigate whether information and referral services led to increased services uptake (McCallion 2004).

Education, marital status, and perceptions about the helpfulness of services were significant predictors of wanting a referral and being amenable and responsive to outreach services (McCallion 2004). A key success factor was having tailored outreach workers who were able to make connections to people from within established community organisations and local service outlets. The information and referral help given by staff of the Alzheimer’s Associations resulted in a significant increase in the use of their services. While this study was limited in testing the effectiveness of their interventions, it notes importantly that within six weeks a relatively low-cost information and referral intervention resulted in significantly increased service use (McCallion 2004).

The significance of this for AAV is that interventions can be as vital and successful for people from different CALD communities, despite some differences in how they appraise their situations as carers. The nature of the support will still vary considerably according to individual need and circumstance.

**Aboriginal and Torres Strait Islander people**

Access Economics data shows that there is wide variation between the states and territories regarding the prevalence of dementia in the Indigenous community, ranging from 3.5% in Tasmania to 21% in the Northern Territory, in which the majority of cases were within Indigenous communities. Prevalence rates were intermediate for Queensland (7%), Western Australia (11.5%), South Australia (12%), NSW (13%), ACT (15%) and Victoria (17%). Although the co-existence of dementia and other lifestyle diseases that can influence the likelihood of developing dementia is likely to increase the prevalence of dementia (see below for more) it cannot be stated conclusively how significant these statistics are in this content.

The nature and extent of dementia in Indigenous communities is largely unknown, as are: the experience and meaning of dementia for Indigenous people; the causes of and risk factors for cognitive decline; and the need for and provision of dementia services. The two known prevalence studies conducted in remote Australian communities show very high
rates of dementia in relatively young populations. There are proportionately high mid-life mortality rates among the number of ‘younger-old’ Indigenous people aged 45 to 64 years.

There is evidence suggesting a gradual shift towards reducing the gap in life expectancy that currently exists between Indigenous and non-Indigenous people in Australia. However, for the vast majority of Indigenous people who live in urban environments, there is a pressing need to:

- determine dementia prevalence and sub-types in urban dwellers
- improve dementia services
- work towards population-based objectives for dementia prevention and healthy ageing, in the same way as current research addresses these issues in the non-Indigenous population.

A number of Indigenous communities in rural and remote regions of Western Australia and the Northern Territory have almost five times the prevalence of dementia as the general Australian population but to date, it is not known if this is the same for Indigenous people in cities and country towns (Broe 2009). Indigenous Australians may be at greater risk of developing dementia because of very high rates of chronic diseases like diabetes and stroke; and the burden of childhood infections including periodontal disease; and the high risk of head injuries and cognitive damage due to drugs and alcohol among younger Indigenous groups. These factors combine to increase the chances of developing dementia in later life (Broe 2009).

In urban areas, many Indigenous people have problems accessing services because they are socially isolated or have personal and health problems affecting their ability to use services. Relatively few Indigenous clients (0 to 3 percent) with dementia use government community programs such as the Aged Care Assessment Service (ACAS) or the National Respite for Carers Program (NRCP). While 2.5 percent of Australians are Indigenous, there is little robust data on dementia prevalence in non-remote Aboriginal and Torres Strait Islander communities.

There is insufficient information about the scale of the problem of dementia in terms of incidence and prevalence among the Indigenous population. Not knowing what types of dementia affect different people in diverse communities across the country, makes it difficult to assess the real extent to which people are able to access programs or whether existing services are meeting the needs of these population groups. University of NSW researchers write that “there is a strong Aboriginal belief that a life ‘out of balance’, losing connection to the land and to traditional relationships causes sickness; some have described dementia as a ‘sick spirit’” (Broe et al 2009).

In some rural and remote communities in WA, reports show that dementia affects around 12% of Indigenous people compared to around 3% in the general population (Access
Economic 2005). Local customs, language and way of life were taken into account when diagnosing dementia in these communities and this approach was successfully used in communities in the Northern Territory (Broe et al 2009). The current picture is that Indigenous men seem to be more greatly affected by dementia than Indigenous women and Indigenous people develop dementia at an earlier age than other Australians.

Indigenous people experience ongoing challenges finding services that are appropriate to their needs and circumstances and may have problems accessing services, where they exist. In rural and remote areas, Indigenous people need transport to services, facilities such as respite and Home and Community Care services (HACC), and staff and services capable of delivering care adapted to their language, culture and local circumstances.

The most noticeable difference between Indigenous and non-Indigenous clients is that far greater percentages of Indigenous clients need dementia-specific and aged care services before age 55. Aboriginal and Torres Strait Islander elders wish to be cared for in their communities where they are close to family and kin and where they can die on their land. To date, there is little known about the impact of this on families and their care arrangements.

"Many Indigenous carers and families lack understanding of what causes dementia and are fearful of the medical system. Language and cultural differences prevent many indigenous people from using early intervention services" (Broe et al 2009). The social and health profile of Indigenous Australians includes many of the risk factors associated with a greater chance of developing dementia in later life in non-Indigenous populations and this is cause for concern.

**Younger Onset Dementia**

Younger Onset Dementia (YOD) sometimes referred to as Early Onset Dementia is dementia that occurs in people who are younger than 65 years. As with all forms of dementia this has increased in occurrence – or, at least, diagnosis - in recent years and in doing so has highlighted the particular issues faced by people who would not generally be considered part of the ‘ageing’ population and therefore not linked in with aged care services. Alzheimer’s Australia research published in 2007 identifies the particular issues faced by people with YOD as follows:

- Difficulty and/or delays in getting an accurate diagnosis
- Family responsibilities including still actively raising a family, including teenage children
- Currently working or being only recently retired
- Having significant financial commitments based on previous earnings
- Needing to revise their expectations of everyday life, such as work, finances, living arrangements, social and sexual relationships, and independence and responsibility for others
• Future plans that are affected at an earlier stage in life
• Being more likely to have a rarer form of dementia than Alzheimer’s disease or a genetically-based cause
• Experiencing difficulty in accessing appropriate services, particularly as younger people with dementia are often otherwise physically strong and healthy (Alzheimer’s Australia 2007).

This essentially means that the range of impacts of dementia on any person is compounded for those who are younger and their families, for whom the diagnosis is likely to be a greater shock and cause greater disruption in their lives. Because YOD is less likely to be Alzheimer’s disease than dementia in older people it may be accompanied by “more unusual types of dementia (which) come with a very different presentation of symptoms and functional disability” (YODA Inc 2010). AD remains the major cause of YOD, but other forms occur in larger proportions than for later onset dementia (Alzheimer’s Australia 2009).

As a NSW review found “People with younger onset dementia need services and workers to understand their very different life stage. This group of people do not identify as aged care clients being younger than aged pensioners and often having been forced into an unplanned, early retirement. They are also likely to have significant physical strength and capacity and want and need significant exercise” (Alt Beatty Consulting 2007).

