Positioning Paper

Future housing and support needs of people with dementia

authored by

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ACRONYMS

AACQA	Australian Aged Care Quality Agency
ABS	Australian Bureau of Statistics
ACAP	Aged Care Assessment Program
ACFI	Aged Care Funding Instrument
ADI	Alzheimer's Disease International
AHURI	Australian Housing and Urban Research Institute Limited
AIHW	Australian Institute of Health and Welfare
DBMAS	Dementia Behaviour Management Advisory Service
DoHA	Australian Government Department of Health and Ageing
EACH	Extended Aged Care at Home
EACHD	Extended Aged Care at Home Dementia
HACC	Home and Community Care
HCP	Home Care Packages
KICA	Kimberley Indigenous Cognitive Assessment
NDSE	National Dementia Strategy for England
NDSP	National Dementia Support Program
NHSC	National Housing Supply Council
PwD	People with Dementia
SA	South Australia
SDAC	Survey of Disability, Ageing and Carers
SHA	State Housing Authorities

EXECUTIVE SUMMARY

In an ageing society such as Australia, there is growing recognition of the importance of planning for the future care of older people with dementia (PwD). Dementia is predicted to become the leading cause of disability by 2016, with the number of cases in Australia expected to increase to close to 1 million by 2050 (AIHW 2007, p.52). While there is a growing literature around managing dementia, to date, insight into the role of housing in supporting PwD and the planning and coordination of health and housing services has been limited. This project on the *Future housing and support needs of people with dementia* aims to address this gap.

In Chapter 1, we provide an introduction to the project and the report. This includes an outline of: the research and policy significance of the project; the major themes and questions that frame the research; and the structure of the Positioning Paper.

In Chapter 2, we examine recent international and national research on dementia and housing. Key findings emerging from this review include:

→ Housing is recognised as a critical protective factor in relation to the health and well-being of older Australians.

→ Older Australians have articulated a desire to retain independence and they support a consumer-directed approach to health care.

→ A substantial proportion of PwD live in the community, an estimated 70 per cent of all PwD, and this is expected to grow over the coming decades.

→ A PwD's home is critical to their quality of life, with PwD more likely than others in the community to be spending a significant proportion of their time in the home.

→ Continuing to live in their family home and share their lives with loved ones is of primary significance in enabling PwD to cope with the challenges of loss of memory function.

→ One of the major advantages of PwD remaining in their own home following diagnosis is that the home is a familiar environment.

→ For PwD, remaining in their own home holds distinct advantages during the mild and moderate stages of the condition, but this situation changes as the condition progresses.

→ Co-resident caregivers become a critical companion in supporting PwD to continue to undertake tasks they are competent in and assisting with tasks when the PwD experiences a loss in capacity.

→ PwD who live alone are at risk of social isolation, self-neglect, self-injury, depression, and exploitation by others.

→ PwD are more likely to be female and to have lower incomes and they are less likely to access services and support.

→ There are a range of design interventions and assistive technologies that can make a difference to the well-being of PwD and allow them to continue to mobilise remaining strengths and capacities.

→ Home modifications are effective in decreasing the incidence of accidents and injury, and they can strengthen home-based social relationships and networks and reduce strain on caregivers.

→ PwD are more likely to remain in place if supported by live-in carers, but carers' own pressing needs for appropriate housing are less often addressed, particularly those on low incomes.

→ The impact of an ageing population on the housing sector is substantial, with older households projected to grow from 1.6 to 3.2 million between 2008 and 2028.

→ An AHURI study of older persons in public housing (2008) found that housing authority staff felt that they were not well-equipped to assist tenants with dementia and that they have little knowledge of, and limited relationships with, community aged care services.

→ The establishment of a *National Indigenous Dementia Strategy* reflects growing awareness of dementia as a public health concern in Indigenous communities and the need for a coordinated, partnership approach between Indigenous communities, governments, health networks and the research community in responding to community need.

→ The role of housing is not well understood in relation to cognitive decline and dementia in Indigenous communities. However, it is recognised that poor living conditions and poor quality housing exacerbate problems for Indigenous people in remote areas with dementia.

→ PwD, as their condition advances, will typically transition into residential care. The literature identifies three consistent predictors of entry into residential care: dementia severity and cognitive decline; behavioural and psychological symptoms of dementia; and caregivers' health and burden.

→ Studies of transitions into residential care highlight the importance of participation by both PwD and their carers in the decision to enter into residential care.

→ Service-integrated housing in Australia is experiencing moderate growth, primarily within the community and private sector. More research and policy development is required to ensure that this form of housing provision can support a diverse aged population.

In Chapter 3, we examine available secondary data on the housing circumstances of older Australians and PwD. Key findings emerging from this review of secondary data sources relating to PwD include:

→ There are 266 574 PwD in Australia in 2011. This is projected to increase to 553 285 people by 2030 and 942 624 by 2050.

→ Dementia rates are relatively low until the age of 70 years and then incidence rates increase rapidly.

→ In 2011, there were approximately 157 864 PwD living in an owner-occupied home, with 145 735 living in a home that is owned outright and a further 12 129 living in a mortgaged home.

→ In 2011, there were approximately 11 756 PwD living in private rental and 8957 PwD living in public housing.

→ The number of PwD living in public housing is expected to increase from 8957 people in 2011 to 12 916 in 2020 and 31 672 in 2050.

→ The number of PwD living in private rental housing is expected to increase from 11 756 people in 2011 to 16 952 in 2020 and 41 570 in 2050.

→ It is estimated that in 2011 there were 6003 CRA recipients aged 55 years and over who have dementia; 643 of these were aged 55–64 years and 5360 were aged 65 years and over.

→ It is estimated that in 2011 there were 1742 CRA recipients aged 55 years and over who have dementia and who were experiencing housing stress; 262 of these were aged 55–64 years and 1480 were aged 65 years and over.

→ It is estimated that in 2011, 30 per cent of PwD lived in cared accommodation, while 70 per cent lived in the community.

→ In relation to living arrangements, in 2009 almost 9 in 10 (88%) PwD who lived in private dwellings lived with others, while 12 per cent lived alone. Men were more likely than women to have been living with others (93% and 84% respectively).

→ In 2009, about 9 in 10 (92%) PwD living in the community were receiving care from one or more carers. Most PwD were being cared for by family, either their spouse/partner or their child/ren. Around 42 per cent of main carers of a person with dementia were the spouse/partner of the care recipient and 44 per cent were the son or daughter.

→ PwD living in the community were most likely to need assistance with mobility (80%), followed by self-care (62%). They were least likely (39%) to need help with communication.

In the final chapter, we provide an outline of the primary data collection stage of our project. This entails interviews conducted in two case sites, South Australia (SA) and Tasmania. The research team will conduct approximately 15 interviews with relevant stakeholders in each case site.Relevant stakeholders include: housing managers, social workers and aged care service providers. The research team will then conduct approximately 10 interviews with PwD and their carers across a range of low cost housing settings, including low income owner-occupiers, private rental tenants and public and community housing tenants. The interviews will be transcribed and analysed using the qualitative data analysis computer software package NVivo.

1   INTRODUCTION

1.1   Research and policy significance

Over the past decade, dementia has gained prominence as a key health, aged care and social policy challenge. Dementia is predicted to become the leading cause of disability by 2016. Recent data analysis, estimates that 298 000 Australians had dementia in 2011, with the number of PwD expected to reach almost 400 000 by 2020 (AIHW 2012, p.ix). Like other first world nations, Australia's population is ageing due to the combined effects of longevity and decreased fertility. Consequently, prevalence of dementia is projected to increase into the future. PwD often have multiple health conditions and they rely heavily on health and aged care services. AIHW (2012, p.ix) data analysis indicates that total direct health and aged care system expenditure on PwD in Australia in 2009–10 was at least $4.9 billion, of which about $2 billion was directly attributable to dementia.

In response, a *National Framework for Action on Dementia* was established in 2006 to improve cooperation and coordination of health care responses across different levels of government (AIHW 2012, p.6). More recently, the Australian Government released an aged care reform package entitled *Living Longer, Living Better* (DoHA 2012), which included additional funding for dementia-related programs and services. Informed by the Productivity Commission's inquiry into *Caring for Older Australians* (2011), this funding was directed towards improving quality of care for PwD living in the community and in residential care facilities (AIHW 2012, p.7). With a change in government in September 2013 and a new policy, *Healthy Life, Better Ageing*, dementia remains a key national health priority, however, the distribution of funds between helping to find a cure and supporting people afflicted by dementia is yet to be determined.

Dementia primarily affects older people, with the main risk factor for most types of dementia being advancing age. Diagnosis of dementia is not straightforward, but relies on multiple screening tools and the collation of information about changes in a person's behaviour, functional capacity and psycho-social issues. As noted in the AIHW's recent report on *Dementia in Australia*:

> Dementia is an umbrella term describing a syndrome associated with more than 100 different diseases that are characterised by the impairment of brain functions, including language, memory, perception, personality and cognitive skills. … The most common types of dementia are Alzheimer disease, vascular dementia, dementia with Lewy bodies, and fronto-temporal dementia. (AIHW 2012, p.2)

Typically, PwD experience a gradual deterioration in their cognitive capacity and, as the severity of their condition worsens, they become increasingly dependent on carers to assist with many aspects of daily living. The course of dementia is described in three stages:

→ Mild or early-stage dementia.

