ACKNOWLEDGEMENTS

The Alzheimer’s Australia NSW Policy, Research and Information Unit gratefully acknowledge:

- Alzheimer’s Australia NSW Consumer Advisory Group members
- Alzheimer’s Australia NSW regional staff members
- Service providers who participated in focus groups in Orange, Dubbo and Tamworth

We also thank The Whiddon Group for sponsoring this project. The Whiddon Group is a large non-profit organisation with over 1,700 staff and 2,000 clients across regional, rural and remote NSW. The organisation has been providing care to elderly Australians for over 60 years through residential, community care and independent living services.

This paper has been developed by the Policy Research and Information Unit, Alzheimer’s Australia NSW. Paper authored by Kylie Sait, Senior Research and Policy Officer, Alzheimer’s Australia NSW.

Alzheimer’s Australia respectfully acknowledges the Traditional Owners of the land throughout Australia and their continuing connection to country. We pay respect to Elders both past and present and extend that respect to all Aboriginal and Torres Strait Islander people who have made a contribution to our organisation.

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EXECUTIVE SUMMARY

This discussion paper aims to raise awareness of the challenges people with dementia, carers and service providers face in regional and rural NSW and the innovative and creative solutions being developed in response. Recommendations are provided for Governments and service providers to improve dementia care and support for people with dementia and their carers in regional and rural areas.

The age profile of rural populations is older than in urban areas, with the average age increasing at a more rapid rate. Risk factors for dementia are more prevalent in regional and rural areas. An increase in the proportion of people with dementia living in rural areas is expected over the next few decades. However, there is a lack of clarity around the current and predicted prevalence rates in regional and rural areas.

Living with dementia brings challenges for all people with a diagnosis and those who care for them. These challenges are compounded for people with dementia and their carers living in regional and rural areas due to geographic isolation, travel distances, and limited services and resources. These issues have been recognised by Governments and attempts made to address them by a range of policy initiatives, yet, despite these efforts, the challenges remain.

Governments, regional health professionals and care service providers need to be prepared to respond to the growing number of people with dementia. They also need to ensure that best practice in dementia care and support is being provided to the current population of people with dementia and carers.

Alzheimer’s Australia NSW (AlzNSW) conducted a number of focus groups in order to hear from a sample of regional and rural consumers and service providers about the issues they face, examples of good practice and their suggestions for service improvements.

Regional and rural communities are not homogenous and this is reflected in the findings of this research. A variety of problems, as well as solutions, were identified in different areas.

A range of social and cultural factors specific to regional and rural communities impact on attitudes about dementia, the seeking of support, and the acceptance of services in regional and rural communities.

The increased prevalence of dementia and risk factors for dementia for Aboriginal people have recently been established. The need for culturally safe services for Aboriginal people have recently been established. The need for culturally safe services for Aboriginal people have recently been established. The need for culturally safe services for Aboriginal people have recently been established. The need for culturally safe services for Aboriginal people have recently been established. The need for culturally safe services for Aboriginal people have recently been established. The need for culturally safe services for Aboriginal people have recently been established. The need for culturally safe services for Aboriginal communities is now more widely recognised.

This research found that the attitudes of some GPs, specialist workforce shortages, especially of geriatricians, and limited access to services impact on the provision of a timely diagnosis of dementia, early intervention and on-going management of the disease progression.

There are particular service access issues for regional and rural communities in the provision of social support, home care, respite, and residential aged care. Dispersed populations, distances from service centres, access to transport and travel times are also key factors. Despite these and other limitations, people with dementia and their carers generally do not want to move from their local communities in order to have greater access to services.

This research identified gaps in service provision and access difficulties across regional and rural NSW. It also identified a number of local initiatives that could be expanded and/or replicated to better support people with dementia and their carers.
The provision of services to people with dementia and carers in regional and rural NSW cannot be a ‘one-size-fits-all’ approach, given the significant diversity across the state. The challenge is to design and deliver services that are flexible, innovative, locally appropriate and culturally safe to ensure people with dementia and carers are well supported through all stages of dementia.

AlzNSW recommends the following:

**Australian Government:**

1. Prioritise access to dementia key workers for people with dementia and carers in regional and rural areas.

2. Ensure that funding and resource allocation decisions take into account the geographical spread of populations and increased travel times that confront organisations servicing regional and rural communities to provide community, respite and residential aged care. These service types should also have flexible program guidelines which encourage innovation.

3. Extend the scope of the *National Rural and Remote Health Workforce Innovation and Reform Strategy* to all staff who have contact with people with dementia (such as GPs, practice nurses, allied health, hospital staff, aged care and pharmacists) to become more adept and skilled in diagnosing, managing and supporting dementia cases in their communities.

4. Provide targeted funding for a dementia risk reduction program directed at regional and rural communities. This should include a specific program for Aboriginal communities that addresses the multiple disadvantages and risk factors that contribute to a prevalence rate of dementia that is three times the general Australian rate.

5. Fund an epidemiological study to determine the incidence of dementia in regional, rural and remote areas.

**NSW Government:**

6. Fund the services, programs and initiatives outlined in the *Dementia Services Framework Implementation Plan* to improve the support that people with dementia and carers in regional and rural NSW receive.

7. Implement quality of care standards for its regional and rural Multipurpose Services which respond to the needs of people with dementia and carers – including staffing, training, program design and activities, environmental design and integration of the community in volunteering programs.

**Local governments:**

8. Expand the *Evocities* campaign to make regional towns more attractive to specialists, especially geriatricians and psycho-geriatricians, and to retain the local dementia-skilled workforce.


**Service providers:**

10. Evaluate innovative models of service delivery and engage in knowledge translation activities to build the evidence-base of best practice in dementia care and support in regional and rural areas.

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1 The seven Evocities are Albury, Armidale, Bathurst, Dubbo, Orange, Tamworth and Wagga Wagga. Each of the seven cities has dedicated resources and funding to the campaign, and has in turn secured Australian Government funding, as well as support from the NSW State Government and corporate sponsors.
Steve² lives on a farm on the mid-north coast of NSW. Five years ago Steve’s mother and father, who lived in Sydney, were both diagnosed with dementia. Soon after their diagnoses, Steve’s father lost his driver’s license and his mother was hospitalised. Steve left his farm and moved into his parents’ house to care for them. However, after several months his parents moved in with Steve and his wife in country NSW.

In hindsight, Steve now believes he made the wrong decision. He says he “removed them from their comfort zone, friends, in fact, their whole way of life as they knew it”. Living on a remote property, Steve was quite isolated and had to deal with a system that was not well equipped to service clients in rural and remote areas. The nearest regional centre is a 100 kilometre round trip and he faced challenges in accessing respite and home care services for his parents. Sadly, Steve says he “only gave them unhappiness for their final years”. Steve believes that there are benefits to living within the boundaries of a large regional service centre but there is little to support and assist both the carer and the person with dementia if you “live out of town”.

Steve’s story reflects that of many carers and people with dementia living in country NSW. His experience illustrates salient issues that are examined in this Alzheimer’s Australia NSW (AlzNSW) discussion paper.

The AlzNSW Policy, Research and Information Unit investigated the challenges people with dementia, carers and service providers in regional, rural and remote areas of NSW face and the innovative and creative solutions developed to respond to these issues. We examined what currently works well and what else needs to be done, drawing on the experiences and voices of people with dementia, their carers and the service providers living in country NSW.