People with YOD require different types of support than those who are older, and care in a residential facility may not be appropriate. For example, people with younger onset dementia are likely to be physically able, which is particularly problematic for residential care and respite services because facilities are often designed for the physically frail or disabled. The emotional impact of ‘premature’ institutionalisation is also significant (Access Economics 2010).

Access Economics, quoting Alzheimer’s Australia, states that:

“Greater support is required in the community care setting to enable younger people with dementia to continue to combine work and family responsibilities. For example, children of people with younger onset dementia may be at greater risk as the family tries to cope with the condition and relationships come under stress. Support services therefore need to be available for children and teenagers to help them cope with the effect of dementia on their parent” (Access Economics 2010).

AAV has identified supporting people with YOD as a priority area for their action research agenda. They are particularly interested in exploring different modes of delivering support for this group, who are generally likely to be more ‘tech savvy’ than older people, and who also require services that can adapt to and fit in with their broader range of responsibilities and obligations.

International support bodies, like the Alzheimer’s Association (US) and Alzheimer’s disease International provide tips and hints for ways in which people newly diagnosed with YOD
can build supports around them, communicate with others about their diagnosis and adjust to it without losing their sense of humour or positivity. In addition to the informational and emotional support that ought to accompany any diagnosis, people with YOD are more likely to require practical support with learning about changing their employment status, superannuation issues, or considering early retirement (Armstrong 2003).

The Younger Onset Dementia Association Inc (YODA Inc) in a submission to the Disability Care and Support Inquiry warns of the need to tailor support to meet the different needs of people with YOD, for example not having physically fit people in their 50s involved in the same activities as frailer older people (YODA Inc 2010).

**Gender**

Gender as well as ethnicity has considerable bearing on the experience of dementia. Significant gender differences have been found in caring roles and experiences between men and women.

**Women**

The degree of stress for carers generally increases as dementia progresses, and the burdens become more numerous and varied. Carers commonly do not “identify and acknowledge the severity of their fatigue, depression, and stress, and even the most vulnerable and exhausted carers may resist suggestions of respite and deny their need for help” (Montgomery and Williams 2001). This is generally more pronounced for women than men.

More women than men are associated with providing 24-hour nursing care, and having higher levels of stress and poorer health. Women are more likely to take on the caregiving role because of socio-cultural expectations to adopt nurturing roles. Many are already in these roles and are more likely to give up paid work, or experience disruption to their working life (Montgomery and Williams 2001). This pattern has been explained as ‘a consequence of the more intense care and the greater amount of personal care that women provide’ (Montgomery and Williams 2001; see also Dupuis, Epp and Smale 2004). This is often a by-product of carer guilt, where the carer falsely believes that because they are caring for a loved one, it should not feel like a burden or a chore. Carers can fail to acknowledge the impact of the simultaneous loss of relationship that occurs at the same time as they take on the responsibility for care-giving.

The experiences of women as carers are not homogenous and will relate to broader factors including family and social support and the nature of the relationship between the carer and the care-recipient. Wives and daughters will also have different experiences. Daughters generally report greater strain and experience higher rates of depression (Tully and Sehm 1994 cited in Brodie and Gadling-Cole 2003), and this is attributed to the ‘sandwich generation’ of women who are torn between caring for their children and their ageing parents (Montgomery and Williams 2001).
Men

In contrast to daughters, few sons opt to take on the carer role (Montgomery and Williams 2001). They are more likely to consider institutionalising the person with dementia or delegate parts of the carer role to other family members (Montgomery and Williams 2001; Dwyer and Miller 1990 in Brodie and Gadling-Cole 2003). When men do take on the carer role this becomes noteworthy and they may get more support and recognition for it, from both family and service providers (Montgomery and Williams 2001). This can influence the carer’s response and interaction with the service system and their relationships with extended family. Daughters may well feel more resentful about the care-giving role because they do it more intensively than sons do, and do not feel they receive societal recognition for it. Daughters are however more likely to avail themselves of wider emotional support in their role than sons do.

This is not to say that the burden on male carers and the different stresses they face are not significant. For elderly male carers, the needs are different again. The loss of their professional role in the world and the meaning they attach to this may explain why fewer men than women are able to maintain the “continuous relationship” with their wives. Women have traditionally been able to find more meaning in the home. Service providers and policy makers are best positioned to deliver effective interventions when they take the following factors into consideration:

- For partners who may be suffering from grieving in response to the relational loss of their mate, psychological support and acknowledgement of loss may be an appropriate intervention.
- In contrast, working daughters may need counselling on balancing multiple roles as a result of care-giving.
- Similarly, husbands who provide care for their wives may benefit most from help with actual care tasks. Such help could include environmental modifications to make physical care and monitoring easier (Montgomery and Williams 2001).

Montgomery and Williams suggest that “the costs of home care are borne disproportionately by women and minorities. For many women, care-giving is an oppressive institution that can interfere with their sense of competence, economic independence and options for equality in adulthood” (Montgomery and Williams 2001).

This suggests that it is not what is done, but who performs these tasks and in what manner that is important. Careful consideration of the care-giving context, especially the relationship between the carer and the care recipient, may lead to a better understanding of the impacts of care-giving and more effective design and targeting of support services.
The Care Relationship

Research in 2001 into family members’ relationships with people with dementia found that three general trends were apparent in the ‘type’ of relationship between carer and care recipient:

Continuous: the essential nature of the relationship remains unchanged. Despite the burden of providing care, the carer can still ‘see’ elements of the person they knew before the disease struck, and derives personal benefit from this continuity. The carer also maintains the care recipient’s habits and patterns while providing care, which they perceive to be of mutual benefit.

Continuous but transformed: carers and their family maintain a relationship with the person with dementia based on the new circumstances that have presented themselves, however they see fleeting or minimal signs that the person they knew is still ‘there’. They are committed to meeting the person with dementia’s needs, however they don’t tend to maintain the person’s previous daily rituals or habits.

Radically Discontinuous: The carer emotionally distances themselves from the person with dementia recognising that the relationship as they knew it is over. This type of relationship is usually a coping mechanism on the part of the carer who finds the ambiguity of the continuous but transformed relationship too difficult to bear (Chesla et al 2001).

If not a partner, the carer is usually another family member. It is known that the process of providing care is emotionally, physically and financially draining (Montgomery and Williams 2001). The experiences of carers, including their stress levels, the ‘burdens’ they face (defined as the ‘cost’ of care), and the types of support they require will vary according to the nature of their relationship (Montgomery and Williams 2001).

This concern for the costs that families bear is based on a belief that families are the ‘best’ source of private care. If carers are not well supported, there may be a shortfall in available care which the state will be required to meet. This will have a longer-term impact on the health service system. Most discussions about supporting carers are premised on the dual focus of preventing carer burnout, increased burden on the system, and the improved care provided to the person with dementia by carers who are healthy and well supported.

Before carers can be adequately supported, it is vital to understand the various dynamics at work in their relationship, and the ways in which ‘the care-giving process seriously damages some individuals and families while others are better able to cope and remain intact throughout the experience’ (Montgomery and Williams 2001).