→ Moderate or middle-stage dementia.

→ Severe or late-stage dementia.

Due to the complexity of the condition and the diagnosis process, dementia is often unrecognised or undiagnosed until it has progressed to middle or late-stage dementia.

People with Dementia have high support needs, which increase as their health deteriorates. Modelling by Access Economics (2011, p.5) estimates that there could

be a shortfall of 213 000 aged care places by 2050, with dementia a major cause of the increased demand, which means that assisting people to remain in the community is increasingly important. However, research on the cost-benefit of community care above residential care is mixed. While economic evaluations indicate that community-based care provides a cost-effective alternative to residential aged care (Lama Consortium 2009, p.23) and it is the preferred option for PwD, uncoordinated services across sectors can compromise service efficiency and client satisfaction. The fragmentation of the Australian aged care system makes it difficult for many older Australians to access the advice, planning, support and care services that they require and increases administration costs for providers(The Myer Foundation 2010). Further, community care is associated with additional psychological and financial costs for carers and families (LoGiudice et al. 1999).

While there is a comprehensive literature around managing dementia, to date, insights into the role of housing in supporting PwD and the planning and coordination of health and housing services has been limited. As identified in AHURI's national housing research agenda, there is a need for further work on the intersection between housing policy and the delivery of community services in the areas of mental health, disability and aged care services. This evidence-base is critical in evaluating the contribution of recent shifts in care provision towards community-based dementia support services and identifying the extent to which this approach is delivering appropriate care to more vulnerable and disadvantaged aged persons who live in insecure housing circumstances.

This project will contribute to current national policy development and reform within housing and the aged care sectors through developing a more comprehensive understanding of the role of housing in facilitating a better quality of life for PwD.

1.2   Research themes and questions

The overall aim of this project is to equip housing practitioners and policy-makers with new knowledge into the future housing and support needs of people with dementia (PwD). Specifically, the project aims to shed light on the experiences of PwD across a range of housing settings, such as those living in insecure private rental housing and people living alone in social housing. In addition, the team will evaluate in-home support services and identify opportunities for great coordination and integration of housing and health services.

The project team will respond to five major research questions:

1. What is known about the links between housing and care provision for PwD?

2. What are the current and projected living arrangements and housing pathways of people with 'mild, 'moderate' and 'severe' dementia in Australia?

3. Are existing community care programs able to adequately support PwD effectively across a range of home settings, particularly those in low cost and insecure housing situations?

4. How do people's initial housing circumstances impact on their housing and care pathways, including their transition into residential care?

5. What policy responses and measures could better support practitioners, housing providers and family carers to respond effectively to the future housing and support needs of PwD?

The team will use a mixed-method approach to answer these questions. This will include: a comprehensive literature and policy review;[1] quantitative secondary data analysis of ABS and AIHW data, which will generate a national picture of the housing circumstances of PwD; and interviews with relevant stakeholders including service providers, PwD, family carers, social and public housing managers, and social workers across two study sites, South Australia and Tasmania. Of all states and territories, these two states have the highest proportion of people aged 65 years and over.

1.3   Structure of Positioning Paper

This Positioning Paper provides an overview of academic literature and policy papers on the housing and support needs of PwD. In Chapter 2, we examine recent international and national research on dementia and housing. This includes: PwD's experience of home; the experiences of PwD who live alone; home design and modification; informal care in the home; formal community-based care; the experiences of marginally-housed and asset-poor older people; housing and dementia support services for Indigenous Australians; and transitions into residential care and end-of-life housing for PwD. In Chapter 3, we review secondary data on the housing circumstances of older Australians and PwD. In the final chapter, we outline the next stage of research, which entails consultation with service providers who are providing care and support for people with dementia in their homes and PwD and their primary carers.

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[1] The search strategy for this review is detailed in Appendix 1.

2 REVIEW OF POLICY DEVELOPMENTS AND LITERATURE ON HOUSING AND DEMENTIA

In Chapter 2, we examine recent international and national research on dementia and housing. In Section 2.1 we begin by outlining the current national policy focus in Australia on ageing in place and the unique ways in which dementia challenges this model. In Section 2.2, we review recent research on PwD living in the community. The search strategy for this review is detailed in Appendix 1.Here we examine PwD's experience of home; PwD who live alone; home design and modification; informal care in the home; formal community-based care; the experiences of marginally-housed and asset-poor older people; and research on housing and dementia support services for Indigenous Australians. In recognition that the majority of PwD will transition into institutional residential care as the severity of their cognitive impairment progresses, also in Section 2.3 we examine research on transitions into residential care and end-of-life housing for PwD. Finally, in Section 2.4, we examine emerging models of housing with care. We conclude the chapter with a summary of key themes emerging from the research.

2.1 Ageing-in-place and the challenge of dementia

Access by all older Australians to safe, secure, affordable, accessible and suitable housing will be a priority as the population ages. Australia's ageing population represents a significant economic and policy challenge, with housing beginning to receive greater recognition as an important dimension of ageing policy. This is reflected in the *National Strategy for an Ageing Australia*, which draws attention to the changing housing needs of older Australians (Australian Government 2002, pp.26–27). The Productivity Commission's recent report on *Caring for Older Australians* (2011) identifies the public expenditure implications associated with housing an ageing population, including the provision of new housing models that are integrated with social support and health care and greater demand for housing assistance. The report estimates that in 2009–10, Australian, state and territory government expenditure on aged care was around $11 billion, with two-thirds of that expenditure directed to residential aged care (2001, p.xxiv).

Appropriate and secure housing is recognised as a critical protective factor in relation to the health and wellbeing of older Australians. A report by Aged and Community Services Australia notes that:

> The health and wellbeing of older people is intrinsically linked to housing and can be influenced by many factors including, the type of housing tenure, the location of the home in relation to neighbours and access to services, the design of the home, the ability to maintain it and the level of financial resources. (2004, p.3)

The capacity of housing to address the individual needs of residents is particularly pressing for the elderly who typically spend more time in the domestic environment doing everyday activities, entertaining or receiving care, and are less likely to want to relocate. Older Australians have also articulated a desire to retain independence and exercise choice in the management of their health and housing situation (Productivity Commission 2011, p.xxviii), which has led to moves towards a consumer-directed approach that entails greater flexibility and choice in the provision and delivery of housing and health care.

In Australia, a key policy response to the ageing population challenge has been to support a model of ageing-in-place. Ageing-in-place is the process through which

older adults continue living in their own homes for as long as possible until a change in circumstances necessitates a move into an age-specific or assisted care environment (Olsberg et al. 2004, p.iii). Recent research on the cost-benefits of using private housing as the home base for the care of older people confirms that supporting people to age in their home is cost-effective in the long-term relative to premature entry to residential care (Bridge et al. 2008). In line with government policies, most older people would prefer to remain in their own homes as long as possible (AIHW 2013a). This is particularly so for those older Australians who own their home. Not only are they more likely to want to remain in their home, but they also express higher levels of satisfaction with their existing housing situation than older Australians who are renting (AIHW 2013a). They value the amenity and familiarity of their neighbourhood, as well as living in close proximity to friends and family (Olsberg& Winters 2005, p.vii).

While research highlights that ageing-in-place reflects the housing preferences of older Australians, this dominant model of people ageing in their homes does not adequately meet the needs of some older Australians, in particular, those who are in insecure, low-cost and marginal housing. Moreover, as Smith et al. (2003, p.519) note, home ownership does not always guarantee a positive experience of 'ageing-in-place'. For example, changed circumstances can render the ideal less attractive, more difficult, or even impossible. These include characteristics of the elderly person, such as health, economic and marital status, and access to formal and informal support systems (Strohschein 2011). Older Australians may experience difficulties with home maintenance and/or adverse life events, such as the death of a spouse, which may prompt older people to reconsider their preference to age in place. Under such circumstances, personal coping strategies and resources such as social networks may be re-assessed, and active measures taken to acquire information about the potential availability of formal support in their current area to meet future needs (Tang & Lee 2011). Strohschein (2011) found that the death of a spouse impacted negatively on the residential independence of seniors, with spousal bereavement operating as a 'trigger event' for institutionalisation or other forms of shared accommodation.

In the UK, Means' (2007) review of studies of vulnerable older people highlights the problematic nature of 'ageing in place' for those living in poor housing circumstances. Means argues that in order to maximise the quality of life for vulnerable older people 'ageing in place' policies must be accompanied by: a commitment to improving the mainstream housing circumstances of all older people; greater investment in specialist support and advice services; and investment in residential care options to enable them to obtain the characteristics of a 'home' in order to support older people for whom this is the best way forward. For PwD, remaining in their own home holds distinct advantages during the mild and moderate stages of the condition, but this situation changes as the condition progresses. As Hyde (2012, p.5) notes:

> Living in one's own home has one distinct advantage for PwD—familiarity. Overlearned patterns of behaviour … allow people with dementia to function in homes that were not well designed for people with disabilities. However, as the disease progresses, this advantage is outweighed by the disadvantages of most of the housing stock throughout the world, which is not designed to support aging and in particular the needs of those aging with cognitive impairments.

Estimates detailed in the AIHW's (2012, p.17) *Dementia in Australia* report, 70 per cent of PwD live in the community and 30 per cent live in cared accommodation.

However, the report notes that people with mild and moderate dementia are likely to be under-represented in the Survey of Disability Ageing and Carers (SDAC).