This discussion paper reports the findings of this research and aims to raise awareness of models of good practice developed by people with dementia, their carers and service providers in response to the issues they face. Recommendations are provided for the Australian and NSW Governments, local governments, and providers of aged, community and health care services. AlzNSW hopes that these recommendations will facilitate improvements in dementia care and support in regional and rural areas of NSW, which will in turn support the clearly stated desire of people with dementia and carers to remain living in their communities.

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² A pseudonym has been used to protect the privacy of the individuals involved.

³ For the purposes of this paper, the terms regional, rural and remote are used to encompass all areas outside of major cities. Major urban centres within inner and outer regional areas are included. This conceptualisation is consistent with the National Strategic Framework for Rural and Remote Health developed by the Australian Government Standing Council on Health in 2012.
Australia needs people living in regional and rural areas. Country populations and communities are essential to our economy and society; Australia draws a great benefit from the primary and service industries in our rural areas. There are also many benefits to country life, such as a sense of community and connection to place.

Living with dementia brings challenges for all people with a diagnosis and those who care for them. These challenges are compounded for people with dementia and carers living in regional and rural areas due to geographic isolation, travel distances, and limited services and resources. Yet decisions around the policy, planning and design of services tend to be city-centric. People living in regional, rural and remote NSW deserve to have equitable access to services and be supported to remain living in these areas throughout their experience with dementia.

Population factors

Older people in NSW live predominantly along the Eastern seaboard or are clustered around larger regional centres in inland NSW. There are also a smaller number of older people living in or near smaller satellite towns and more remote communities. These remote regions of NSW are typified by a dispersed population over a large geographic area.

“Compared with the 65–74 years age group, older people aged 75–84 years were more likely to live in either Major or Other Urban areas and less likely to live in the more rural areas. The proportional shift to the Major Urban areas increased for the oldest age group. Many complex factors including industry or work issues, lifestyle choices and family considerations affect decisions to move from one type of area to another, but for the two older age groups, illness and the availability of health and aged care services can be compelling factors.” (ABS, 2013)

The data from the Australian Bureau of Statistics (ABS) cited above suggests that older Australians in rural areas are not being supported to age in place due to the lack of availability of health and aged care services. This is exacerbated for people with dementia and their carers.

The age profile of rural populations is older than urban areas; the average age is increasing at a more rapid rate, led by the emigration of younger people to urban areas for education, employment and lifestyle opportunities. 36% of the Australian rural population are aged 65 years and over compared to the total NSW population where 15% is aged over 65. These statistics highlight the fact that rural and regional area populations are much ‘older’ than metropolitan centres.

Rural communities have poorer health outcomes than in metropolitan areas due to a number of factors including low socio-economic status, lower levels of education, environmental risks and poor access to health services. Common risk factors for poor health including obesity, smoking, heavy alcohol consumption, environmental dangers, personal injury, hypertension, high cholesterol and diabetes are more prevalent in rural areas. These health conditions are also risk factors for dementia.
Dementia prevalence in regional NSW

The current proportion of people with dementia in rural areas is consistent with that in metropolitan areas. In 2009, people with dementia represented 1.1% of the total population in Australian capital cities and 1.2% in the balance of the states and territories. Consistent with the ageing of the population outlined above, an increase in the proportion of people with dementia living in rural areas is expected over the next few decades. By 2050, it is projected that 2.9% of the population living in capital cities will have dementia compared with 3.8% in the balance of the states.

However, as can be seen in Figure 1, there is a visible difference in the cases of dementia with higher numbers estimated by Deloitte Access Economics in coastal areas, for example Tweed and Port Macquarie, whilst inland areas have low estimates, for example Barwon and Monaro. These estimates use a weighted average of prevalence rates and apply this to the age profile of a population within a given area. The dementia prevalence rates “follow an exponential growth rate with age”.

Life expectancy is lower in rural areas than urban by up to 7 years, which will result in less people in rural areas living to 85 and beyond. This reduced life expectancy in rural areas equates to a life expectancy level that Australia had in the 1970s – a time when dementia was not well known or acknowledged in the community. AlzNSW believes that this reduced life expectancy in rural areas means that the population is not living long enough in sufficient numbers to generate large estimates of people with dementia. There appears to be a divide in the regional population of NSW, with the ‘healthy aged’ living in coastal areas, and less healthy populations living in inland areas. An epidemiological study is needed to more accurately determine the prevalence of dementia.

Figure 1: Dementia cases by region 2011
Source: Deloitte Access Economics
Key issues

The key concerns and challenges for people with dementia, carers and service providers in regional, rural and remote Australia have been documented in previous research\(^1\)\(^2\)\(^3\)\(^4\)\(^5\)\(^6\)\(^7\)\(^8\). These issues include:

- assessment, diagnosis and management of dementia
- education and awareness of dementia
- opportunities for social engagement and community participation for people with dementia and carers
- access to community, respite and residential aged care
- workforce issues for community, respite and residential aged care services.

Whilst these issues are also experienced in urban areas, for people in regional areas they are exacerbated by geography, distance, inadequate access to transport, limited resources and city-centric policies and service models.\(^4\)

Dementia, aged care and health policy settings for regional and rural NSW

A number of NSW and Australian Government policy documents\(^1\)\(^2\)\(^3\)\(^4\)\(^5\) identify people with dementia and carers living in regional, rural and remote areas as ‘special’ or ‘diverse’ needs groups and acknowledge that they face additional challenges to those living in cities and urban areas\(^5\).

Policy initiatives have been implemented by the Australian and NSW Governments to compensate for increased travel time and the costs associated with service delivery in rural and regional areas. These include:

- remoteness funding supplements for residential and community aged care
- prioritised access to capital grants for residential aged care
- a resource allocation formula for block funded community care programs
- incentive payments for use of telehealth
- improved access to mental health services and supports
- a practice incentives program with targeted initiatives for GPs in rural areas
- the purchase of more flexible service delivery arrangements to meet local needs.

Concerns have been expressed that the current Australian aged care reforms may affect the viability of providers in regional, rural and remote areas and therefore impact on the provision of care to people with dementia and carers\(^2\)\(^2\). The National Aged Care Alliance in its advice to the Australian Government on the Home Support Program recommended that support for people with dementia and carers in rural communities.

The NSW Ageing Strategy does not outline any initiatives specifically for older people in regional or rural areas.

The consultation paper for the National Framework for Action on Dementia 2013-2017 recognises people with dementia from rural and remote areas as a ‘diverse needs group’ in this document however there are no specific strategies identified to address their needs.

The National Strategic Framework for Rural and Remote Health (2012) does not refer to dementia. As dementia is now the ninth national health priority, it should be included.

The Australian aged care reforms outlined in Living Longer, Living Better will impact on people with dementia and carers living in regional and rural areas.
in the short term, access and equity are addressed through the application of a resource equity formula at the global program level and viability supplements are made available to individual, eligible services. In the longer term, the Alliance recommends that funding is variable to reflect the different costs of service delivery experienced as a result of location (for example, rural and remote).

Service provision: limitations and innovations

Although there are some provisions made for the additional costs of providing dementia care and support in regional and rural areas, there are still significant limitations in the service system. Regional and rural service providers are working within the same policy settings as their urban counterparts but have the additional challenges identified earlier.

It is suggested although such limitations can lead to innovation and creativity; that new models of service delivery are developed by providers out of necessity and resourcefulness\(^{23}^{24}\). Service providers need to evaluate the effectiveness and efficiencies of such programs and services to build an evidence base from which to improve provision and create best practice.