These relationships ‘work’ for different carers in different ways. Counselling can assist by supporting the relationship to maximise what works in it or counselling can assist carers who might wish to change the nature of the relationship, e.g. from radically discontinuous back to continuous. Counselling the carer will reveal whether this framework is useful or
desirable. It is perhaps most useful in defining the core of the relationship ‘as it is’ at the
time the counselling relationship begins.

Caring may require the carer to give up their employment (Gutheil and Chernesky 2001),
which in many cases, may be a primary link to the outside world. For men in particular,
their employment may also be ‘that which defines them’. Therefore, the cost to society is
much broader than just the substitute cost of the person with dementia being in private
care as opposed to state-subsidised care; it includes ‘losing’ people who transition from
employment to welfare — and this applies to both the person with dementia and the carer.

Carers are frequently short on time, and tend not to look after their own physical and
mental health. They may be depressed and lack the inclination to self-care, or they may
simply be too time-deprived. The depression can stem from the loss of relationship with
the person with dementia, loss of their broader social world as well as the daily demands of
care-giving. Regardless of who the carer is, the nature of their relationship with the person
with dementia prior to diagnosis will have an impact on the relationship afterwards.

In the case of sons and daughters, relationships that have reached filial maturity (that is, the
point in adult parent-child relationships where they respect and acknowledge each other as
adults, beyond the traditional role of parent and offspring) will cope much better. The
type of relationship that existed prior to the disease striking will impact on the relationship
after diagnosis and on the efficacy of supports provided to both the carer and the person
with dementia (Pusey 2001).

The type of care will vary with children providing a less intimate style of care to partners,
with sons distancing themselves from the care-giving role more than daughters, and more
inclined to delegate some of the responsibility. However, burden is not necessarily
proportional to increases in physical disabilities. Greater stress has been noted among
individuals caring for a relative with dementia than for those with physical disabilities
(Levesque et al 1999). Yet others note fewer burdens for some family members caring for
a loved one with dementia than for family members caring for a physically disabled person
(Montgomery and Williams 2001).

Social Networks
Social networks can be particularly impacted for male carers. Older male carers tend to
classify their relationships rigidly in black and white terms (Hanks 1992), and this
demarcation can make them less inclined to seek help from others and outside sources.
Men also may experience considerable isolation as a result of their social networks
changing as they give up paid work to become carers. For older men in particular, “the
transition to social locations other than market economy work often denotes a relinquishing
of identity, and their experiences as gendered individuals are significantly diminished in
importance” (Hanks 1992). Questions regarding this transition include:
• “How do their social networks change and evolve from the market economy or the workplace to the emotional economy of spousal care? and
• In what ways do social networks affect their lives as carers, compared to their careers in the market economy?” (Russell 2003).

For many men, their social world is largely the workplace, and their emotional support comes from their partners. When their partner develops dementia, the changes to the relationship are profound. Research into support for older men carers found that group activities that were marketed as information provision, not as “support groups” were most well received (Russell 2003). Sources predict that the ranks of older male carers are “expected to increase as an aging society continues into the new millennium [as] men’s mortality declines, and conceptions of family and gender roles continue to broaden” (Russell 2003). It is vital therefore that service providers explore “gender-sensitive modes of carer support” (Ibid). Regardless of gender, each carer adopts societal norms relating to his or her family circumstances and context, which creates expectations that are unique to that carer. The way they relate to the care-recipient and their care-giving role in general, is determined by this set of expectations. It follows that care styles result in different consequences for carers, and therefore different requirements for support.

What do carers need?

Relationships (see 5.5) are not the only determinant of a carer’s needs. Beliefs that carers hold about their caring situation are central to counselling. For example, the stress model discussed by Mittelman (2003) involves helping stressed people change their perceptions of stressors, providing them with strategies to help them cope and improving their confidence in their ability to do so.

Effective counselling therefore requires the counsellor to identify these variables to uncover the essence of the relationship between the carer and the person living with dementia, the changes that have occurred as a result of taking up the care-giving role, their extended family support and social networks and the key needs of carers. This is discussed in the following chapter.

The needs of carers will vary considerably depending on a number of factors considered in more detail, below.

Partners

In many cases, the carer of a person with dementia is their partner, which means that carers are also elderly, and have their own distinct set of needs. Spouses experience their caring role differently to other family members and differently to the way other partners might. Spouses may be at increased risk because of their own physical frailties and loss of support however they may also persist with the care-giving role because they view it as a part of their marriage commitment (Vitaliano 2006).
Intimacy

Caring for a partner has been described as a double bind, where ‘the marital bond and physical presence of the partner endures, but the carer feels emotionally and sexually abandoned on the one hand, and trapped on the other’ (Hanks 1992). This can have implications for the carer’s mental and physical health, as well as the quality of the care they are able to offer the person with dementia as ‘the multiple cognitive deficits and behavioural disturbances resulting from dementia have an immediate impact on the impaired couple and either or both individuals may be directly or indirectly affected’ (Hanks 1992).

The intimate relationship previously known with their partner seldom endures, and what makes the relationship ‘different’ to other relationships in the carer’s life, often ends. A number of marital difficulties frequently occur after diagnosis and worsen as the disease progresses (Hanks 1992). The partner will continue to provide care that reflects the intimacy of the relationship in an atmosphere that is often devoid of intimacy.

Guilt

Guilt is a dynamic that afflicts dementia carers, particularly partners, and impairs the natural functioning of a relationship. In the early and mid-stages of dementia, sexual closeness remains an option, but many ‘carers choose to prematurely isolate and distance themselves from their mates’ (Hanks 1992) as they worry mostly about their partner’s ability to consent. Withdrawing affection can be a characteristic of the ‘continuous but transformed’ or ‘radically discontinuous’ relationship types discussed previously. This change can have unfortunate consequences for the person with dementia and their partner by terminating what could otherwise be a source of comfort to them. Even in the terminal stages of life people with a diagnosis of dementia may still enjoy and respond to affection (Hanks 1992).

Guilt may lead carers to resist suggestions of respite and other supports offered to them. “Their list of ‘shoulds’ becomes endless as they intensify their nursing responsibilities. In direct proportion to their level of guilt, carers typically find that little personal time is available for outside activity or socialisation” (Hanks 1992; see also Brodie and Gadling-Cole 2003). Activity restriction is a key factor in increasing risk of depression for spousal carers (Niebor et al 1998 quoted in Montgomery and Williams 2001).

Spouses are identified as providing more intense care and more personal care than the children of people with dementia do, and daughters provide more help with household tasks and personal care than sons do. These patterns reflect “choices made by family members to assume or abdicate the carer role” (Montgomery and Williams 2001). For all these reasons, a partner tends to report greater subjective and objective burden than other carers (Dupuis et al 2004). Therefore the familial relationship provides critical direction for counsellors in how to best support the carer.
This difference in role type is also influenced by generational factors. Particularly for the wives of people with dementia, their primary role in the family has been to support their husbands and children in living their lives outside the home (Montgomery and Williams 2001). Generational roles and expectations will impact on the characteristics of the carers and their needs. Combined with the expected increase in the number of dementia diagnoses, this will have implications for AAV’s future role.