Dementia is an age-related condition and consequently as PwD age and as they experience progressive decline in their cognitive capacity the option of remaining in their home becomes problematic (Karmel et al. 2012). People with late-stage dementia typically move into residential care accommodation in order to access more intensive support. Results from the SDAC indicate that the age profile of PwD who are living in the community is substantially younger than those living in cared accommodation, with 69 per cent of those with dementia in the community aged less than 85 years and 42 per cent of those in cared accommodation aged less than 85 years (AIHW 2012, p.34). Further data on housing settings is provided by the Aged Care Assessment Program (ACAP) survey. In relation to clients with dementia, survey results indicate that 'living in the community' was recommended as the accommodation setting most appropriate to the long-term care needs of 42 per cent of clients, whereas low-level and high-level care in a residential aged care facility was recommended for 17 per cent and 41 per cent ofclients respectively. Around half of the clients who were currently living inthe community received a recommendation to move into a low or high-level aged care residential facility (AIHW 2012, pp.91–92).

In the past, housing provision for older Australians was marked by a clear distinction between the development of ordinary housing to meet housing needs and specialised, institutional facilities to meet the health and care needs of this population. Reflecting this we review existing research related to these two distinctive housing experiences. In Section 2.2, we provide an overview of current research on people living with dementia in their home within the community, including attention to low income and marginally housed older people. We then examine, in Section 2.3, people living with dementia in residential care and housing options for end-of-life and in Section 2.4emerging models of housing and care.

2.2 Managing dementia at home

In this section, we review existing research on the experience of living at home in the community with dementia. This section addresses a range of themes including:

→ PwD's experiences of home.

→ PwD who live alone.

→ Home design and modification to support PwD at home.

→ Informal care for PwD at home.

→ Community care for PwD at home.

→ PwD living in low cost and marginal housing.

2.2.1 People with dementia's experiences of home

As noted above, in Australia a substantial proportion of PwD live in the community, an estimated 70 per cent of all PwD, and this is expected to grow over the coming decades. It is anticipated that as the population ages there will be an increasing demand for limited residential care beds, with the consequence that an increasing number of PwD will need to be residing in the community for longer periods than has occurred previously. This raises concerns about the quality, accessibly and safety of housing in which people live; the security of the PwD's financial and housing situation; and the capacity for PwD and their families to access appropriate levels of support and care within the home.

A PwD's home is critical to their quality of life. PwD are more likely than others in the community to be spending a significant proportion of their time in the home. Moreover, continuing to live in their family home and share their lives with loved ones is of primary significance in enabling PwD to cope with the challenges of loss of memory function. Co-resident caregivers become a critical companion in supporting PwD to continue to undertake tasks they are competent in and assisting with tasks when the PwD experiences a loss in capacity (Steeman et al. 2007, p.128). In addition, PwD benefit from the sense of belonging that comes from being in a long-term home and the memories that reside within the home and the familiar objects that surround them. The familiar home holds special value for older people as it embodies recollections and attachments formed over the years (Oswald et al. 2007) and plays a crucial role as a source of identity, comfort, family connection, and community involvement. Percival (2002, p.747) notes that domestic spaces 'embody familiar routines, individual strategies, family connections, personal identity and emotional meanings'. Oswald and Wahl (2004, p.229) further note that:

> Especially in old age, housing is defined not only by functional links related to maintaining autonomy but also by *meaningful links* related to maintaining well-being and identify…important in this respect are not only types of physical behavioural, and social but also of cognitive and emotional bonding.

Beyond daily connection with loved ones, one of the major advantages of PwD remaining in their own home following diagnosis is that the home is a familiar environment. As PwD experience cognitive decline they typically struggle to acquire new knowledge and skills, however they often retain the ability to perform previously learned skills, which rely on repetitive motions (van Hoof et al. 2010, p.206). Therefore, a familiar, unchanged environment supports PwD to maintain their capacities and independence.

Dementia is a complex and varied condition, with individuals requiring different levels of support and specific modifications in order to ensure that they are able to retain wellbeing within their own home. However, in view of the cognitive impairment and associated difficulty with everyday tasks brought by the condition, carers and health professionals often express concerns about the risk that this entails for PwD (Tuokko et al. 1999) and for others who might by affected by accidental occurrences, such as fires. In the Alzheimer Australia's study of PwD who live alone, case managers were asked to select their top five concerns about people living at home alone. These included medication, wandering, falls, malnutrition, and exploitation (Alzheimer's Australia 2013a, p.15).

People with Dementia require appropriately targeted resources such as social support, in-home services and home modifications in order to reduce the risk of adverse developments such as self-neglect, self-injury, depression, and exploitation by others. Soniat (2004, p.1577) observes that:

> Physicians and other professions have a critical need for evidenced-based assessment tools to predict their patients' risk for harm and to begin to explore strategies for reducing the incidences of harm for cognitively impaired patients who live alone. The issue is even more complex because, throughout life, individuals vary in their risk tolerance levels. Ethical treatment of patients with cognitive impairments will require consideration of individual, pre-morbid risk tolerance profiles and life-long values and preferences when making treatment recommendations and planning interventions.

Alzheimer's Australia (2013a) cautions that not all PwD who wish to remain at home will be able to do so safely and that the goal is to prevent premature institutionalisation, rather than institutionalisation per se.

2.2.2 People with dementia who live alone

While managing dementia at home is difficult for PwD, the challenges are even greater for those who live alone. Rubinstein et al. (1994, p.70) note that living alone provides a great structural potential for social isolation. The term 'social isolation' refers to 'the separation of individuals from others, especially a lack of strong social ties' (Smith et al. 2009). Social isolation has both physical and psychological dimensions; perceived isolation and a dearth of enacted interactions both contribute to a decline in wellbeing. Socially isolated people have higher mortality and morbidity rates and are more likely to have low self-esteem, high anxiety and suffer from depression, and with a consequent higher risk of suicidal ideation (Smith et al. 2009). PwD who live alone are also at risk of self-neglect including poor nutrition (Alzheimer's Australia 2013a, p.9).

The growth in PwD living alone is part of a general trend towards single person households in the developed world and also a consequence of population ageing. The ABS estimates that 31 per cent of Australians aged over 75 years live alone (Alzheimer's Australia 2013a, p.8). In regards to the household composition of PwD, the SDAC estimates that of those PwD who live in private dwellings in the community, the majority 88.1 per cent live with others and 11.9 per cent live alone. This excludes other types of dwellings in the community such as self-care aged accommodation and boarding houses (AIHW 2012, p.41). Data from the AIHW on Aged Care Assessment Program (ACAP) clients suggests that the proportion living alone may be higher, with 34 per cent of ACAP clients living in the community living alone. Research also indicates that PwD living alone are more likely to be female and to have lower incomes (Alzheimer's Australia 2013a, p.12).

A review of the Australian and international literature conducted by Alzheimer's Australia (2013a) found that PwD living alone are less likely to have a formal diagnosis of dementia, due to a dearth of ongoing interactions with intimate others who could observe changes in memory or behaviour and bring them to the attention of the person with dementia and/or health professionals. However, even when friends, neighbours and other community members are in regular contact they may lack information about dementia and not know where to turn for help (Alzheimer's Australia 2013a). PwD who live alone may also attempt to conceal evidence of cognitive decline from support workers, in order to preserve access to valued spaces and activities(Witt et al. 2009).

As a consequence of the absence of a formal diagnosis, PwD living alone are less likely to use support services and may not receive any formal support at all until a crisis situation leads to hospital admission or a community services referral. Moreover, PwD who live alone have fewer choices in a service system designed primarily around the needs of informal carers and may transition to residential care because of a deficiency of options. Consequently, they are also likely to be admitted to residential care at an earlier stage of the dementia trajectory than PwD who live with another person.

In addition, Alzheimer's UK (2013) reports that PwD are more likely to be lonely than the population as a whole. This may be due to the interaction of dementia symptoms and structural conditions affecting older people in general. The Alzheimer's UK report (2013) records that, while a third of respondents spoke to their neighbours everyday, 19 per cent did so less than once a month.

Like all people, PwD experience loneliness in different ways, but some aspects of their loneliness experience can be directly attributable to the effects of the disease. PwD face particular challenges to sustaining meaning in their lives, due to diminishing capacity for self-determination and decreasing opportunities for equal, reciprocal relationships with others. For people in this situation, proximate others who once represented a source of social contact, may now be seen as a source of surveillance, threatening to expedite unwanted transitions to institutional care in response to observable frailty and perceived inability to 'cope' (Seale 1996). In addition, the forgetfulness that characterises dementia may mean that their subjective perception of how many social contacts they have had, or the nature of those contacts, may be at odds with reality. PwD can easily forget that they have had visitors at all, and may consequently reflect on imagined abandonments (Alzheimer's UK 2013). Furthermore, loneliness in PwD who live alone may also be the result of deteriorating social skills and personality changes that often occur as dementia progresses.