AlzNSW research project

AlzNSW conducted an exploratory qualitative research project to investigate the issues people with dementia, carers and service providers face in regional and rural NSW and to identify models of good practice that respond to the challenges. Focus groups were conducted in order to hear from a sample of AlzNSW consumers, AlzNSW regional staff and regional service providers. Service provider focus groups were conducted in Orange, Dubbo and Tamworth. See the appendix for a more detailed explanation of the research methodology.

Issues explored in the focus groups included: examples of local good practice, the role of technology, the potential of Consumer Directed Care (CDC), and suggestions for improvements to service provision, funding and resource allocation.

The following sections report findings from the research around six key themes:

1. Social and cultural issues
2. Working with Aboriginal communities
3. Diagnosis and on-going management of dementia
4. Access to services
5. Building capacity to respond to dementia
6. The challenge of distance and remoteness

Local examples of good practice identified through the research are provided throughout this paper. These models could be replicated in other areas to improve support for people with dementia and carers in regional and rural NSW. While we have identified these services and programs as examples of good practice, this does not indicate that AlzNSW endorses them, especially as some have not been evaluated.

The culture of the country

“I think you get a lot of country folk saying ‘my business is my business’ and they’re very private. And especially with something like this [dementia] where someone’s mind and capacity is affected. There’s a lot of rallying around the person to make sure they remain as respected as they have been in their community. Dementia is hidden.” (AlzNSW staff member)
Throughout the focus groups, people spoke about the ‘culture of the country’ and the impact that this has on feelings of stigma around dementia, willingness to accept help, and use of available support services.

“When you are in a smaller town the stigma can be very obvious. People back away because they notice the little changes. It can be very socially isolating.” (AlzNSW consumer)

Given the diversity within and between regional communities, views on this varied; some felt that the stigma of dementia was more strongly felt in regional and rural communities, while others felt that communities were more accepting of people with dementia. Likewise, some believed that the country culture helped, while others believed it was a hindrance, in terms of seeking and accepting help.

“Some people in the country aren’t comfortable coming to or speaking at support groups because everyone knows one another...there’s a bigger chance of seeing one another at the supermarket, even though we do have that confidentiality clause.” (AlzNSW consumer)

Country people are often regarded as proud and self-reliant, pragmatic, resilient, stoic and reluctant to seek and accept help; they are more likely to offer help than accept it. Research conducted by Orpin et al. (2012:18) found that formal and informal support use by carers of people with dementia in rural Tasmania was shaped by the “emotionally intense, clearly bounded and inwardly focused nature of the caring relationship and the manner in which carers perceived and sought to fulfil their assumed role as the person primarily and ultimately responsible for the care and wellbeing of the person with dementia.”

AlzNSW also found evidence of this intense caring experience in our research. We heard reports of couples, in particular those on farming properties, who had developed a co-dependency over the years; they have worked a farm and raised a family together. When one partner develops dementia, they face the dementia together and may wait until they reach crisis point before reaching out for assistance. This pattern also occurs in urban areas but we suspect that it may be more common in rural areas where access to family networks and services are limited. This issue warrants further investigation and may have implications for how services are targeted and delivered.

People living alone with dementia, particularly in remote areas, are a concern for regional service providers because they often will not accept support. They are used to living an independent, isolated life and do not want strangers in their home. The challenges identified in AlzNSW’s previous discussion paper on living alone with dementia are exacerbated by geographical isolation.

Sea changers and tree changers

“Sea change” is an Australian term that describes individuals abandoning city living in favour of a romanticised and perceived easier life in rural coastal communities. The phenomenon has resulted in the sea change effect, a rapid boom in tourism and real estate development in coastal Australia, particularly in NSW. A similar term, tree change, describes the movement of urbanites to the countryside.

AlzNSW regional staff members told us about the challenges faced by sea and tree changers who move to small towns or isolated properties in their retirement and who often do not consider the future consequences if their health is compromised.
“We have clients who have lived in cities all their lives and then as they were going into their retirement years they decided to have a ‘bush change’ rather than a sea change and the idea was they’d be able to live off the land. And they’ve bought into very isolated little areas that are often along dirt roads, an hour or two hours’ drive from the nearest town...But now they’re finding that they’re becoming quite frail and really need services a) they can’t get to the services and b) they’re on a property so services don’t come out. And they don’t have the knowledge and skills that people who were born and bred in the bush tend to have. They’re not planning ahead or thinking ahead particularly well when they buy into these situations.” (AlzNSW staff member)

They are geographically isolated from their family and friends; they may not have developed friendships and social support networks in their new communities, and; they often have greater expectations of service provision than those who have lived in the country for most of their life. They may also be unable to move back to their family and support networks in urban areas due to property market forces – they either cannot sell their homes or cannot sell them for a price that would enable them to buy back into their previous hometowns.

It is only relatively recently that the dementia prevalence and specific needs of Aboriginal communities have been investigated. In 2011, Smith et al. reported the findings of a study, the first research to undertake in-depth interviews with carers and service providers for people with dementia living in remote Aboriginal communities. They identified several principles to form the basis for the development of a model of dementia care for Aboriginal communities28.

Most recently, Professor Tony Broe and colleagues reported findings from the Koori Growing Old Well Study that the rate of dementia in Aboriginal communities is three times that of the general population. Of the causes for dementia in Aboriginal Australians, Alzheimer’s disease was the most common. Vascular dementia and dementia due to head trauma were also common, but alcohol related dementia was uncommon. They suggest that this higher rate of dementia could be associated with factors across the whole life course, from disadvantage in early childhood onwards, and including mid-late life systemic diseases29.

Following on from this research, the Koori Dementia Care Project aims to inform, educate and build capacity in urban and regional NSW Aboriginal communities, and with associated service providers, about the effects of dementia on older Aboriginal people and their families. It aims to facilitate improved and timely diagnosis of dementia, increased take-up of support for carers through increased community and family education, increased understanding and acceptance of the range of community support services available for carers and development of a person-centred and community-centred model of care within Aboriginal care30.
At the focus group in Dubbo, AlzNSW heard of the good work being done by the Aboriginal Specific Dementia Advisory Service. This service is funded by the Home Support Program and operated by Catholic Community Services NSW/ACT. The service works with local Aboriginal communities in 10 Local Government Areas including the Warrumbungle Shire, Narromine and Cobar. This program aims to promote local community awareness, provide referral to access diagnostic and support services, create awareness and appropriate responses to the needs of all people with dementia and assist local networks of needs and develop implementation plans. An Aboriginal dementia support worker works closely with Aboriginal people with dementia and their whole family and community throughout their experience with dementia.

As outlined in our Aboriginal Engagement Strategy, AlzNSW is committed to improving equity and access to culturally safe dementia services for Aboriginal and Torres Strait Islander peoples of Australia. AlzNSW aims to be a culturally safe organisation that actively consults, nurtures, maintains positive and respectful relationships with Aboriginal and Torres Strait Islander peoples and communities, and includes Aboriginal people as active and equal partners in service development and delivery. The strategy outlines a commitment to building and strengthening positive relationships with Aboriginal and Torres Strait Islander people and communities in NSW; ensuring services are relevant and appropriate; and increasing the number of Aboriginal and Torres Strait Islander people within the organisation. An Aboriginal Dementia Awareness Project Officer works across the organisation to assist staff with Aboriginal engagement and to raise awareness of dementia in Aboriginal communities.