When the person living with dementia can no longer recognise and interact with their carer as a partner, the partner grieves the loss of the relationship. At this point, a partner carer may finally make the decision to abdicate the care-giving role (Montgomery and Williams 2001).
Modes of Counselling Delivery

Counselling can be offered in a number of forms other than traditional face-to-face service modes. Over the past decade or so, there has been a marked increase in a range of telephone, internet and e-health services in the fields of medicine and counselling. These services have increased dramatically over the past decade and have been particularly successful in meeting the needs of younger age groups of clients as well as those people who are comfortable and proficient with internet-based applications such as chat rooms and online discussion groups.

Dementia-related peak bodies in the UK and USA for example, have established, run and where applicable, moderated, a suite of regular online services that are tailored to a range of support groups and provide information and counselling to families, carers and people living with dementia. There is much scope for AAV to modify similar initiatives for its emerging needs of counselling and support services.

Counselling the person living with dementia

Most Alzheimer’s organisations provide counselling to the person with dementia as well as to their carer. The needs of the person with dementia will change through the progression of its different stages. The Alzheimer’s Disease Research Centre (ADRC) states that it takes time to work through the stages normally associated with the diagnosis of a terminal illness: denial and isolation; anger and resentment; bargaining; depression; and finally, acceptance (Alzheimer’s Disease Research Centre n.d).

Counselling takes these stages into account and treats a person living with dementia appropriately according to the stage and that person’s own set of needs. According to the ADRC, people living with dementia who have reached the acceptance stage and accept the terminal nature of their situation are much more able to enjoy life and adapt (ADRC n.d.). The Alzheimer’s Disease and Memory Disorder Centre (ADMDC) caution that:

Medical counselling should not be confused with therapy. Counselling within the setting of the ADMDC is intended to educate the person living with dementia and family about their condition, determine factors influencing the immediate and long-term management…and assist in developing a treatment plan. Treatment plans are tailored to the specific needs of each person and family based on a psychosocial assessment performed at the time of diagnosis (Baylor College of Medicine 2007).

This position confirms the ‘practical’ nature of counselling offered to people with dementia and carers. ADMC’s counselling is also offered to the person living with dementia and their carer and family members together, as a group, to address everyone’s concerns.

AAV’s services for people living with dementia and their carers involve:
- Services and support: people and the expertise to provide the information, practical advice and support
- Counselling and individual support: emotional, practical and family issues in confidence with professional counsellors
- Education & Training information sessions and education programs: to learn more about dementia and practical ways of dealing with it
- Living with Memory Loss Program: A Commonwealth funded national service for both people with early stage dementia and family members to get information and talk through issues, in a group program
- Multicultural Services: meeting the language and cultural needs of all members of the community
- National Dementia Helpline: for 24 hour information and support service
- Telephone Outreach Program Support: through regular telephone calls delivered by trained telephone advisors
- Telesupport Program: a group telephone program for people caring for a family member or friend with dementia
- Consumer Advocacy provided to all people living with dementia.

This list shows that AAV has a considerable understanding of the range of supports required, combining practical and emotional supports to meet a variety of needs in the dementia-affected population. The purpose of this action research project is to explore different modalities through which this support can be offered.

**E-health and the Internet**

E-health is essentially an emerging field of medical informatics, referring to the organisation and delivery of health services and information using telephone, internet and related technology such as SKYPE. (The Royal Australian College of Physicians). Its main advantage is to “provide access to health care across time, social, and cultural barriers” (Stanberry 2000). E-health encompasses a broad range of possibilities ranging from diagnosis, treatment, education, and research that influences how the care for people with dementia is provided (Dyer 2001).

Broadly, e-health includes not only technical development but also a new way of working, an attitude and a commitment for networked global thinking, to improve health care locally, regionally and worldwide by using information and communication technology (www.ahcwa.org.au/index.php?option=com_docman). For example, over the past five years or so, traditional face-to-face counselling services, such as those mainly offered by services such as Relationships Australia have expanded their range of services to offer e- and video-counselling (http://www.relationships.com.au/). There has also been a growing number of private counselling practitioners in the Australian and international market that exclusively offer internet and/or video-linked services.
The definition of web-based or internet-based counselling is not conclusive. Elly Robinson writes that internet-based counselling can vary considerably according to:

- whether it includes human communication (e.g., online therapy conducted with the involvement of a therapist), or is a self-help, website-based therapy (e.g., an Internet-based program that a client can use independently of contact with a counsellor or therapist);
- real-time (synchronous) or delayed (asynchronous) communication;
- mode of communication (audio, video, text);
- individual or group; and
- type of therapeutic approach (Robinson 2009).

The advantages of internet-based services include its:

- Convenience to carers of being able to access services from home
- Anonymity for users
- Ability to access resources that may be located far away
- Capacity to form counselling groups that do not have to rely on geographical proximity (‘New Technology for Service Delivery—Counselling, Support and Groups’ n.d; see also Serafini 2007)
- Potential for counselling clients to take their time expressing themselves by putting their thoughts into text
- Quality, because there is capacity to reproduce, re-read and review the counselling advice given (Elder Care Resource Centre 2008).

There are also some potential short-comings to e-health noted in the literature such as:

- Lack of visual cues provided by face-to-face contact making counselling challenging
- Time delay of email may be detrimental to a carer who is in crisis
- Lower levels of literacy and IT skills of the carer can be limiting
- Potential miscommunications that can occur in text are more difficult to resolve (Elder Care Resource Centre 2008).

However, these short-comings can offer guidance for how best to maximise and tailor the advantages appropriately to the needs of the particular groups such as: young people whose parents or carers have a diagnosis of YOD; carers who work full-time, have limited time and are comfortable with IT; and some rural and regional-based people who already use internet for a range of tasks.

One of the reservations regarding e-health is the lack of guidelines, standards and regulations available to ensure that it is practiced legally, ethically and meets high practice standards in a variety of settings (Stanberry 2000). There is concern that any person or professional can develop a web-based practice, and the quality of the service is not usually addressed except by service users who are unqualified to judge whether the therapist
meets professional practice standards (Pusey 2001). There are some ethical issues with delivering internet based services not limited to informed consent, privacy, confidentiality, and the duty to protect (Pusey 2001).

An evaluation of an internet based counselling service for carers, Link2Care, found that up to 80% of carers refer to the internet for information and support (Kelly 2003). Link2Care, provided by the Family Caregiver Alliance in the US, was designed in recognition of the fact that carers of people living with dementia may find it more difficult to access community-based services in person compared with other carers. “The goal of Link2Care is to increase carer wellbeing and coping skills through convenient access to information, connection to other care-givers, and other services provided in the home” (Kelly 2003: 88). Of the 700 carers enrolled with Link2Care at the time of writing in 2003, 74% were female and most aged 40 to 79 years.