Respondents' comments from the Alzheimer's UK report (2013) also illustrate the close connection between reduced mobility and social isolation/loneliness in this group. Although PwD retain a desire to interact with public space, they are more likely to favour familiar environments. Outdoor activities are also more appreciated by PwD when they serve more than one purpose. A shopping trip, for example, was valued by some respondents for the opportunity it afforded for exercise and social engagement, and well as for consumption (Brorsson 2011). Physical impairment prevented PwD who live alone from engaging in valued activities outside the home in over 60 per cent of cases reported by Alzheimer's UK (2013). A lack of companionship also influences community engagement, or there may be a dearth of activities available that they actually enjoy. PwD may also remain at home and cease activities that had provided purpose and pleasure in public space because of potential problems of disorientation and getting lost, even though they have not yet personally experienced those problems. They may also fear experiencing negative reactions from others if they become disoriented. These concerns were particularly constraining in relation to public transport use in urban areas. A lack of appropriate, available transport was a major concern for the people in the Alzheimer's UK study (2013). If transport is not available, interesting and appealing activities, such as attending clubs and other social events, cannot be accessed by PwD living alone.

Volunteer befriending services can address the need for social contact and make a valuable contribution to reducing social isolation and loneliness in PwD who live alone. Telephone communication can also help reduce loneliness in PwD who live alone (Alzheimer's Australia 2013a), but the symptoms of dementia may present challenges to using telephone support and make conversations more difficult to follow without visual cues. The Alzheimer's UK report (2013) also calls attention to the value of companion animals in reducing the loneliness of PwD who live alone. Caring for and interacting with pets provides PwD with companionship and can fill otherwise empty hours for PwD who live alone. However, as is noted in the report, companion animals cannot provide the practical support required from other people. PwD who live alone have increased need of formal and informal carers to help them navigate everyday tasks with an acceptable level of safety and efficiency.

While many of the support needs of PwD living alone overlap with those of PwD living with carers, they constitute a specific sub-population with particular needs, and therefore require specifically targeted interventions (Nourhashemi et al. 2005). However, few services in Australia specifically target PwD who live alone and acknowledgment of this cohort in Australian policy documents is limited (Alzheimer's Australia 2013a). An advocacy model such as one implemented by Advocacy Tasmania in partnership with Alzheimer's Australia maintains ongoing contact with

PwD living alone, focusing on early intervention. Through this intervention, clients are supported and empowered 'to articulate their preferred future, establish their wishes, make financial plans, strengthen the environment around them and to reduce their vulnerability to abuse (Alzheimer's Australia 2013a, p.28).

2.2.3 *Home design and modification to support people with dementia at home*

In general, Australia's housing stock has been designed to meet the needs of young families, without regard to accommodating the needs of older people, particularly those with limited mobility. While there is a need to incorporate key universal design principles into new build in order to meet the growing demand for accessible and safe housing that can support older people to retain their independence within the home, there is also rising demand for modifications to improve people's quality of life at home. In response, the New South Wales Government in association with Alzheimer's Australia (Department of Family and Community Services, 2011) has developed a comprehensive manual that details appropriate home modifications to support PwD to prolong independence within the home. This includes a room-by-room guide to appropriate modifications and it addresses a range of issues related to supporting PwD at home such as neighbourhood wandering, companion pets, facilitating a calm environment and home-based activities that can engage and stimulate a person with dementia.

In their recent study of dwelling, land and neighbourhood use by older homeowners in Australia, Judd et al. (2010) identify three broad approaches to the design of housing that can better facilitate ageing in place. These include: visitable (i.e. ease of access for visitors with limited mobility); adaptable (i.e. housing that can accommodate changes in human ability over the lifespan) and universal design (i.e. design and spaces that are accessible and usable by persons of all ages and abilities). These design approaches are part of a growing trend to develop uniform standards for people with diverse health conditions and levels of ability within the U.K. In Australia, universal design principles are incorporated into the building code in relation to public buildings, but not private dwellings. Judd et al.'s (2010) survey data indicates that the majority of older home owners living in conventional housing expect to undertake home modifications at some point in the future. However, despite holding this expectation, 46 per cent of these respondents thought that they would be unable to do so or they were uncertain about their ability to pay for them. They highlight the need for more readily available consumer information about home modification in order to support older people to incorporate accessibility and safety features during major renovations and to anticipate future housing design needs.

When the home can be adapted to changing needs and the resident is supported by timely and appropriate services, ageing in place can be beneficial for PwD, as it can: assist in managing symptoms; delay the need for more intensive forms of care; and help to prevent hospital admission and readmission (Andrews &Molyneux 2013). In her overview of dementia and housing, Hyde (2012) identifies the multiple cognitive deficits associated with dementia that make everyday tasks difficult for PwD. These include difficulty with short-term memory; decline in ability to plan and execute complex tasks; difficult way-finding and 'mental maps'; poor safety awareness; loss of visual acuity and other sensory losses; decline in balance and mobility; and increased depression and emotional liability. Given that dementia prevalence rates increase with age, many PwD are also living with multiple health conditions, which need to be considered when adapting the home and integrating appropriate assistive technology (Lawrence & Murray 2009).

For PwD, the optimal living environment enables productive and desired action and promotes self-expression while decreasing the presence of features that can cause

worry, confusion or harm (Topo & Kotilainen 2009). While most ordinary housing is not designed to meet the needs of PwD, the familiarity of home is critical in enabling PwD to retain independence in undertaking everyday tasks and navigating around the home. The familiarity of the private home enables PwD to continue enacting material connections with their past, even when such interactions entail risk (Matthews et al. 2006, p.176). Within the home, material objects evoke and preserve memories (Attfield& Kirkham 1996), and serve as symbolic links to valued relationships, personal and historical events and past identities (Kroger & Adair 2008). While the value of some objects inheres in their symbolic dimension, most material forms are important for the potential they provide for actions that are functional and meaningful for particular individuals. Van Hoof and Kort (2009, p.212) note that the optimal environment for PwD will vary among individuals and there is a need to strike a balance between the removal of clutter in order to avoid confusion and accidents and the need to ensure that the home offers sensory and stimulating experiences.

Beyond the security of a familiar environment, there are a range of design interventions that can make a difference to the wellbeing of PwD (Hyde 2012, pp.6–7).They include clarifying orientation by ensuring that destinations are clearly visible and visually distinct; reducing frustration by making egresses as unobtrusive as possible; installing appropriate lighting and contrast as low levels of light can create confusion; appropriate levels of auditory, olfactory and social stimulation; and personal space. These types of modifications may apply to either a private home or a residential setting. Common modifications such as the installation of grab bars, handrails, raised toilets, and ramps within existing housing stock can make performing tasks easier, reduce accidents, and support independent living. A comprehensive list of appropriate environmental interventions for PwD in relation to each room of the house has been compiled by van Hoof and Kort (2009, pp.213–23). Individual room modifications are also detailed in the Department of Family and Community Services manual (2011) *At home with dementia*.

PwD require living environments that will help to compensate for the debilitating effects of the condition and allow them to continue to mobilise remaining strengths and capacities (Van Hoof & Kort 2009). Home technologies are an intrinsic part of late modern understandings of home and many are enmeshed in the fabric of everyday domestic experience. Increasingly sophisticated technological dimensions of everyday life, such as electronic washing machines, digital watches and automated telephone services, become harder to use as cognitive capacity declines (Nygård & Starkhammar 2007). Combined with community services, home modifications that are targeted to the needs of individual PwD can also enable PwD who have been hospitalised as a result of crisis or illness to return to their own homes upon recovery (National Housing Federation 2013).

Assistive technologies that can benefit PwD include medication reminders; emergency response systems; videophones; temperature monitors for the house and refrigerator; robots for companionship; global positioning systems; and pre-programmed music and lighting (Gould et al. 2010 cited in Alzheimer's Australia 2013a, see also Housing LIN (2012). Assistive technology can increase independence by enhancing mobility and general independence and reduce the need for human home-based services (Allen et al. 2001). In practice, however, the utility of such interventions is likely to decrease with the loss of cognitive function as the dementia progresses (Alzheimer's Australia 2013a). Moreover, appropriate solutions will vary depending on an individual's capacity. For example, visual aids would not be appropriate for someone with visual impairment. Nygård (2008, p.498) notes the importance of attending to the individual values and motivations of PwD when considering the potential value of technological support in the home, writing that:

It is critically important to consider the individuality of each older adult with dementia when it comes to supporting or giving advice concerning technology use. … [I]f a person's experienced need of a piece of technology and its significance in his or her life was strong enough, learning to manage unfamiliar technology such as a computer also seemed to be possible. Hence, the individual's motivation and experienced need of a technical item together with very frequent current use seemed to override the importance of familiarity and habit from before, and even make learning new technology possible.

Similarly, Neven (2010) calls attention to the need to consider identity threats that can be posed by technologies that are associated with negative stereotypes such as 'elderly', 'lonely', 'dependent' and 'infirm', as such associations can lead to rejection of helpful technologies by potential users.

Heywood and Turner's (2007) comprehensive review of the evidence on the cost-benefits of home adaptation found that housing adaptations and assistive technologies can produce savings in four ways by reducing or removing completely an existing outlay; reducing the cost of homecare; prevention of an outlay that would otherwise have been incurred; and prevention of waste. Tanner et al. (2008, p.207) note that home modifications can also reinforce positive meanings of the dwelling as home, 'by restoring or strengthening home as a place of security, safety, and comfort' and by 'supporting the continuation of habitual personal routines or rituals through which people are linked to their home and by which identity, self-esteem, and control are reinforced'. Further benefits included strengthened home-based social relationships and networks and reduced strain on caregivers. Under some circumstances, however, the positive meanings of home were diminished when modifications prioritised accessibility and functionality at the expense of the personal and social meanings of home. As Tanner et al. (2008) observe, this finding underscores the importance of foregrounding the values and preferences of residents by support services in relation to home modifications. Wilton and Hall (2012) concur, noting that 'without a full understanding of the impaired person, 'quality' design can prioritise access and safety at the expense of embodied needs of dignity, control, and the securing of identity'. While initial research on the cost-benefits of home modification indicate multiple benefits for residents, their families and their carers, further evaluative work on the specific benefits for PwD is required.