Example of Good Practice: Employing Aboriginal staff

The Whiddon Group was the first aged care provider to partner with the Replay Groups’ Indigenous Program which supports Indigenous people to undertake training in child care or aged care. The program recognises the importance of local communities having qualified staff for their community services.

The Whiddon Group currently has 13 Replay trainees employed in their residential aged care homes across NSW. Trainees are provided with specialised small group training in Whiddon residential aged care services throughout NSW and achieve Level 3 Certification through the Replay Group. At the end of their training, they are offered ongoing work with The Whiddon Group aged care services either where they trained or in their local communities.

Whiddon has found that the partnership with Replay has been a good way to grow a workforce and create valuable cultural links with local Indigenous communities. The Whiddon Group, and the Indigenous women who have participated in the program, report that the partnership is of great mutual benefit. It supports Indigenous women in balancing family with lifelong learning practices and their development as leaders in their communities as well as launching their careers in the sector.

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6 This program is funded by the Department of Education Employment and Workplace Relations as part of the Indigenous Employment Program.
DIAGNOSIS AND ON-GOING MANAGEMENT OF DEMENTIA

GPs and specialists
There are many barriers to the diagnosis of dementia in general practice, including time constraints, diagnostic uncertainty, denial of symptoms and stigma. There is also a shortage of GPs in rural areas with evidence of lower GP-to-population ratios in rural and regional communities compared with urban areas. It was reported to AlzNSW that there are lengthy waiting lists to see a GP in some regional areas, with a number of GPs having closed their books to new patients.

GPs are most often the first port of call for people with memory concerns and their families. Yet in all the focus groups, consumers and service providers alike spoke about the difficulties people with dementia have in obtaining a referral to a specialist, for example geriatricians, from their GP.

“In our area, there’s a handful of GPs who are great, but then there’s others who don’t give much information at all.” (AlzNSW staff member)

Several reported that some GPs have the attitude that there is no point in going to the effort of making a definitive diagnosis of dementia when there is no cure. AlzNSW encourages people with memory concerns to be assessed in order to ascertain whether they have dementia. A timely diagnosis of dementia is very important to enable people with dementia to make plans and preparations for their own future while they still have the capacity to do so.

Many focus group participants spoke about the need for more GP education about dementia. Suggestions included expanding the Alzheimer’s Australia ‘Detect Early’ website and increasing the promotion of events such as timely diagnosis and management of dementia education sessions so that more regional GPs and practice nurses can attend them. Online learning also provides opportunities for rural and remote health professionals to maintain and improve their knowledge and capacity to diagnose and manage dementia.

In addition to the concerns raised about GPs, access to specialists was difficult in many areas. For example, people living in the Tweed, Richmond and Clarence Valleys in Northern NSW only have access to one geriatrician who is based in the Richmond Valley. Many people in regional areas are required to travel significant distances to see specialists, and, with more than one appointment needed to confirm a diagnosis of dementia, this places considerable time and financial pressures on people with dementia and their families. The issue of retiring geriatricians and psycho-geriatricians and the lack of replacements was raised as a major problem.

“We had someone to do the assessment but no geriatrician to follow up with the diagnosis.” (AlzNSW consumer)

The Report on the Inquiry into Dementia: Early diagnosis and intervention released in June 2013 recommended that the then Department of Health and Ageing facilitate early and timely diagnosis in regional, rural and remote communities by coordinating multi-disciplinary teams comprising primary health care practitioners and visiting medical specialists, and supplemented by primary or specialist assessment provided via telehealth facilities. This report noted that the need for multi-disciplinary teams should be assessed at a local level, via Medicare Locals, or other such local health networks.
Example of Good Practice: Timely diagnosis and support

The Memory Assessment Program and Support Services (MAPSS) is run by the New England Medicare Local and has been operating in the New England region since 2003. The MAPSS multi-disciplinary care program was developed to address the shortfall in dementia diagnosis and care within the New England region of NSW, following reports that patients were presenting to the local geriatrician in advanced stages of the disease, and often in crisis. The aim of the program is to maintain the dignity and enhance the quality of life for people living with dementia, as well as decrease carer burden, through early diagnosis, referral, and carer support.

MAPSS provides early assessment and diagnosis for people with mild to moderate cognitive impairment, and an integrated and multi-disciplinary care model to support patients and carers from diagnosis of dementia through the progression of dementia. The comprehensive assessment and report provided by the MAPSS clinical coordinator supports the geriatrician and reduces the number of appointments required by the client.

The model of care and support provided by MAPSS has been recognised in the NSW Dementia Services Framework as an “example of existing good practice” in integrated care. The MAPSS program aims to support the hospital-based geriatrician and GPs in their care of people living with cognitive impairment. The program provides early assessment and diagnosis for people with mild to moderate stages of dementia, and an integrated and multi-disciplinary care program to support clients and carers for as long as they require support.

Clients are referred to the Dementia Education and Carer Support (DECS) Program, which is funded by AlzNSW. This program provides information, support, education, advocacy and advice to people living with dementia, their carers and families. Carers of people living with dementia are offered additional support through dementia specific carer support groups.  

Telehealth

“For those living in rural, remote and isolated communities across NSW, receiving expert care can be a challenge due to workforce availability and geographical isolation. Telehealth can help break down the barrier of distance for patient treatment and care and also improve staff education and networking. Telehealth can be used to deliver a service to a community that they may not have otherwise had access to.” (Agency for Clinical Innovation, 2013)  

Telehealth services are being used very successfully in some areas of regional and rural NSW, for example in Western NSW. Yet in other areas, telehealth services have not been introduced. During the focus groups, some service providers indicated that this was due to a preference for face-to-face contact by consumers or because the technology required is not available yet in that particular area.

Others, however, acknowledged that telehealth is likely to be the way of the future for regional, rural and remote communities and that over time people in these areas would accept and get used to this way of interacting. The consensus among the AlzNSW consumers was a preference for face-to-face contact but an acknowledgement that telehealth was inevitable.

“Video conferencing with a specialist doesn’t always work for a person with dementia.” (AlzNSW consumer)

The confusion that telehealth consultations can create for some people with dementia was also discussed. To overcome this, some geriatricians operate a “fly-in fly-out” model to provide face-to-face consultations, to complement telehealth contact. Local health district staff support clients to engage with telehealth in their own home.

Section 4 of the new Home Care Packages Program now specifies the use of innovative digital technologies to expand services to consumers. This could include the use of telehealth, video conferencing, remote monitoring and other assistive technologies. It will be interesting to
observe how this unfolds, how providers respond, and whether consumers choose to include assistive technologies as part of their packages.

**Example of Good Practice: Telehealth**

“...it was well because we ensure, as clinicians, there is a continuum of care. So we take the client and the family member through the consultation, we sit in on that consultation and then part of the role is ensuring that the clinician refers the client on to the most appropriate services after consultation...it works very well...the good thing about it is our geriatricians insist on having two face-to-face consultations per year so they actually come up ...and the fact that they’re willing to do that is really helpful because some people [with dementia] do need face-to-face. “ (service provider, Dubbo focus group)

The Western NSW Local Health District (LHD) Aged Care Service operates geriatric telehealth services throughout the LHD. A referral from a GP is required for assessment by an aged care specialist to be conducted. Support workers visit the client in their home and take them through the telehealth process. Face-to-face consultations also take place with the telehealth geriatricians from Sydney who visit the regional centres on occasion.