The Australian Department of Health and Ageing (n.d.) report that the lack of evaluation research into web-based counselling in particular presents a challenge to e-therapy as a useful mode of service delivery. There is little research into the issues of efficacy, ethics, liability, license regulations and laws as they apply to e-health. Any evaluations that have been undertaken have been limited in scope and sample size, leaving unanswered many crucial questions relating to the quality and effectiveness of internet-based counselling. Until such evidence is available, there are likely to be continuing polarised views regarding the appropriateness and effectiveness of web counselling as an intervention. The few studies on the effectiveness of web counselling indicate that clients:

- perceived some positive benefits from their contact with the service
- reported some reduction in levels of anxiety
- rated the counsellor’s helpfulness reasonably highly
- were referred to other avenues of support
- demonstrated considerable improvement in relation to self reported measures of well-being” (New Technologies for Service Delivery – Counselling, Support and Groups’ n.d).

The practice standards required for delivering internet-based services as opposed to face-to-face counselling are different (Serafini 2007). E-therapy, as Grohol (1999) argues, can more effectively target particular issues—either emotional or practical—for the carer and does not need to be responsive to the flow of conversation in the way that face-to-face counselling is. The counsellor, particularly in an email situation, is able to think through their response and not have to “think on their feet” (Grohol 1999). This suggests that the advice/support the carer receives might be more effective and efficient than in a face-to-face setting. However, there is a danger that without a face-to-face component the counsellor does not have all the information they need to work with somebody most effectively. Robinson (2009) qualifies that it is the counsellor’s comfort level in operating
without these visual cues that will determine whether this impacts on effectiveness (Robinson 2009).

**Telephone Counselling**

Telephone technology has been identified as having a positive effect on a range of dementia related outcomes such as counselling, education and support provision. The following areas are noted in the literature: counselling for individuals, couples and groups of carers (Steffen 2000); for education on dementia and services available (see, for example, Teel & Leenerts 2005); as part of a multi-component interventions to address carer stress, mental health and wellbeing (see, for example, Clay 2004; Davis et al 2004; Nichols, Chang et al 2008); self-care through exercise (Connell & Janevic 2007), and telephone-based CBT programs (Glueckauf & Stine 2005).

One of the challenges is that the telephone is often part of a broader intervention, which makes it difficult to isolate the effects of that component. However, there are promising findings that demonstrate telephone counselling is as effective as face-to-face counselling when used appropriately and tailored to the needs of the carer (see, for example, Bank et al 2006).

Overall, ‘New Technologies for Service Delivery–Counselling, Support and Groups’ (n.d – provided by client) identify the advantages of telephone counselling as including:

- Convenience of communicating from home, especially for active carers
- Choice of anonymity if desired
- Access to resources which may not be available in the home area
- Phone technology is widely available and well used by all ages
- Specialised Groups can be formed where population numbers would not support face-to-face programs
- Lack of visual cues, but many auditory cues available
- Can be as effective as face-to-face counselling as some people are more comfortable in ‘phone communication

Telephone counselling can occur either as a one-on-one arrangement between the carer and the counsellor, or as group counselling via teleconferencing. It requires counsellors to be trained without the aid of visual cues (as with internet-based support), and can be used either exclusively or to supplement face-to-face counselling.

One project designed a low-cost, telephone-based intervention to reduce anxiety, depression, and feelings of burden and stress in carers of people living with dementia, as well as to improve quality of life and family functioning (Tremont 2001). The overall goal of this project was to establish preliminary efficacy of the intervention.

The initial phase of the project involved adapting an existing telephone-based intervention for carers to use with people living with dementia, as well as creating measures of
treatment satisfaction and intervention compliance and adherence. A randomised, controlled pilot study compared the intervention to standard care for reducing carer distress.

Carers received a resource packet containing information about caring for someone with dementia and a listing of local resources. Those carers in the comparison group did not receive the intervention but were not restricted in their use of available, standard care interventions. The intervention group received a series of telephone calls over 12 months, during which emotional support and training in problem-solving skills was provided by trained therapists. The intervention resulted in moderate levels of reduced carer burden and emotional distress, as well as some improved quality of life, family functioning and increased use of community resources (Tremont 2004).

Bank et al (2006) examined the usefulness of technology for conducting telephone-based support groups for ethnically diverse dementia carers. Participants were 41 White American and Cuban American dementia carers participating at the Miami site of the Resources for Enhancing Alzheimer’s Caregiver Health (known as REACH) program. Support groups were conducted over the telephone in English and Spanish as appropriate. Eighty-one percent of the participants found the group “valuable,” largely because of the social and emotional support and useful information obtained from other group members. The majority of carers also reported that participating had increased their knowledge and skills as carers. The findings demonstrate that telephone technology can overcome the often formidable logistical problems faced by both English- and Spanish-speaking carers, and it can provide benefits similar to those obtained in face-to-face support groups.

In some cases, the telephone is part of an intervention. Investigating the efficacy of an anger-management video series and workbook for dementia family carers, Steffen (2000) used materials from a previously developed intervention to create a videotaped version of the treatment program. The eight-week intervention focused on cognitive and behavioural skills to manage anger and frustration (i.e., relaxation training, cognitive restructuring, and assertion training).

Compared to control participants, carers in both of the treatment conditions had lower post-treatment levels of anger and depression, and higher ratings of caring self-efficacy. Results from this preliminary study suggest that innovative multi-component interventions can be effective for middle-aged and older carers of people living with dementia with the telephone an effective means of having ongoing support.

A program of Self-Care Talk was conducted by Teel et al (2006) through a series of telephone-based sessions between advanced practice nurses and older adults. Session content included practicing healthy habits, building self-esteem, focusing on the positive, avoiding role overload, communicating, and building meaning. Specific self-care strategies were explored in the context of an individual’s experiences, relationships, and
condition. Intervention implementation was evaluated using Lichstein’s criteria of delivery, receipt, and enactment.

Six partner carers of people living with dementia participated. Participants reported understanding session content, and planned to use the information (enactment). Participants also reported an increased awareness about self-care practices and offered specific examples of how they intended to practice better self-care. (Teel et al 2006) suggest that this Self-Care Talk intervention can be implemented as intended and is ready for use with older partner carers of persons with dementia.

A multi-component intervention aimed at increasing social support for partner carers was developed at the NYU Silberstein Aging and Dementia Research Center to address their psychosocial needs (Clay and Mittelman 2004). In this randomised, controlled trial, participants in the intervention group received counselling sessions by 'phone, agreed to join support groups, and had continued access to counsellors, while participants in the control group received usual services offered by the centre.

Satisfaction with social support, reaction to memory and behavioural problems, and depression each played a part in whether the intervention was able to prevent or delay nursing home placement. Regardless, the long-term effectiveness of this psychosocial intervention is beneficial to carers and cost saving in terms of delaying nursing home placement, while considering the role of other variables.