While the adaptation of housing can enable independence at home, other mainstream social spaces, including other people's homes, shopping malls, and recreational facilities remain inaccessible. Bartlett and Peel (2005, p.108) note that '[d]esign of the internal environment of the home is important in terms of space, layout, safety and use of technology …Dimensions of the external environment are important too, and include public spaces, transport, recreation and urban planning. Where the built environment is age-friendly, older people are more likely to remain independent even if their functional capacity has deteriorated'. Understandings of what ageing-in-place means to older people can guide the development of appropriate and effective community-based interventions that support the autonomy of older adults (Black 2008). In the UK, there is growing recognition of the need for dementia-friendly communities and 'lifetime neighbourhoods' that can support people to age in place at home (Mitchell 2012; Alzheimer's Society 2013).

2.2.4 Caring for people with dementia at home

Informal care

Live-in or regularly visiting carers play a vital role in enabling PwD to continue to age in place for as long as possible, particularly when the condition has progressed

beyond the early stages. Family carers often help with personal care, transport, housework and other activities, as well as managing behavioural problems and providing supervision. Access to such assistance can improve a PwD's quality of life and may also help them delay or avoid entry into residential aged care services (Drameet al. 2012). Galvin et al. (2005) highlight the role played by 'intimate' dementia carers in mediating between the private world of the care recipient and the public world of health and social care systems. As noted in the AIHW (2012, p.117) *Dementia in Australia* report, there is no single definition of 'carer', however, the term 'loosely refers to someone who provides ongoing informal assistance to a person living in the community who cannot care for themselves because of a disability, mental illness, chronic health condition or frailty. It does not include paid workers or volunteers arranged by an organisation or formal service'.

Comprehensive data on the number of carers of PwD living in the community are not available. Instead, estimates must be derived using available information. The AIHW report estimates that the number of carers of PwD in 2011 ranges from 58 200 to 240 300, with a likely figure around 200 000 (AIHW 2012, p.122). Further, data from the 2008–09 ACAP data collection indicates that 9 in 10 (91%) PwD living in the community have a carer (AIHW 2012, p.120).According to the SDAC data, the most common relationship between the co-resident primary carer and the person with dementia was a spouse or partner caring for the other. Just over one-third (36%) of primary carers were the son or daughter of the person with dementia, and 7 per cent were another relative, friend or neighbour (AIHW 2012, p.124).

Demands on carers are high, both physical and emotional, and they increase over time. SDAC data show that 94 per cent of co-resident primary carers provided continuous rather than episodic care and 81 per cent were, on average, providing 40 or more hours of care per week. In contrast, the caring intensity was lower for co-resident primary carers in general, with 72 per cent providing continuous care and 42 per cent providing 40 or more hours of care per week on average (AIHW 2012, p.129). In regards to duration of care, 41 per cent of primary carers of PwD had been providing care (whether as a primary or non-primary carer) for less than five years, while 38 per cent had provided care for five to nine years, and 22 per cent for 10 years or more (AIHW 2012, p.129). It is anticipated that growing demand for residential care places will increase this duration of care period over time.

The financial situation of carers is significant. According to SDAC data: '29 per cent of primary carers of PwD received the Carer Payment, 39 per cent did not receive it but had looked into their eligibility, and 32 per cent did not receive it and had not looked into their eligibility'. Those in the latter group were asked about the main reason they had not looked into their eligibility. The most common response was that they would not be eligible or that they were eligible for a payment type that meant they would not be eligible for this payment as well (35%) (AIHW 2012). Carers may also face challenges in managing their own housing costs and circumstances. PwD are more likely to remain in place if supported by live-in carers, but carers' own pressing needs for appropriate housing are less often addressed, particularly in the social/public rental context (Princess Royal Trust for Carers 2010).

SDAC data also provides some insight into the use of respite care services by co-resident primary carers of PwD who are living in the community. When asked generally about their need for respite care, '63 per cent of these carers indicated they did not need respite care. Most (61%) co-resident primary carers of PwD reported they had never used respite services. The main reasons given were that they did not need the service (38%) or the services were not wanted by either the carer or care recipient (39%)' (AIHW 2012, p.100).Conversely, '39 per cent of co-resident primary

carers of PwD had used respite care, with most of these carers having done so in the previous three months' (AIHW 2012, p.100). Finally, '[t]he use of respite services by primary carers of PwD was higher than the use of these services by all co-resident primary carers' (AIHW 2012, p.100).

There is an extensive evidence-base relating to carers of PwD. This research encompasses documentation of carers' views, experiences and coping strategies (Nolan et al. 2002; Lin et al. 2012); interventions designed to support carers(Zarit&Leitsch 2001); recognition of carer expertise (Chung et al. 2008); information and service access (Robinson et al. 2009); and carers' experiences of grief and loss (Gillies 2012; Raymond et al. 2014).

Community-based care

The needs of PwD are high and at times extend beyond the capacity of the primary carer. There are also PwD who live alone and either have limited or no support from a family member. Alzheimer's Australia's (1996, p.17) *Living alone with dementia* study asked case managers to identify the most important thing that PwD living alone need. These included increased number of visits (50.0%); greater community involvement (27.7%); home safety and security alterations (13.8%); more frequent telephone monitoring (2.1%); regular health check-ups and consultations (2.1%); meal delivery services (2.1%); and home maintenance (2.1%).

A key challenge for PwD with a limited support network in the community is social isolation. Socially isolated older people tend to be 'invisible' to the wider community, and particularly to institutions, until personal or natural disasters bring them to attention. The challenge is to identify and engage with this hard-to-reach group, in order to provide effective interventions under everyday circumstances, and with the goal of preventing, as well as ameliorating the negative effects of social isolation. MacKinlay (2002) argues that the lack of deep meaning in relations with others reduces quality of life in elders living alone, whose main source of social relationships may be with aged care service workers, who cannot meet deeper existential needs. There is a need for structural support for opportunities to engage with others in such a way that satisfies the need for meaningful social connections for socially marginalised groups, rather than social connection per se. An advantage of 'ageing in place' is the maintenance of social networks that help prevent social isolation in the elderly. Clarke et al. (2012) argue that communities that are rich in institutional resources such as community centres, schools and libraries can support cognitive health in later life, unless language and/or cultural barriers prevent engagement. Neighbourhood affluence, and the consequent availability of institutional resources, can act as a source of 'cognitive reserve', particularly for the older adults.

There are a range of community-base services available to support PwD who live in the community and their carers. These include the National Dementia Support Program (NDSP); Dementia Behaviour Management Advisory Service (DBMAS); Home and Community Care (HACC); and Home Care Packages (HCP) [formerly referred to as Community Aged Care Packages]. A summary of these programs is provided here:

National Dementia Support Program

The NDSP aims to improve the quality of life of PwD and their carers and, where appropriate, support those with dementia to remain in their homes. The Australian Government funds Alzheimer's Australia and its state and territory member organisations to deliver the NDSP. The program includes a range of free support services provided by Alzheimer's Australia including: a helpline and referral service; counselling; and education and information sessions or activities (AIHW 2012, p.62).

AIHW data indicates that in 2010–11 there were 118 759 contacts (i.e. contact between a staff member and client) with the NDSP (AIHW 2012, p.62).

Dementia Behaviour Management Advisory Service

The DBMAS program is funded by the Australian Government and has been established in each state and territory to provide appropriate clinical interventions to help aged care staff and carers improve their care of PwD where the behaviour of the person with dementia impacts upon their care. The DBMAS consists of multi-disciplinary teams that may include, but are not limited to, psychologists, registered nurses and allied health professionals. Their core functions include:

→ Provision of information and advice.

→ Undertaking assessments and short-term case management, including mentoring and modelling management techniques.

→ Delivery of tailored information and education workshops (AIHW 2012, p.63).

Home and Community Care

Home and Community Care (HACC) services moved from joint funding by the Australian and state and territory's governments in 2012 to having separate responsibilities. The Commonwealth HACC program has full responsibility for services for older people and the states and territories fund services for those under age 65 apart from in Victoria and Western Australia, which are either transitioning to this arrangement or in discussion (http://health.gov.au/hacc). The Commonwealth HACC services are designed to help older people and people with disability to remain at home and prevent their inappropriate or premature admission to residential care. Assistance provided through HACC includes help with household chores; health and personal care; activities and transport, short breaks; and home maintenance and modification (Alzheimer's Australia 2013a, p.9).

The HACC program includes a dementia monitoring service program, which supports people living at home with dementia and in particular targets people who live alone (Alzheimer's Australia 2013a, p.9).

Home Care Packages

Home Care Packages provides up to four levels of services for older people living at home. The care needs range from those with basic care needs through to needs equivalent tohigh level residential care. The types of assistance available include help with personal care, meals, domestic assistance and transport (http://www.myagedcare.gov.au/aged-care-services/home-care-packages).

Level 1: Supports people with basic care needs.

Level 2: Supports people with low-level care needs (equivalent to the former Community Aged Care Packages).

Level 3:Supports people with intermediate care needs.