“People with dementia seem to cope quite well with the format and families quite like it because they might only have to have an hour off work instead of a full day or an overnight trip to Sydney.” (service provider, Orange focus group)

This service is convenient for carers and families; it saves them time and money that would have been previously spent on transport and accommodation to attend specialist appointments in Sydney.

Consistent with previous Australian research AlzNSW found that access to a range of dementia care services was very limited in many regional and rural areas. Consumers and service providers reported that home care packages, day and overnight respite services, and places in residential aged care facilities (RACF) are not available for everyone who needs them. For those exhibiting behavioural and psychological symptoms of dementia (BPSD), this situation is even worse, particularly with regard to overnight respite and permanent placement in RACFs. ‘Ageing in place’ for people with dementia in regional, rural, and especially remote areas is an admirable, but not always achievable, goal.

**Social support for people with dementia**

Limited access to social support and day programs for people with dementia was raised as a concern. These types of programs are an important source of support and socialisation for many people with dementia and provide respite opportunities for carers. Research has shown that social networks often decrease following a diagnosis of dementia.

Service providers reported that a lack of availability of social support programs had significant impacts including being a trigger for premature entry to residential aged care. Programs specifically designed to meet the needs of men, especially those of retired farmers, are particularly lacking.

Yet, examples of innovative social support programs for people with dementia were also identified. AlzNSW staff in Port Macquarie singled out the Hastings District Respite Care service on...
the NSW mid-North Coast as providing excellent social support opportunities for people with dementia, including water-based activities such as swimming, canoeing and fishing. They also told us about an innovative art appreciation program for people with dementia held at the Lighthouse Art Gallery in Port Macquarie.

The importance of volunteers and partnerships with local organisations were recognised as key to establishing innovative social support programs for people with dementia. Many social support programs are dependent on a strong volunteer base to resource the program. Organisations must ensure that these volunteers are well trained and skilled in working with people with dementia.

The importance of transport access to facilitate participation and inclusion was noted. There are many barriers to accessing transport for people with dementia in regional, rural and especially remote areas. Driving cessation is a particular issue as there are often not alternative modes of transport, such as public transport options, available. Social support programs that include linked transport are required. AlzNSW is currently conducting a research project on the transport needs of people with dementia and regional and rural communities are a target population of this research.
Example of Good Practice: Men’s Sheds

The “Every Bloke Needs a Shed” pilot project was an initiative of AlzNSW funded as part of Community Builders, NSW Department Family and Community Services, for two years from October 2011 to September 2013. The goal of the project was to increase social engagement of socially isolated older men through participation in local men’s sheds, with a particular focus on men with early-stage dementia and male carers of people with dementia. The project encompassed the Hunter region and involved eight Men’s Sheds.

Participation in the sheds has a number of benefits for men with dementia such as:

- a sense of belonging and purpose
- increased self-esteem, self-worth and social inclusion by providing a venue and activity that is flexible and accommodating
- the company and friendship of men outside the family
- a work-like setting and meaningful activities that provide a sense of purpose
- a setting that normalises dementia
- an opportunity to contribute to the community.

“The Cessnock Men’s Shed has kept me going. Without the shed I don’t know what I would have done, probably curl up and die (laughs)”

(program participant)

An external evaluation of the shed program found there was a reduced burden on the spousal carers of men with dementia through:

- the provision of regular respite
- greater access to information
- a contact at AlzNSW
- a happier husband with more to talk about.

The other men at the shed gained an increased understanding of dementia and skills in communicating and working with people with dementia and a sense of purpose and worth through helping the men with dementia.

More information about the benefits of this program can be viewed in the short video, Alzheimer’s Australia and Men’s Sheds: Making a Difference, available online at: http://www.youtube.com/watch?v=80dHGWP-p_o
Home care packages

This research found evidence of lengthy waiting lists for packages and, in some areas, a lack of packages, particularly those that are high care and dementia specific. Service providers reported that many places west of Dubbo do not have high care packages available; there has been none allocated in these areas and there is a lack of qualified staff to deliver them.

“We find, because of a lack of available packages and any other assistance in the way of respite, we have more and more turning to Neighbour Aid volunteers, which is not always the most appropriate or best way to deal with it. But when there’s nothing else available, you like to be able to say to the carer, who is almost falling, crumbling in a heap, that ‘yes, we can offer you something’. Unfortunately there’s just not enough packages out there.” (AlzNSW staff member)

When packages are available, clients may not receive the hours they need. In Tamworth, focus group participants were disappointed that some people in receipt of Extended Aged Care at Home (EACH) and Extended Aged Care at Home Dementia (EACHD) packages were only receiving nine hours of service per week. For some, this is due to the time taken to travel to a client’s home being included as a cost of delivering the service. This is a major issue for those living in remote communities and one that must be addressed more equitably.

“People that live in towns, within town limits, can access their packages in care hours. People who live outside of town, outside town limits, a large component of those hours are taken out because of travel times. There is no longer equity in those packages depending on where people live. It’s appalling. People who are getting EACH packages and EACHDs are only getting three one-hour visits a week and yet they’re still having to pay because of that component of travel. It is appalling.” (service provider, Tamworth)

However, AlzNSW also heard examples of service providers who go beyond what they are funded to do to provide the best support they can for their clients with dementia and carers. For example, participants in the Dubbo focus group told us of care workers who take a woman with dementia who lives alone in a caravan to a nearby RACF once a week for her to shower. This is an innovative approach to maintaining hygiene which also introduces this woman to both the facility and staff should she need to move into the RACF in the future.

Example of Good Practice: Mobile Respite Team

AlzNSW Mobile Respite Team (MRT) service covering the Bega Valley Shire has been operating for more than ten years. It is currently funded through the National Respite for Carers Program (NRCP), until June 30 2014.

MRT is a multi-component intervention consisting of five main components to help caregivers of persons with dementia. These include psychosocial intervention; general support; respite; training for people with dementia; and supporting the carer and person with dementia through the transition into residential aged care.

In an external evaluation of the services, clients and stakeholders of MRT communicated extremely high levels of satisfaction with the MRT service and its staff. All stakeholders demonstrated they clearly understood the goals and objectives of MRT and were able to provide concrete examples of how MRT has helped carers and people with dementia in the region. The only suggestion for improvement offered by stakeholders and clients alike was to increase the hours of the service from three days a week to at least five days a week.

Outcomes of the MRT service included: the provision of appropriate support, education and guidance delivered through a multi-component intervention that is responsive to the needs of clients; social support including emotional and instrumental support contributing to better health, increased life satisfaction and decreased risk of burden in the carer, and; assistance to navigate the medical, legal, and social systems.49

“Our carers, they say, ‘this isn’t anywhere else?’, then suddenly they realise, ’aren’t we lucky!’ and they think ‘how on earth does anyone else manage without this sort of service?’” (AlzNSW MRT staff member)
Respite and residential aged care

Previous research has examined barriers to the use of care services for people with dementia in rural areas. Barriers include distance and remoteness, knowledge of available services and reluctance to accept service support.

Barriers to care services identified in this research were largely related to the limited availability of services and the distance of some populations from major regional service centres. Many AlzNSW consumers in regional and rural areas and especially for those on more remote properties had difficulties getting day respite.

“I couldn’t get respite because when I was living on the property with mum I was out of the kilometre range for the provider to travel.” (AlzNSW consumer)

“I had to get my neighbour to come help out with Mum and Dad because I couldn’t get respite, just to do the shopping!” (AlzNSW consumer)

Access to respite services can be the tipping point when it comes to being able to continue to care for a person with dementia at home, as the carer in the quote below experienced.