AAV research ('New Technologies for Service Delivery—Counselling, Support and Groups') found that research into the efficacy of 'phone counselling suggests that the results compare favourably to face-to-face counselling. To summarise, telephone support meets four sets of needs for carers:

- the need for information and education
- referral and/or assistance required to navigate through the system
- emotional support
- carer support that is convenient and hassle free (Salfi, Ploeg and Black 2005).

**Group Activities**

**Living with Memory Loss Programs**

In 2000, the Federal Government funded Alzheimer’s Australia to deliver standardised Living with Memory Loss (LWML) programs in every State and Territory of Australia. Alzheimer’s Australia staff facilitate these LWML programs and provide groups for people with early stage memory loss who still have some level of insight into their situation and

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8 Please note this is referred to in the methodology for the Self Care Talk evaluation, however no further explanation of what Lichstein’s approach entails has been found.
their carers/family members. The groups are run once a week for 6-8 weeks, and people with memory loss and their carers/supporters meet both separately and together.

The main function of these groups is to provide information and advice about dementia, how to manage the available services, drug treatment options, stress management techniques, communication skills, and strategies for coping with changed behaviour. Emotional and social support is also available in the groups providing the opportunity for carers/family members and people with memory loss to share their experiences with others going through similar situations, and with understanding staff.

Evidence from evaluations demonstrate that the Living with Memory Loss programs appear to be delivering well chosen material very effectively, and it has a significant effect on those who participate in it. This relatively low-cost and brief intervention has a ‘significant clinical impact, even though some of the effects were not apparent until the three month follow-up’ (Bird et al 2005).

There were generally high levels of satisfaction towards the program from people with memory loss and their carers/supporters. The main benefits identified by these two groups were that they learned useful information about dementia, were able to talk freely and openly with others, and felt that they were not alone. An important finding is that ‘people with early dementia retain considerable insight, confirming one of the basic premises of the LWML program’ (Bird et al 2005).

Other benefits of the program include significant improvement in depressive symptoms for people with a diagnosis yet there was an expected slight decline in cognitive ability that was identified at the three month evaluation point. For those people who were clinically depressed when they started the group, there was some decline noted in depressive symptoms (Bird et al 2005).

Carers and supporters reported a decrease in stress-related incidents that were attributed to the changed behaviours of their family member with a diagnosis accompanied by an increase in how they perceived the caring experience as positive and rewarding. According to Bird et al (2005), these results were ‘not due to changes in cognitive or functional status, nor to increased use of health services after the group [but] evident at the end of the group and at the three month follow-up’.

Following the LWML program at the three month period, carer and supporter mental health along with the likelihood of making legal/financial plans for the future showed significantly improvement. However, at the 15 month follow-up period, there was some reduction of depressive symptoms in only a few of the people with a diagnosis who could be interviewed.

An encouraging finding at this final follow-up period was a general positive regard for the value of the group in the context of the cognitive and emotional circumstances that had changed. Bird et al (2005) states that the ‘majority endorsed the program strongly, both
for other people with memory loss and their carers/supporters’. Because of the improvements noted during the three months after the program, this largely fulfils its core purpose of providing assistance. The peer support element of the group was well received.

Bird et al (2005) argue that these evaluation results are important because “changes in validated outcome measures over time are comparatively rare in the support group literature [and] the variables included in this study are predictive of other negative events, including physical morbidity, inappropriate medication use, and institutionalisation”.

The LWML program is based on the professional and collective wisdom of the needs of carers/supporters collected by Alzheimer’s Australia. Social support and training in practical problem solving (according to Cooke et al. 2001) is known to be a crucial component in other contexts and is a key part of the program which may explain why the material is positively regarded by all of its participants.

In terms of cost-effectiveness, the LWML program is short (2 hours, once a week for 6-8 weeks) and delivered in a group setting making it an attractive option to operate within limited financial resources (Bird et al 2005). While some carers/supporters noted that they continue to use the services of Alzheimer’s Australia after the LWML program, there is benefit gained from having a “concentrated burst of information, social support, and problem solving that is shown to be effective in itself” (Bird et al 2005: 49).

Increased capacity to cope with changed behaviour is of major importance in the lives of families who are affected by dementia. Behaviour which is hard for family members to accept and understand is a major predictor of allowing those they care for to go into residential care. There are financial costs as well as emotional ones as the transition into care signifies the closing phase of a couple’s married life, followed by the pragmatic decisions needed with regard to residential care placement (Bird and Parslow 2001).

Bird (2005) attributes the improvements in stress to a likely combination of three factors: a decline in difficult behaviour; carers and supporters understood and accepted it more; and carers learned better ways of dealing with stress. The improvement in stress noted from Bird’s evaluation was clear and likely to be a direct result from attending the LWML programs.

Another significant improvement was the scores for the sub-sample of participants with memory loss who reported depressive symptoms. There were increased use of antidepressants noted after attending the LWML groups. I.e. carers were found to be actively taking steps to treat or reduce their depression. Depression increases the risk of a number of adverse outcomes for this population, including physical morbidity (Bird and Parslow 2001) further cognitive decline (Bassuk et al. 1998) and institutionalisation (Steeman et al. 1997). Depression in the person living with dementia is also a source of distress for family members that can be worse than effects of challenging behaviour (Teri 1997).
Research canvassing the opinions and experiences of both people living with dementia and their carers/supporters is rare and methodologically challenging. However, Bird positively values the content and method of delivery of the LWML programs. There were improvements identified on validated measures up until the three month follow-up.

**Meeting Centres Support Program**

Another form of group activity noted in the literature is the Meeting Centres Support Program (MCSP). This program, developed in Amsterdam, has been evaluated and found to result in significantly decreased carer psychological and psychosomatic symptoms (Droes et al 2006). Droes et al argue that emotional support, opportunities for respite and ‘fun’, as well as information/education and practical skill development are crucial for reducing vulnerability in carers (Droes et al 2006). Essentially, any support option will be insufficient on its own, and should be part of a package (Droes et al 2006).

MCSP was found to have a greater positive effect of helping care-givers to feel competent and reduced some of the behavioural problems in people living with dementia than other forms of ‘day care’ (Droes et al 2006). It also was found to delay institutionalisation. Droes et al (2006) attributes the success of the MCSP to the fact that it targets both the person living with dementia and the carer (Droes et al 2006).

In sum, these group programs demonstrate the important role of group programs as effective support interventions that can achieve results for the mental health and wellbeing of carers and people living with dementia.

These two examples of group support programs identify the benefit of peer support models, demonstrating that this is an area of research that AAV can continue to engage in.

**Family meetings**

Family support and relationships between family members can be as impacted by dementia as social networks are. Research in Western Australia found that “family support is essential to the ability of carers to cope but for the vast majority of participants family support was either unavailable and/or inappropriate. This finding is contrary to the common assumption that families have the capacity to undertake the role of caring and are supportive to the primary carer“ (Centre for Social and Community Research 2003).

AAV has anecdotally reported that counselling can ‘lay the ground work’ for carers to communicate better with extended family about ways to make care-giving less stressful. As discussed above, it may also be the case that a family meeting can reduce the need for more intensive counselling down the track, by giving the family some common goals in their care-giving, and viewing care-giving less as one person’s responsibility.