Level 4: Supports people with high-level care needs (equivalent to the former Extended Aged Care at Home and Extended Aged Care at Home Dementia packages).

EACHD packages providing services for older PwD living at home with care needs equivalent to high-level residential aged care were replaced in August 2013 with Home Care Level 4 packages (http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/factsheet-on-home-care-packages-program-for-cacp-each-and-eachd-consumers).

The Home Care Level 4 package is supplemented with a Dementia and Cognition payment to service providers for PwD. Services provided will continue largely unchanged from the EACHD and can include qualified nursing input, particularly in the design and ongoing management of the package clinical care, personal assistance, meal preparation, continence management, assistance to access leisure activities, emotional support, therapy services, and home safety and modification (AIHW 2012, p.93).

2.2.5 People with dementia living in low cost and marginal housing

A key priority as the population ages is ensuring that older people have access to secure and affordable housing. The challenge of managing dementia at home in the community is compounded by problems of social and economic disadvantage and access to appropriate housing. As Jones et al. (2007, p.42) note:

> A major economic divide among older Australians is between the large majority in home ownership and those in private rental housing. Public policies towards older people in Australia assume and rely on high levels of home ownership to underpin older people's wellbeing. Community care policies designed to support people as they age assume older people have a stable home in which such care can be delivered.

The majority of older Australians own or are buying their own home. Not only are owner-occupiers more likely to be middle to high income households than rental households, they are also more likely to hold other forms of wealth such as savings, superannuation and shares (Yates 2012). In contrast, renters are more likely than home owners to be asset poor with little or no savings and inadequate superannuation. In addition, property owners potentially have more choice in their housing situation and lifestyle as they are able to draw on the equity in their home to cope with changed circumstances (Jones et al. 2007; Wood et al. 2010).

Housing tenure has been associated with health in a number of studies. Those who rent their houses appear to have poorer health than those who own their houses, even after controlling for age, gender, and education (Howden-Chapman 2002). A comprehensive review of health and housing literature indicates that renters are more likely to develop respiratory diseases and diseases of the digestive tract, while home ownership is 'significantly associated with a lower risk for cervical cancer, prostate cancer, and bladder cancer, when controlling for education' (Fuller-Thomson et al. 2000). In the US, Fisher et al. (2007) found that older home owners in their study had higher median incomes, consumption flows, and net worth than renters, and were better off in terms of disposable income and consumption flows. Conversely, people with health problems are less likely to own their own homes. In a longitudinal study of housing condition and cognitive decline in the US, the authors identified a relationship between these two variables (James & Sweaney 2014). The study found that Americans over the age of 50 who rated the physical condition of their dwelling as 'poor' were significantly more likely to experience cognitive decline in subsequent years. In addition, Rabins et al.'s (1996) study of health and housing found that older Americans living in public housing reported higher rates of psychiatric disorders, including mood disorder, schizophrenia and substance abuse, than elders living in independent homes and apartments.

While acknowledging the privileged situation of home owners compared with renters, Wood et al.'s (2010a) modelling challenges the notion that home ownership provides a guaranteed buffer against financial hardship in old age. Their analysis highlights that significant life events can result in older people losing their home. Moreover, they find that 'owner occupiers who exit home ownership after 50 years of age are significantly

more likely than longer term renters to make transitions onto housing assistance' (Wood et al. 2010, p.3). Wood et al. (2010a) also conducted in-depth interviews with asset-poor older Australians. Their respondents identified financial security and housing as critical to achieving an ontologically secure retirement (Wood et al. 2010, p.34).

The National Housing Supply Council's 2nd *State of Supply Report* (2010, p.136) highlights the impact of an ageing population on the housing sector, with older households projected to grow from 1.6 to 3.2 million between 2008 and 2028. The report also provides projections of underlying demand for private rental older households, which are projected to rise from 146 000 in 2008 to 321 400 by 2028, and public rental demand projected to rise from 86 500 in 2008 to 189 800 in 2028. Similarly, Jones et al.'s (2007, p.viii) recent study on rental housing provision for lower-income older Australians documents significant growth in the demand for older rental housing, but from a fairly low base (approximately 248 600 or 11% of the total aged population, in 2001) (Jones et al. 2007, p.19). Citing ABS data, they observe that the number of people aged 65 and over living in lower-income rental households is projected to increase by 115 per cent from 195 000 in 2001 to 419 000 in 2026. While such growth in demand will also occur in both the private rental and social housing sector, there are questions over the capacity of the social housing system to adequately respond to such demand thereby resulting in an increasing proportion of older people seeking low-cost housing in the private rental market (Jones et al. 2007, p.viii). McNelis et al. (2008, p.6) note that:

> Currently public housing meets 42 per cent of demand from eligible older persons. If it is to continue to meet this level of demand, then an average of an additional 4391 older person households will have to be housed each year to 2016. (McNelis et al. 2008, p.6)

Among older renters, around half reside in the private rental market and the remainder reside in public housing. Jones et al. (2007, p.27) note that older people in public housing tend to be older on average, more likely to be single person household and are more likely to be female. Public tenants also consistently report lower incomes, whether measured on the basis of individual or household income. Drawing on data from the 1999 *Australian Housing Survey*, Jones et al. (2007, p.24) note that more than 87 per cent of renters are reliant on government pensions or allowances as their principal source of income, compared with just 61 per cent of owner-occupiers.

While the ageing population profile of public and community housing tenants has resulted in the emergence of new practice guidelines from state housing authorities and community housing providers and improved linkages between health services and housing, the issue of increasing rates of dementia has not been addressed in a systematic way. An AHURI study of older persons in public housing conducted in 2008 examined the housing policy and management issues associated with older tenants. The study reported on findings from interviews with older tenants and state Housing Authority staff and other support service providers. SHA staff identified tenants with dementia as a key challenge, which they were not well equipped to assist with:

> One of the most difficult issues for staff to deal with is coming across older people who are not coping, who are suffering dementia or who need assistance with daily tasks. SHA managers and frontline staff expressed varying views as to how they dealt with such complex situations and their duty of care in relation to these older tenants. Many noted that there were no specific SHA policies and guidelines on duty of care (except in relation to statutory responsibilities e.g. children at risk) and that any action depended

upon the goodwill of each individual staff member, though one participant did note that 'duty of care' was built into their day-to-day policies and procedures. Both managers and staff clearly expressed the view that their role is housing and they didn't want to become involved in coordinating care and support for tenants. (McNelis et al. 2008, p.6)

The report authors note that SHAs officers tend to have little knowledge of, and limited relationships with, community aged care services and that there is a need for SHAS staff to engage more closely with support services (McNelis et al. 2008, p.6). The support service providers identified some strategies for improving outcomes for older public tenants. These included:

First, that they shift from a transactional relationship with older people to one that listens more and spends some time chatting; second, more regular inspections that cover not just maintenance issues but also how well the tenant is managing; and third, more information and understanding about older people and community aged care services, in particular, the extent to which these services can now maintain older people in their homes. (McNelis et al. 2008, p.5)

This situation contrasts with the UK where the housing sector is recognised as playing a critical role in alleviating cost burdens occurring in different parts of the care and health system (Andrews &Molyneux 2013, p.5) and housing forms a core component of a *National Dementia Strategy for England* (Department of Health 2009; Quince 2012). Responding to the Alzheimer's Society's (2012) report *Home Truths*, Amy Swan (2012), a policy officer at the UK National Housing Federation, argues that community services need to be supported by mainstream housing staff in order to address the challenges of dementia. She also notes in her article that:

Housing providers are already doing a lot to help PwD live independently by ensuring their communities and housing are dementia-friendly. Good housing and related services play a vital role in improving the lives of PwD and helping them stay in their own home, which in turn helps to reduce the ever-increasing costs to health and social care. … The nature of the dementia challenge means it cannot be met by specific care and support services alone. Housing staff working in general needs accommodation are helping to increase the rate of diagnosis and signposting to packages of support. (Swan, *The Guardian*, 22 August 2012)

More targeted housing and neighbourhood policy responses are detailed in the *National Dementia Strategy for England* (Department of Health 2009). These include:

1. Raising community awareness and understanding about dementia.

2. Early diagnosis and support, with housing professionals playing a role in encouraging and supporting tenants who show possible dementia symptoms.

3. Providing people with dementia and their carers with good quality information about housing and support service options.

4. Enabling easy access to care, support and advice following diagnosis, with housing professionals playing a role in facilitating contact with a dedicated local dementia care advisor in their neighbourhood or working with this care advisor to support a tenant to remain in their home.

5. Development of structured peer support and learning networks, with housing providers supporting this objective by opening their facilities to

people with dementia and their carers. For example, running healthy ageing or memory cafes that facilitate peer support and group activities.

6. Improved community personal support services, with housing professionals ensuring that tenants are aware of and able to access comprehensive community personal support services and/or participating in the delivery of these home-based services.

7. Providing people with dementia the opportunity to access home-based assistive technology and telecare solutions to support and prolong independent living and delay reliance on more intensive services.

8. Up-skilling housing professionals to ensure they have a comprehensive understanding of dementia and its different manifestations and how to support people with dementia and their carers through housing and support services.

9. Improved end of life care for people with dementia and their carers, with staff in accommodation-based services responding to individual people's plans and preferences regarding care, support and housing, including responding to the desire to die at home.