“I think we could have kept Mum at home longer with us but the respite I needed just wasn’t enough or available for the days I work.” (AlzNSW consumer)

AlzNSW staff identified emergency respite funded through the National Respite for Carers Program (NRCP) as being helpful while people are waiting to receive packaged respite hours. However, they pointed out that emergency respite is only provided if the need is considered urgent and for people in the early stages of dementia, it is very difficult to find respite opportunities for carers.

“There needs to be more creative options for providing respite, especially in those early stages, and new thinking about ways to provide respite.” (AlzNSW staff member)

Access to overnight respite facilities was very difficult in some areas. Service providers reported that some facilities are no longer taking people for respite because they are at capacity and there is too much paperwork for respite for just a few nights.

Permanent placement in regional and rural RACFs is difficult, with access to dementia-specific units even more so. As with other services, choice is limited.

“I was told that I should take the available bed at the nursing home in town for my husband, or risk having to take a bed in the next town. I would have liked the luxury of choice” (AlzNSW consumer)

AlzNSW staff and service providers reported that many regional and rural facilities are at capacity and that consumers are “waiting for someone to die” to get a place. They also reported that there are long waiting lists and that because of this, facilities can select whom they accept as residents and that people with dementia exhibiting BPSDs were sometimes denied access to respite and places in residential aged care facilities. At times, these people were inappropriately admitted to psychiatric and mental health facilities.

“We still have people who have dementia ending up in psychiatric care unnecessarily. There are times when there is no option but the distinction is being in our rural area as opposed to being in Sydney. If they were living in Sydney they wouldn’t be in acute psychiatric care.” (service provider, Orange focus group)

AlzNSW consumers indicated that there is a need for higher staff to resident ratios in residential aged care facilities for people with dementia.
“In residential care we don’t just need more staff trained in dementia care, we need more staff!”

“In residential care we don’t just need more staff trained in dementia care, we need more staff!”

“Where mum is the ratio is one staff to 32 residents at night”

“It all boils down to dollars.”

(AlzNSW consumers)

This research found that moving a person with dementia into residential aged care has significant financial consequences for those living on rural properties. Even without the complication of asset assessments and payments for residential aged care, inter-generational transfer of farms to children through wills or trust arrangements while still alive can be emotionally wrenching. Whilst the home on a family farm is excluded from the assets assessment for residential aged care payments, the paddocks surrounding the home and home paddock of the farm are still counted as part of a persons assets. A situation where any component of a farm is needed to be sold to contribute to costs of care will have adverse consequences on its future capacity to generate income due to reduced size, or challenges in timing the sale when the costs are due because of the often protracted period of sale for farms.

Example of Good Practice: Staff training and development

In the Narrabri Shire, The Whiddon Group provides care for clients with mild, moderate and severe dementia through two residential homes and community care services. This includes a dementia specific unit in one of the homes.

Employing qualified and experienced staff can be a challenge in rural and remote communities, where there is not a large human resource to draw from. Staff training and development opportunities are therefore very important. The importance of employing experienced nursing staff and collaborating with other local health and community services to provide specialist training is particularly important to support their clients with dementia and other complex health needs. Whiddon residential services, for example, have collaborated with Tamworth hospital to provide staff with specialist training around brain injury induced dementia.

Innovative training practices and partnerships with organisations are often required to improve quality of life for clients with dementia. The Whiddon Group has collaborated with the Arts Health Institute to implement the Play Up Program in their residential facilities. This is a humour based therapy program that helps improve enjoyment of life, manage challenging behaviour, and reduce reliance on medication. In Narrabri, Whiddon has two staff members trained as Play Up partners who, together with a specialist Play Up facilitator, run weekly sessions at the dementia specific unit.
During the focus groups, it emerged that there is a need to build the capacity of the service system to respond better to people with dementia and carers in regional, rural and remote NSW. Service providers and consumers identified some specific services that they felt had the capacity, with additional support and resources, to do more to respond to the needs of people with dementia and carers in regional NSW.

Improving the service system

Some participants discussed the need to improve the mechanisms of the dementia service system as a first step. They described the siloed and fragmented nature of the service system yet emphasised that providers know one another in regional areas and they should therefore be able to collaborate and work together well.

“[The dementia system] is a mish-mash. There’s no central direction, it’s just everyone’s just off doing their own thing. There’s little buckets of money but we’re talking about this tsunami of dementia coming but everyone’s just grabbing their own little buckets of funding. There’s no coordinated services.” (service provider, Tamworth focus group)

The need to coordinate and streamline the funding and resourcing of programs and services was highlighted. Service providers spoke of the need for adequate on-going recurrent funding to ensure certainty and continuity for programs.

Multipurpose services

The Multipurpose Service (MPS) Program is a partnership between the Australian and State Governments that pools funding and sets aside the normal program guidelines and constraints to allow small communities to integrate acute and aged care services\(^{54}\). The program developed in response to the need for more flexible models and integrated services in small communities.

The objectives of the MPS model are improved access to health and aged care services available in the local community; increased service coordination through integration, innovation, and flexibility in the delivery of health and aged care services; improved economic viability and cost effectiveness of service delivery; and improved community participation in the planning of local health and aged care services. MPSs provide a range of health services, including acute care, subacute (including respite and palliative care), emergency, allied health, oral health, primary health and community services\(^{55}\).

Focus group participants spoke of the need for MPSs to better accommodate and meet the needs of people with dementia in smaller rural towns. They felt that the built environments of many MPSs are not dementia-friendly or enabling for people with dementia. In addition, more education and training for staff is needed but concerns were raised that some MPS staff may “not view dementia as their core business”.

They believe that MPSs currently face challenges in accommodating people with dementia but that there is potential there. Often the only service available in small town is a MPS so they need to be dementia-friendly and supportive and have the flexibility to address the needs of people with dementia in their community.
Regional and rural workforce

Research participants reported that more has to be done to build the capacity of health professionals and care staff to work with people with dementia in regional and rural areas.

“We need to engage with the practice nurses because they’re the ones who know the couples with dementia. But they often don’t know where to refer them for support.” (AlzNSW staff member)

They believe that practice nurses and GPs require more training for initial screening for dementia and then on-going management and monitoring of symptoms in patients with dementia.

Workforce shortages and the high turnover of staff in community and residential aged care in some areas was also a concern, with more effort needed to keep qualified and skilled staff in regional and rural areas.

“I think we need to have a premium for dementia workers to attract people of quality. There’s a lot of people go into aged care because it’s a job not because they enjoy it.”

“Yes! They give certificates [3 and 4 in aged care] out like lollies!” (service providers, Tamworth focus group)

Participants identified that education and literacy levels may be lower in country areas which may present challenges in delivering education and information about dementia to care staff.

“You’ve got to be conscious of people’s level of education, especially in rural areas, in how you present information” (AlzNSW staff member)

Service providers’ spoke highly of online dementia training modules such as those offered by NSW Health and the Dementia Training Study Centres (DTSC). Yet they also indicated that alternatives to online training need to be provided due to issues of access to the internet and inability to use computers.

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Aged care reforms and consumer directed care

“Maybe this new consumer directed care they’re talking about will help the situation” (AlzNSW consumer)

During the focus groups, the potential impact of the current aged care reforms, and in particular the introduction of consumer directed care (CDC), was discussed.