Family Decision Meetings have been proposed as a form of intervention for over two decades now. Hartman and Laird (1983) describe Family Decision Meetings (FDMs) as “semi-structured gatherings that recognise the value of extended family members, open
up the lines of communication, and allow service providers and families to work together...Family meetings may be initiated to help a family deal with a crisis, to aid in its problem-solving efforts, or to increase its competence as a functioning group” (Hartman & Laird, 1983, p. 305 — see also Brodie and Gadling-Cole 2003; Joling et al 2008).

Joling et al (2008), describe the aims of a family meeting as being to:

- educate families about dementia consequences and resource information for care support;
- mobilise naturally existing family networks of the person with dementia and primary carer in order to improve emotional and instrumental support;
- teach problem solving and techniques that can be used after family counselling ends.

**Summary**

To summarise, research has found that telephone and internet-based counselling and support are emerging modes of service delivery that have proven to be effective under certain circumstances. While not individual modes, Living with Memory Loss programs and Family Meetings are examples of group activities incorporating peer support elements that offer some benefit to AAV in considering which modalities to pursue for their action research agenda.
**Conclusion**

This Background Paper has established, based on recent Access Economic data that dementia is an ever-increasing problem in Australia with both incidence and prevalence expected to increase dramatically over the period 2010 – 2050, creating further stress on the service system. In Victoria, CDAMS provide the main public health diagnostic link between the community and dementia specialist providers like AAV. Referral pathways are required to be particularly adept at ensuring people receive the support they need and that this support does not end with diagnosis.

Even with the presence of CDAMS in Victoria, greater community awareness is still required to ensure people can access CDAMS for a diagnosis. Late diagnosis of dementia is an alarming and growing trend internationally as well as in Australia (Access Economics 2005). If dementia is diagnosed as early as possible, then research shows that the person with a diagnosis and their carers and families have a greater possibility of planning for their future and of availing themselves of the help, support and treatments available.

The benefit of early diagnosis is that both the person with dementia and their carers and families are able to plan, while in the early stages, for how to cope practically, financially and emotionally as life becomes more stressful. This is known to improve carer wellbeing and to lessen the likelihood of the breakdown of home care and increase coping skills of carers and families, minimising the need for care settings and respite.

Regardless, caring for a person living with dementia can involve prolonged grief, compounded by the daily demands of care-giving and the loss of identity that may come with giving up work or other responsibilities to take on the caring role. Carers also experience ambiguous loss – losing the relationship and its intimacy (particularly in the case of caring for a partner), while still having the person with dementia physically present in their lives.

Every person with dementia and their family members experience the disease differently, and this is often related to their social setting, cultural status, socio economic status or gender. For example, people from some CALD communities might find the language barrier prevents them from knowing about or accessing support services, and in some cases this stress may be balanced by a greater sense of familial unity and cooperation. Women tend to bear the greater brunt of the ‘burden’ of caring, sometimes for parents and children at the same time, whereas men may find the loss of social networks through forced retirement particularly difficult to bear.

To date, the most successful counselling interventions have been those that target the specific needs of carers. These needs will differ as different people experience situations differently and hence need different types of support. When ‘support services such as respite have been offered with little attention to the specific care-giving context, these
supporters have failed to make a significant impact on carer outcomes’ (The Commonwealth Fund 2009).

The mode of delivering counselling and support has been discussed in this review with particular emphasis on non-traditional methods of delivering counselling—telephone and internet based. These are modes that might better suit some carers for their convenience and accessibility, and some people with dementia, particularly those with younger onset dementia, who more likely to be receptive to these technologies.

The Background Paper shows that despite what some might describe as a ‘paucity’ of literature on how best to support people with dementia and their carers, there is sufficient evidence to confirm that AAV’s action research agenda adequately reflects the range of issues currently dominating the dementia field and can add value by helping to identify which modes of support are best suited for which carers and care-recipients.
## Appendix B: List of interviewees

<table>
<thead>
<tr>
<th>Name</th>
<th>Role/Agency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maddie Adams</td>
<td>Eastern Metropolitan CDAMS</td>
</tr>
<tr>
<td>Diana Bilotta</td>
<td>AAV</td>
</tr>
<tr>
<td>Emma Bourne</td>
<td>Helpline and Counselling Manager, AANSW</td>
</tr>
<tr>
<td>Di Calleja</td>
<td>Service Development Unit, Aged Care Branch, Department of Health</td>
</tr>
<tr>
<td>Elizabeth Crask</td>
<td>AAV</td>
</tr>
<tr>
<td>Alison Dalzeil</td>
<td>Ballarat CDAMS</td>
</tr>
<tr>
<td>Sandra Davidson</td>
<td>Hume CDAMS</td>
</tr>
<tr>
<td>Female (10)</td>
<td>Carers</td>
</tr>
<tr>
<td>Norminda Forteza</td>
<td>AAV</td>
</tr>
<tr>
<td>Lynn Gray</td>
<td>Southern Metropolitan CDAMS</td>
</tr>
<tr>
<td>Dominique Horne</td>
<td>AAV</td>
</tr>
<tr>
<td>Francesca MacNamara</td>
<td>AAV</td>
</tr>
<tr>
<td>Jennine Melville</td>
<td>Southern Metropolitan CDAMS</td>
</tr>
<tr>
<td>Michele Mew</td>
<td>Sunshine CDAMS</td>
</tr>
<tr>
<td>Male (2)</td>
<td>Carers</td>
</tr>
<tr>
<td>Suzie Nimmo</td>
<td>AAV</td>
</tr>
<tr>
<td>Patricia O'Brien</td>
<td>AAV</td>
</tr>
<tr>
<td>Debra Parnell</td>
<td>Council on the Ageing (COTA)</td>
</tr>
<tr>
<td>Jenny Philipp</td>
<td>AAV</td>
</tr>
<tr>
<td>Penelope Poulier</td>
<td>AAV</td>
</tr>
<tr>
<td>Name</td>
<td>Organization</td>
</tr>
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<td>-----------------------</td>
<td>--------------------------------------</td>
</tr>
<tr>
<td>Vicky Powell</td>
<td>AAV</td>
</tr>
<tr>
<td>Elizabeth Rand</td>
<td>Caulfield CDAMS</td>
</tr>
<tr>
<td>Ruth Rechner</td>
<td>Carers Vic</td>
</tr>
<tr>
<td>Ann Reilly</td>
<td>Services Operation Manager, Support Services AAV</td>
</tr>
<tr>
<td>Grace Roberto</td>
<td>Co-ordinator Multicultural Services AAV</td>
</tr>
<tr>
<td>Anne Ryan</td>
<td>AAV</td>
</tr>
<tr>
<td>Maree Ryan</td>
<td>AAV</td>
</tr>
<tr>
<td>Yvonne Shaw-Truex</td>
<td>AAV</td>
</tr>
<tr>
<td>Donatella Spatari</td>
<td>AAV</td>
</tr>
<tr>
<td>Alan Stott</td>
<td>Information &amp; Infrastructure Specialist, AAV</td>
</tr>
<tr>
<td>Catherine Watson</td>
<td>Parkinson’s Victoria</td>
</tr>
<tr>
<td>Sonie Wilson</td>
<td>AAV</td>
</tr>
<tr>
<td>Marie Wiseman</td>
<td>Loddon Mallee CDAMS</td>
</tr>
<tr>
<td>Leanne Wenig</td>
<td>General Manager, Support Services AAV</td>
</tr>
</tbody>
</table>
Appendix C: Interview Schedule