2.2.6 Housing and dementia support services for Indigenous Australians

The establishment of a *National Indigenous Dementia Strategy* reflects growing awareness of dementia as a public health concern in Indigenous communities and the need for a coordinated, partnership approach between Indigenous communities, governments, health networks and the research community in responding to community need. In 2006, participants of a two-day *National Indigenous Dementia Forum* agreed on a national program of action. Key priorities included community awareness and prevention; care and support; research; diagnosis, referral and treatment; workforce issues, including developing a sustainable local workforce that is able to deliver services with regard to appropriate cultural frameworks; partnerships and collaborations (Alzheimer's Australia 2007).

There a substantial evidence-base to support policy action and practice. Arkles et al. (2010) recently undertook a comprehensive review of literature on ageing, cognition and dementia in Australian Aboriginal and Torres Strait Islander peoples. They found that dementia is an emerging public health concern among Indigenous communities, with prevalence rates of dementia around four to five times higher among Indigenous people in the Kimberley region than those in the general community. This finding is based on the project, *Dementia Cognitive Impairment in Kimberley Indigenous Australia*, which entailed assessments of people aged over 45 years in six remote communities in the Kimberley region. A tailored Kimberley Indigenous Cognitive Assessment tool (KICA) was used to assess people's cognitive capacity. The literature review also highlighted that Indigenous people face multiple and confounding risk factors for cognitive decline and dementia across the lifespan. Moreover, Indigenous PwD and their families experience problems with accessing services and that services adapted to local language, culture or circumstance are limited (Arkles et al. 2010, p.i). Arkles et al. further identified significant gaps in the literature, including Indigenous understandings of ageing and dementia, the experiences of caregivers in Indigenous communities, and the comparative experiences of people living in urban and remote areas, including access and service use.

A key issue raised in literature on dementia in Indigenous communities is the need to develop culturally appropriate service responses (McLeod 2012). In Lindeman and

Pedler's (2008) study of assessment of client needs in determining access to Home and Community Care (HACC) services in Central Australia, they highlight the challenges of delivering services in cross-cultural contexts and determining access in communities with high service needs. They note that most people in HACC assessment and coordination roles are non-indigenous and not from the local community. This presents difficulties as cultural practices can be extremely complex and varied between different groups and gaining an understanding of these practices takes time (Lindeman & Pedler 2008, p.91). Smith et al.'s (2011) study of dementia care in the Kimberly region of Western Australia similarly identifies the importance of developing culturally appropriate service responses in improving community care. Based on qualitative interviews with service providers and caregivers, Smith et al.'s (2011, p.12) research highlights the need to expand access to services in remote areas and to ensure that current services are culturally safe, that is, that the recipient of care's cultural needs are met. They recognised that a culturally safe model of dementia care entails both up-skilling existing service providers and the employment and training of community-based Aboriginal staff.

A community-based approach is also recognised as an effective response to supporting Indigenous PwD. Lindeman et al. (2010) undertook an evaluation of a dementia awareness resource, *Looking out for dementia*, for use in remote Indigenous communities. They found that the resource was effective in raising awareness among remote communities, including health service providers. More specifically, they found that while language was valued and enhanced engagement, the capacity to contextualise discussions within a structured implementation program was particularly effective in engaging the community. The researchers recommended that the use of resources is most effective when integrated into a whole-of-community approach to dementia awareness.

Our review of literature indicates that housing is not a central focus of the current evidence-base relating to cognitive decline and dementia in Indigenous communities. However, it is recognised that poor living conditions and poor quality housing exacerbate problems for Indigenous people in remote areas with dementia (Lindeman & Pedler 2008).

2.3   Transitions into residential care and end-of-life housing for people with dementia

People with Dementia, as their condition advances, will typically transition into residential care. Residential aged care in Australia is predominantly funded by the Commonwealth Government with additional funding available through state and local government and user co-contributions (Alzheimer's Australia 2013b, p.28). The Australian Government funds aged care facilities to provide residential aged care to older Australians whose needs are such that they can no longer remain in their own homes. These facilities provide accommodation and services that are relevant to a client's needs, such as living services (e.g. meals, laundry and cleaning), assistance with personal tasks (e.g. dressing and bathing), and allied health and nursing care. The majority of service providers are in the not-for-profit sector (60%), 29 per cent are private 'for profit' providers and the remaining 11 per cent are government facilities (AIHW 2012, p.106).

The AIHW's 2012 report, *Dementia in Australia*, provides an overview of aged residential care in Australia. The report notes that in 2010 '2772 service providers provided 179 749 Australian Government-subsidised residential aged care places across Australia (excluding places that flexible programs provided)' (AIHW 2012, p.106). It further notes that 'about 53 per cent (112 139 residents) of all permanent

residents in Australian Government subsidised aged care facilities in 2009–10 had a diagnosis of dementia' (AIHW 2012, p.107).

Runge et al. (2009) recently conducted a systematic review of literature on transitions in care of PwD. Their review provides insights into predictors of care transition. Here the research identifies three consistent predictors of entry into residential care: dementia severity and cognitive decline; behavioural and psychological symptoms of dementia; and caregivers' health and burden. The review also examines evidence relating to the effectiveness of community-based interventions in modifying care pathways. There is some evidence that early intervention that targets both the PwD and their carers is successful in delaying entry into residential care, however, the effectiveness of intervention is diminished as the dementia progresses to a severe stage (Runge et al. 2009, p.2). The review also highlights gaps in the existing literature, in particular, the lack of understanding of the care pathways and transitions experienced by people from special population groups including: people with younger-onset dementia; Indigenous Australians; PwD from culturally and linguistically diverse backgrounds; people living in rural and remote areas; and people with intellectual disabilities and dementia. There is also a gap in current understanding of the interaction between community-based services, short-term care such as dementia day services, and respite services and hospitals, as well as the interaction between dementia specific services and dementia-sensitive mainstream services (Runge et al. 2009, pp.2–3).

In addition to predictors of transitions, there are also numerous studies from the UK, US and Canada that address carers' experiences of the transition process (Lundh et al. 2000; Davies & Nolan 2003; Crawford Mead et al. 2005; Flynn Reuss et al. 2008; Robinson et al. 2010; Shanley et al. 2011), and to a lesser extent, the PwD's experience of the transition process (Thein et al. 2011). Alzhemier's Australia report on the experience of moving into residential aged care provides a summary of this literature and highlights key issues from both the carers and PwD's perspective. As Brown (2012, p.5) notes:

> For the family and carer, the experience of placing a person with dementia into residential aged care can often be characterised by stress, emotional upheaval, and feelings of relief, loss, grief and guilt. For the person with dementia, moving into residential aged care can also be disorienting, disempowering and emotional. In addition, the progression of dementia is also occurring, which can exacerbate the problem.

Alzheimer's Australia's survey of carers, highlights that a key problem for many family carers is that this transition can be sudden without adequate time for planning. The study found that a high proportion of PwD are transitions direct from hospital to a residential facility and that a need to act quickly compounds the emotional stress associated with the transition. In contrast, positive transition experiences are associated with adequate time for gathering information, participation by carers and PwD in the decision-making process and a staged approach, which may entail the PwD using respite care in the facility on a short-term basis or arranging visits to the facility to familiarise themselves and to alleviate fears of the transition.

Studies of transitions into residential care in the UK highlight the importance of participation by both PwD and their carers in the decision to enter into residential care. Where both are actively involved in decision-making the transition is more likely to be a positive experience. Davies and Nolan's (2003, p.446) recent qualitative study of carers' experiences of moving a close relative into a nursing home in the UK also emphasises the need for PwD and their carers to work in partnership and where possible retain control of the decision-making process. They also emphasise the value

of readily available information about their options and the availability of ongoing practical and emotional support for PwD and carers during the transition and settling-in phase. Thein et al.'s (2011, pp.15–16) interviews with PwD both before and after moving into residential care identify participation in the decision-making process as a critical factor in minimising feelings of a loss of independence. They also observe that arranging pre-move visits to the facility is important in enabling PwD to participate in the transition process and can reduce fears about the transition. Other key factors that support a PwD transition into a residential care facility include their own acceptance of their situation, acceptance by staff and other residents, and ongoing contact with family and friends.

Another critical aspect of the transition process is ensuring that the emotional needs of both carers and PwD are met during this stressful process. From the carers' perspective, this process entails relinquishing their role as the primary carer and trusting that nursing home staff are going to meet the individual and personal needs of their loved one. For the PwD, the process entails acceptance of their condition and acceptance of increased dependence and care. Shanley et al.'s (2011) qualitative study of carers' experiences of end-stage dementia distinguishes between instrumental needs of carers and psycho-social needs, which entails the need for empathy and understanding from family and friends and health professionals. Similarly, Robinson et al.'s (2010) study of the meaning of home following transition into a residential care facility, highlights that 'home-likeness' is determined by the individual, but that it can be facilitated through the enactment of supportive caregiving practices and communication; that is, through the building of supportive relationships between the person with dementia, family carers and staff. Alzheimer's Australia's report on moving into residential aged care identifies practical strategies which can address these needs and which include access to dementia specific counselling, participation in carer support groups, standardised forms that are accepted by all agencies, implementing person-centred approaches in the residential facility with a strong emphasis on high quality communication at all levels, as well as staff validating the knowledge of the carer and involving them and the person with dementia in their care planning, decision-making and service delivery (Brown 2012, p.5).