Service providers raised concerns about the sustainability of some regional and rural providers under the CDC model. Focus group participants believe that some service providers will not survive as they are neither person-centred nor flexible.

“I think there’s going to be organisations across the New England area who are going to sink because they’re going to say ‘oh we can’t do this’” (service provider, Tamworth focus group)

They also highlighted the need for more resources and funding to facilitate true consumer choice.

“Some carers would find it a little bit overwhelming...I think it would need a key worker to manage it on their behalf.” (AlzNSW staff member)

“In theory it’s going to be really good….we may not have the resources to give them what they want.” (service provider, Dubbo focus group)

“In small regional areas, how much choice do you really have?” (AlzNSW staff member)

Amongst AlzNSW staff and service providers, there was some cynicism about CDC and the notion of choice. Without additional infrastructure and funding for services, ‘choice’ in regional and rural areas remains mere rhetoric.

“It still comes back to the capacity of the provider to provide the service. So, you know, I can say ‘I want my shower at 11 o’clock at night just before I go to bed’ and the service provider will say ‘yes you’re entitled to that’ but if they can’t get a worker who is prepared to work then or can’t broker the service at 11 o’clock at night, well then, the fact that I’m entitled to it means nothing.” (AlzNSW staff member)

Concerns were also raised that consumers will have little understanding of what their choices actually are.

“Choice works in the supermarket but that’s only because you understand what you’re choosing.” (service provider, Dubbo focus group)

However, the positive impact of CDC was also discussed, with service providers and AlzNSW consumers noting that this model has the potential to significantly improve the provision of care services to people with dementia and their families. They also believe that CDC has the opportunity
to formalise existing informal arrangements and naturally occurring support networks. For example, a carer living on a remote property may be able to organise for their neighbour to become a paid carer to provide respite, rather than be dependent on in-home respite that includes travel time in the respite time.

“CDC is a very good way to go; it’s possibly a brilliant way to go. It gives people want they want and there’s more transparency.”
(service provider, Orange focus group)

Local community groups

AlzNSW consumers and service providers felt that many local community and faith-based groups would be willing to assist people with dementia and carers but that there needs to be more community awareness to reduce stigma and more education to ensure that volunteers have the appropriate level of knowledge and skills to support people with dementia. Organisations such as Rotary, Lions Club and the Country Women’s Association (CWA) were highlighted as examples of groups that could build their capacity to support people with dementia and carers.

“In rural areas, because we often don’t have enough people to run a dementia specific something, maybe we need to empower all the groups to support a person with dementia to be a part of that group.”
(AlzNSW staff member)

The need for people with dementia to be included in their community, to continue to do the activities they enjoy, rather than participate in a ‘dementia’ group was discussed. It was felt that staff and members of local bowling and other sporting clubs need to be provided with training to ensure that people with dementia are included in activities to enable their continued participation and engagement in social activities and community life.
THE CHALLENGE OF DISTANCE AND REMOTENESS

“There are little tiny villages that are miles away but have lots of old people and no access to services” (service provider, Tamworth focus group)

The tyranny of distance and the geographic isolation of many regional and rural areas pose challenges that are difficult to overcome and impact considerably on service access.

“One of the things about being a rural worker is often our colleagues in metropolitan areas just simply don’t have an idea about what our difficulties are or what we have to deal with.” (AlzNSW staff member)

A major frustration identified by regional service providers is the lack of understanding by city-based bureaucrats of the geography of NSW, the large boundaries of regional areas and the vast travel distances. Some re-enacted conversations with bureaucrats, for example:

“I was told well, ‘it’s only 5cm on the map!’”

“I was actually asked, ‘can you just pop on down to Dubbo for the day?’ from Armidale!”

Service providers articulated the need for decisions around funding and resource allocation to be based not just on population sizes but also on geography and travel time.

“32,000 square miles is too big an area for one person to service!” (AlzNSW staff member)

AlzNSW asked our consumers directly whether they would consider moving to the city in order to have greater access to services. Overwhelmingly their response was no. They highly value the quality of life and sense of community in regional and rural areas and are not prepared to trade these for greater choice of and access to specialist services. They may be prepared to move off their farm or property into the closest town but would not consider moving to ‘the city’, away from their families, social support networks and community. Therefore, improved flexible service provision is required in the areas where they choose to live. At present, there is a limited pool of funds, resources and qualified staff in many rural areas. This dilemma poses considerable challenges for Governments, policy makers and service providers when making decisions about allocation and prioritisation of funding and resources and staff recruitment.

Outreach to regional and rural populations is a key component of the work of AlzNSW. Services and supports are provided to people with dementia, their carers, and service providers through the National Dementia Helpline, counselling via telephone and Skype, carer support groups and education, the Memory Van, library services and collaboration with our regional partners. AlzNSW seeks to continually improve our services for people with dementia and carers in regional and rural NSW and will work to build the capacity of regional providers of dementia services to support their clients.
People with dementia and carers living in regional, rural and remote NSW have a right to equity of access to dementia care and support services. This paper has discussed the challenges people with dementia, carers and service providers’ face in regional, rural and remote NSW. It has highlighted the innovative work being done which could be replicated in other regions throughout regional and rural NSW, and indeed, throughout Australia. It has also drawn attention to improvements needed to ensure good practice in the care and support of people with dementia and their carers in regional and rural NSW.

The provision of services to people with dementia and carers in regional, rural and remote NSW cannot be a ‘one-size-fits-all’ approach, given the significant diversity across the state. The challenge is to create policies and systems in which service design and delivery can be flexible, innovative, locally appropriate and culturally safe to ensure people with dementia and carers are well supported through all stages of dementia, no matter where they live.
**RECOMMENDATIONS**

**Australian Government:**

1. Prioritise access to dementia key workers for people with dementia and carers in regional and rural areas.

2. Ensure that funding and resource allocation decisions take into account the geographical spread of populations and increased travel times that confront organisations servicing regional and rural communities to provide community, respite and residential aged care. These service types should also have flexible program guidelines which encourage innovation.

3. Extend the scope of the *National Rural and Remote Health Workforce Innovation and Reform Strategy* to all staff who have contact with people with dementia (such as GPs, practice nurses, allied health, hospital staff, aged care and pharmacists) to become more adept and skilled in diagnosing, managing and supporting dementia cases in their communities.

4. Provide targeted funding for a dementia risk reduction program directed at regional and rural communities. This should include a specific program for Aboriginal communities that addresses the multiple disadvantages and risk factors that contribute to a prevalence rate of dementia that is three times the general Australian rate.

5. Fund an epidemiological study to determine the incidence of dementia in regional, rural and remote areas.

**NSW Government:**

6. Fund the services, programs and initiatives outlined in the *Dementia Services Framework Implementation Plan* to improve the support that people with dementia and carers in regional and rural NSW receive.

7. Implement quality of care standards for its regional and rural Multipurpose Services which respond to the needs of people with dementia and carers – including staffing, training, program design and activities, environmental design and integration of the community in volunteering programs.

**Local governments:**

8. Expand the *Evocities* campaign to make regional towns more attractive to specialists, especially geriatricians and psycho-geriatricians, and to retain the local dementia-skilled workforce.


**Service providers:**

10. Evaluate innovative models of service delivery and engage in knowledge translation activities to build the evidence-base of best practice in dementia care and support in regional and rural areas.