Generic telephone interview schedules for clients

1. What is your name?
2. Please specify your age range:

<table>
<thead>
<tr>
<th>Age Range</th>
<th>25 yrs. and under</th>
<th>26 – 35</th>
<th>36 – 45</th>
<th>46 – 55</th>
<th>56 – 65</th>
<th>66 – 75</th>
<th>76 – 85</th>
<th>Over 85</th>
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</tbody>
</table>

3. How did you find out about the [action research project] model being trialled?
4. Which mode of service have you used?
5. Were the hours offered for appointments sufficient?
6. What were your expectations of the trialled service?
7. To what extent has the trialled service met your expectations?
8. Were you hoping to gain anything from your participation that you do not feel you received?
9. Do you feel the sessions were worth your time and effort?
10. How would you rate your participation experience?
11. What do you feel you have gained from participating in this trialled service?
12. How important has this gain been for you on a personal level?
13. What, if anything, has worked well in this trialled service?
14. What, if any aspects of the trialled service could be improved?
15. Would you choose to receive this type of trialled service in this manner again?
16. Would you recommend the delivery form of this trialled service to others?

Generic Interview and Focus Group schedule

1. Where is the project up to?
2. What the process has been like so far?
3. What have you learnt about your pilot project so far?
4. What have you learnt about your client group?
5. What is assisting the pilot being established?
6. What is getting in the way of the pilot being established?
7. What plans do you have for the program based on what you have learnt so far?
8. Is there anything else you want to say about the pilot and the preparation process?
Appendix D: Alzheimer's Australia Victoria agency data

Program Level Data

The data below for the period July 2003 - June 2008 was supplied by AAV.

Figure 1: Group Type by Contacts (July 2003 - June 2008)

- The above chart refers to 69,426 contacts from July 2003 to June 2008. A ‘contact’ refers to any form of communication between staff and the client group including facsimile, telephone call, email, face-to-face, or mail where some sort of relevant exchange of information takes place (e.g. discussion of dementia/caring). A contact records what service was provided and when.

- The client group (those other than service providers) with the largest percentage of recorded contacts (more than three-quarters) was family (75%) (including the person of concern, family members, the counsellor(s) and others concerned with services to the family.)

- Service providers/professionals represented 14% of recorded contacts. Contacts with service providers include client specific contact and non-client contact e.g. talking about AAV services or working on a project.

Figure 2: Primary Contact Mode (July 2003 - June 2008)
- The most common primary modes of contact involved telephone usage, comprising two thirds of contacts (66%).
- The most common way for clients to come into primary contact with the service (33%), is through the Helpline, which is a support service provided by Advisors (trained volunteers), and counsellors.
- Note: Most Helpline contacts are brief whereas counselling sessions are usually 1-1.5 hours. Many people receive information and referral; a comparative few receive core counselling. Also many Helpline contacts are once–only callers whereas core counselling is usually at least a few contacts and sometimes many. The other variable is that core counselling sessions may involve different configurations from whole families to couples or individuals.
Contacts overall are rising. The lower number in 2004-2005 is attributed to a breakdown in the database. The increase in 2007 is partially attributed to the implementation of a metro intake system resulting in many more contacts of comparatively short duration.
• The family group had the largest number of contact hours in terms of ‘direct time’, followed by the general public. This pattern was consistent across number of hours for travel time, as well as total time.

Figure 4: Contact Time (no. of hrs) by Group Type (July 2003 - June 2008)

• The family group has the largest percentage (64%) of direct contact time with the service, followed by service providers/professionals (17%).

Figure 5: Direct Contact Time (%) by Group Type (July 2003 - June 2008)
The groups with the largest percentages of over 45 minutes of contact time were the early stage group (81%), the information/awareness group (72%), and support groups (50%).

The ‘anonymous’ group had the largest percentage of 1-10 minutes contact (47%) and this likely reflects brief enquiries to the helpline.

Overall, 50 percent of all groups were in contact with the service between 1-20 minutes, and 50 percent were in contact over 21 minutes.

Groups which had reasonable spread of contact proportions across the time categories included families, the general public, and service providers/professional.
Across all years family was the group with the largest percentage of contacts. There has been a steady increase in the relative percentage of family contacts from 70% in 2003 to 81% in 2008.

There has been a steady decrease in the relative percentage of contacts involving service provider/professional from 17% in 2003 to 10% in 2008.
Client demographics snapshot date for 2007-08

Figure 8:  Gender

- The majority of carers were female (73%), compared with one-quarter male (24%).
- The gender distribution for ‘persons of concern’ was female (56%) and male (39%).

Figure 9:  Age of Person of Concern

- For persons of concern, the overwhelming majority were over 70 years of age (84%).
Female relationships to persons of concern mainly included daughters (52%), and wives/female partners (27%).

Figure 11: Relationship to Person of Concern - Male
- Male relationships to persons of concern mainly included husbands/male partners (45%), followed by sons (36%).

**Figure 12: Accommodation Setting - Person of Concern**

![Accommodation Setting - Person of Concern](image)

- The overwhelming majority of persons of concern were living in their own homes (85%).

**Figure 13: Living Arrangements - Person of Concern**

![Living Arrangements - Person of Concern](image)
- More than one half of persons of concern (57%) were living with their spouse/partner. Of these persons, one third were living with their wives/female partners, while one quarter were living with their husbands/male partners.
- One fifth of persons of concern live alone (21%), 10 percent live with their daughter and 6 percent live with their son.
- Other common living arrangements for persons of concern included living with daughter/son-in-law, a brother/sister, and other relatives/friends.

**Figure 14: Interpreter Use**

- The overwhelming majority of people and contacts did not involve an interpreter.
One fifth of ‘persons of concern’ were born overseas. Countries of birth most commonly included Italy (23%), the UK (19%), and Greece (11%).

The overwhelming majority of persons of concern had been diagnosed with dementia (79%), while 16% had not been assessed yet but had symptoms of dementia/memory loss.
• A small percentage of persons were being formally assessed for dementia (4%), while in 1 percent of the cases assessed dementia was not diagnosed.

Figure 17: Diagnostic Source

• The most common diagnostic sources for persons of concern included Memory clinics/CDAMS/Other diagnostic services.
• Geriatricians, GPs, and Neurologists were also common diagnostic sources.
• The Aged Persons Mental Health Team was the least common diagnostic source.
Appendix E: Bibliography


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