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9 The seven Evocities are Albury, Armidale, Bathurst, Dubbo, Orange, Tamworth and Wagga Wagga. Each of the seven cities has dedicated resources and funding to the campaign, and has in turn secured Australian Government funding, as well as support from the NSW State Government and corporate sponsors.
A literature review was conducted to inform the focus of this project. Previous research identifies the issues that people with dementia and their carers living in regional, rural and remote areas may face. AlzNSW therefore decided to focus on identifying innovative solutions to address these issues. This project sought to examine what is working well and what more needs to be done to best support people with dementia and their carers in regional and rural NSW.

Focus groups with AlzNSW Consumer Advisory Groups (CAGs)

Focus groups were conducted with members of AlzNSW CAGs in March 2013. AlzNSW currently has eight CAGs located in Sydney, Wollongong, Newcastle, Port Macquarie, Armidale, Orange, Cooma and Wagga Wagga. Each group has 8 to 12 members.

Focus groups with AlzNSW regional staff members

AlzNSW regional offices and partners are located in Newcastle, Port Macquarie, Coffs Harbour, Armidale, Orange, Moss Vale, Bega and Wagga Wagga. Three focus groups were held via teleconference in July 2013 and 13 AlzNSW regional staff members participated.

Focus groups with regional service providers

Focus groups were held in the regional centres of Orange (ten participants), Dubbo (nine participants) and Tamworth (eight participants) for service providers in August 2013. A diverse range of organisations and service types were represented at these focus groups. Service providers from the three towns and surrounding areas attended. Staff working in respite, behaviour management, mental health, community care and residential aged care services participated.

All participants self-selected to participate. Focus groups were audio-recorded with the permission of participants and transcribed for thematic data analysis.
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OTHER AlzNSW RESEARCH PUBLICATIONS

Living alone with dementia - Discussion Paper #7 June 2013

It is estimated there may be up to 65,000 Australians with dementia who live alone. However research shows that people living alone with dementia have a higher risk of economic insecurity and abuse, loneliness and depression, poorer health outcomes due to self-neglect and increased vulnerability to malnutrition, falls, accidents and hygiene problems. There is often an underlying assumption in dementia and aged care policy that there is a spouse, relative or friend who lives with and cares for the person, and this is reflected in the way services are delivered. This discussion paper examines the implications of this for social policy and service provision.


Football, head injuries and the risk of dementia. Discussion Paper #6 Mar 2013

Alzheimer’s Australia NSW hopes to raise public awareness of the potential risks of later-life cognitive impairment and dementia for football players who suffer multiple concussive and subconcussive injuries throughout their playing career. This paper examines the research emerging from the USA, reports of memory loss in current and retired football players in Australia, and the possible implications for the football codes.


The most difficult decision - Dementia and the move into residential aged care - Discussion Paper #5, Oct 2012

Adjustment to residential care is more than just a discrete event. It begins well before placement actually occurs and continues beyond. While policy direction and the wishes of the person with dementia and their carer can dictate that people with dementia may stay living at home for as long as possible, the impacts of the symptoms and behaviours of dementia mean that ultimately a large number of people with dementia will move into residential aged care.


What prevents people with dementia making plans for their future? - Discussion Paper # 4, Mar 2012

Planning ahead is important for the whole population. We all need to make sure if we get to a point where we can no longer make our own decisions that our wishes about our health care and financial plans have been set out in legally binding documents. Failure to do this can lead to added stress on our family and carers who will not have the legal ability to make sure our wishes are followed or who could be unsure of our wishes. People with dementia have the right to make decisions about their future while they still have the capacity to do so. It is therefore imperative in the early stages of the disease that people with dementia are provided with opportunities to plan for their future and record their wishes, while they still have capacity.

Building Dementia and Age-Friendly Neighbourhoods - Discussion Paper # 3, July 2011

The needs of people with dementia and other types of cognitive impairment have helped shape the design of residential facilities, but the issue of accessibility to public places and spaces for people with dementia and their carers has been almost completely neglected. In a series of focus group consultations we asked members of the eight Alzheimer’s Australia NSW regional consumer committees to describe how they experienced their surrounding neighbourhoods once they stepped outside the safety and familiarity of their front gate and made their way to the local shopping centre, park, doctor’s surgery or club.

Building Dementia and Age-Friendly Neighbourhoods - Discussion Paper 3 July 2011(PDF)

Addressing the stigma associated with dementia - Discussion Paper # 2, Sep 2010

The purpose of this paper is to raise public awareness about the effects of stigma associated with dementia, to address the need to change the way we, as a society, approach dementia, and to make recommendations for further action.

Addressing the Stigma associated with Dementia Discussion Paper 2 (PDF)

Dementia is a condition that carries a heavy burden of stigma. People’s attitudes, perceptions and understanding of the nature of dementia can determine how a person diagnosed with dementia, their carer and family accept and learn to live with the condition. The stigma associated with dementia can often lead to social exclusion, discrimination and disempowerment.

Alzheimer’s Australia NSW – Addressing the Stigma associated with Dementia - Executive Summary (PDF)

Driving and dementia in New South Wales - Discussion Paper #1, Apr 2010

A new discussion paper, Driving and Dementia in NSW, indicates there is little clear, accessible information about the rights and responsibilities of a driver after a diagnosis of dementia.

Driving and Dementia in New South Wales Discussion Paper 1 (PDF)

Issues raised include:

- Driver testing for people with dementia must be improved
- Legal obligations for a driver with dementia are unclear
- Call for improved transport alternatives for a person with dementia
- Need for better support for transition from driver to non-driver in NSW

NSW Discussion Paper Key Recommendations (PDF)
Quality Support Groups Research Project

There is little knowledge of the way support groups in New South Wales are currently functioning, or how effectively they are providing support to their participants. The purpose of the Quality Support Groups Research Project is to understand the operation and structure of dementia support groups in New South Wales; ascertain what constitutes a quality support group; and determine how a quality support group can be achieved.

Quality Support Groups Research Project - Phase 3  The purpose of Phase 3 is to analyse findings from Phase 1 and Phase 2 of the Project. The Quality Support Groups Research Project provides a comprehensive understanding of quality in a support group and formulates best practice guidelines to enhance the delivery of quality service to carers of people with dementia. This research upholds the mission of Alzheimer’s Australia NSW to minimise the impact of dementia through leadership, innovation and partnerships.

This is the third and final report into a research project that spanned 5 years and looked at what comprises a quality support group. This is the first comprehensive state-wide Australian study of ongoing support groups for carers of people with dementia. Over the five years of the project more than 350 people took part, including leaders of the groups and carers who had at some time attended a support group.

Significant findings of the report are:

- Huge benefits of supports groups for people who attend on a regular basis
- The uncelebrated capacity of mutual aid amongst group members to assist each other
- The unexpected finding of the profound impact of grief and loss on the health and well-being of a carer of a person with dementia
- Some carers reported the grief and loss felt at the time of diagnosis was equal to or even greater than the grief felt when the person with dementia dies

Quality Support Groups Research Project - Phase 3 Executive Summary (pdf 45 KB)

The full Phase 3 report is available to purchase from Alzheimer’s Australia Online Bookshop.

Quality Support Groups Research Project - Phase 2 (pdf 1.92 MB)

This report presents the second phase of the Quality Support Groups Research Project, which acknowledges the voices of past and present members of dementia carer support groups.

Quality Support Groups Research Project - Phase 1 (pdf 764)

The focus of phase one of the Quality Support Groups Research Project is a literature review of research conducted into dementia support groups and a survey of existing support groups in New South Wales to investigate the views of support group leaders.
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This is an initiative of the Australian Government

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