A key issue in relation to residential care is the quality of accommodation and care within residential care facilities, as well as the availability of appropriate end-of-life care for PwD and grief support for families. The Australian Government's recent *Living Longer. Living Better* aged care package introduces new quality frameworks for aged care and promotes a consumer-directed approach to service delivery within the sector. This includes the introduction of national quality indicators for residential care facilities and community care. It also entails the establishment of a new agency, the Australian Aged Care Quality Agency (AACQA), to manage accreditation and monitoring of the quality of aged care facilities. Unlike the previous responsible agency, this new body is also responsible for monitoring quality care standards within the home (Alzheimer's Australia 2013b, p.30). Since 2007, consumers have had access to an Aged Care Complaints Scheme that examines complaints about care or services and an independent Aged Care Commissioner, which can examine complaints regarding decisions, processes or conduct of either the Scheme or AACQA (Alzheimer's Australia 2013b, pp.30–31).

In relation to end-of-life care, Hines et al. (2010) have recently conducted a comprehensive review of research on a palliative approach to care for people with advanced dementia. They note that while the studies reviewed cover a wide range of strategies to help care for PwD at the end-of-life, a consistent theme is the need for advanced care planning to be undertaken between the PwD and their carers, ideally during the early stages of dementia. This is critical in enabling care providers to

respond appropriately and act consistently with an individual's beliefs, values and practices surrounding death. As they note, 'care is most effective and appropriate when it is individualised to meet the physical, emotional and spiritual needs of the patient' (Hines et al. 2010, p.1).

In relation to appropriate management of end-of-life care, the existing evidence-base indicates that interventions such as feeding tubes, intravenous antibiotics and admission to hospital did not substantially improve the quality of life for PwD. Instead, strategies designed to treat the unpleasant symptoms of advanced dementia such as pain and agitation were found to be of most benefit to patients (Hines et al. 2010, p.1). In the UK and the US, recent research indicates that there is scope for improving palliative care for PwD in residential care settings. Mitchell et al.'s (2006, p.325) comparative study of PwD and people with terminal cancer, highlights that PwD are less likely to be identified as having a terminal condition and to have advance directives limiting aggressive care and therefore are more likely to receive non-palliative, uncomfortable interventions just before death. Similarly, Thune-Boyle et al.'s (2010) qualitative study of end-of-life care among PwD in the UK finds low prevalence of advanced directives, which in turn can lead to over or under treatment of PwD. A key recommendation emerging from this research is the need for increased education for relatives, carers and PwD to enable them to have realistic expectations, to plan for the future and to make informed decisions about end-of-life treatments care.

2.4   Emerging models of housing and care

Australia's ageing population has facilitated moderate growth and diversification of new models of housing and care directed towards supporting older people. There are many terms covering these new models of housing, which share in common a component of care provision. They include extra care housing, supported housing, assisted living facilities, independent living units, service housing, and service integrated housing. In their recent report, Jones et al. (2010) provide a comprehensive review of new models of housing provision for the aged. They use the term 'service integrated housing' and classify this housing in terms of: sector (community or private), dwelling form (detached villa, apartment or shared, dwelling), and service arrangements (onsite or external agency). They observe (2010, pp.5–6) that this form of housing is under-developed in Australia, compared with the US, the UK and Europe. Moreover, in Australia the public sector has only played a relatively minor role in the development of service integrated housing. Instead, a resident-funded model of financing has facilitated growth in service integrated housing through the community and private sector.

In the UK, there has been considerable investment and growth in extra care housing over the past two decades. Key features of extra care housing are self-contained accommodation, ability to exercise choice with respect to meals and activities, provision of security and safety through co-location of staff at facility, and access to health and care services. An evaluation of 19 extra care schemes in 2009 found that 17 of the 19 schemes were making provision for PwD (Darton& Callaghan 2009). While this model of housing is appropriate for PwD, the evaluation found that residents in extra care schemes were substantially less physically and cognitively impaired than those who moved into residential care homes. Darton and Callaghan (2009, p.291) note that although the schemes support residents with dementia, there is a preference to accept residents with early onset dementia and relatively few problems with cognitive functioning. The evaluation raises concerns about the capacity of extra housing to accommodate residents as they experience progressive

decline in their condition, including the potential need for specialised segregated units for PwD and problems of integration with the general resident population.

In the US, service integrated housing is commonly referred to as assisted living (see http://www.ahcancal.org/ncal/resources/Pages/default.aspx). A national profile of residents of assisted living facilities indicates that this form of housing is currently supporting people with early and moderate dementia, with around 42 per cent of residents having some form of dementia (see website: http://www.ahcancal.org/ncal/resources/Pages/ResidentProfile.aspx). These facilities also offer specialised dementia units. Research on PwD in assisted living found that they are providing intermediate level of care for PwD prior to entry into a higher care facility such as a residential nursing home (Kopetz et al. 2000). In their review, Jones et al. (2010, p.63) note that despite the model emphasising high levels of privacy combined with access to care, this ideal often falls short in practice, with a national survey indicating that around 38 per cent of all units requiring residents to share a bathroom and 25 per cent of all units requiring residents to share with a non-related person.

In comparison with the UK and US, service integrated housing in Australia has been slower to develop, with only moderate growth in serviced apartments and assisted living facilities in retirement villages. Jones et al.'s (2010) report on service integrated housing in Australia includes descriptions of case studies in the private, community and public sectors. They note that currently provision of service integrated housing in the private sector is dominated by small-scale retirement villages that rely on local community care organisations to deliver government-funded care packages. In contrast, providers in the community sector are more likely to be approved providers of community care and they therefore are able to combine clustered housing with internal service arrangements. To date, the public sector has combined external and internal arrangements through partnering with community organisations in the delivery of housing and support services. They conclude that despite growing demand for this form of supported and serviced housing among older Australians, to date the sector has developed without significant public investment and policy input. They argue that more research and policy attention is required in order to facilitate a high quality service integrated housing sector that can accommodate the needs of a diverse population, including: low income and low asset people, Indigenous people, people from non-English speaking backgrounds, people with multiple health conditions, and those living in regional and remote areas.

2.5   Chapter summary

This chapter has provided an overview of recent policy developments and existing literature on housing and dementia. The review highlighted that while there is an extensive evidence-base relating to the capacity of home design and modification to enhance quality of life for PwD, there are few studies in the Australian context that have examined the role of housing and community care in alleviating cost burdens occurring in the health system and the way in which housing circumstances mediate health service access and care pathways. This research gap reflects the policy landscape, with the housing sector not featuring prominently in Australia's national dementia response. This contrasts with the UK experience in which housing providers are recognised as playing a central role in facilitating access to community support and information, facilitating early diagnosis and assessment and, in some instances, providing dementia-relevant on-site services such as memory cafes in housing developments.

Key findings emerging from this review include:

→ Housing is recognised as a critical protective factor in relation to the health and well-being of older Australians.

→ Older Australians have articulated a desire to retain independence and they support a consumer-directed approach to health care.

→ A substantial proportion of PwD live in the community, an estimated 70 per cent of all PwD, and this is expected to grow over the coming decades.

→ APwD's home is critical to their quality of life, withPwD more likely than others in the community to be spending a significant proportion of their time in the home.

→ Continuing to live in their family home and share their lives with loved ones is of primary significance in enabling PwD to cope with the challenges of loss of memory function.

→ One of the major advantages of PwD remaining in their own home following diagnosis is that the home is a familiar environment.

→ For PwD, remaining in their own home holds distinct advantages during the mild and moderate stages of the condition, but this situation changes as the condition progresses.

→ Co-resident caregivers become a critical companion in supporting PwD to continue to undertake tasks they are competent in and assisting with tasks when the PwD experiences a loss in capacity.

→ PwD who live alone are at risk of social isolation, self-neglect, self-injury, depression, and exploitation by others.

→ PwD are more likely to be female and to have lower incomes and they are less likely to access services and support.

→ There are a range of design interventions and assistive technologies that can make a difference to the wellbeing of PwD and allow them to continue to mobilise remaining strengths and capacities.

→ Home modifications are effective in decreasing the incidence of accidents and injury, and they can strengthen home-based social relationships and networks and reduce strain on caregivers.

→ PwD are more likely to remain in place if supported by live-in carers, but carers' own pressing needs for appropriate housing are less often addressed, particularly those on low incomes.

→ The impact of an ageing population on the housing sector is substantial, with older households projected to grow from 1.6 to 3.2 million between 2008 and 2028.

→ An AHURI study of older persons in public housing (McNelis et al. 2008) found that housing authority staff felt that they were not well-equipped to assist tenants with dementia and that they have little knowledge of, and limited relationships with community aged care services.

→ The establishment of a *National Indigenous Dementia Strategy* reflects growing awareness of dementia as public health concern in Indigenous communities and the need for a coordinated, partnership approach between Indigenous communities, governments, health networks and the research community in responding to community need.

→ The role of housing is not well understood in relation to cognitive decline and dementia in Indigenous communities. However, it is recognised that poor living conditions and poor quality housing exacerbate problems for Indigenous people in remote areas with dementia.

→ PwD, as their condition advances, will typically transition into residential care. The literature identifies three consistent predictors of entry into residential care: dementia severity and cognitive decline, behavioural and psychological symptoms of dementia, and caregivers' health and burden.

→ Studies of transitions into residential care highlight the importance of participation by both PwD and their carers in the decision to enter into residential care.

→ Service integrated housing in Australia is experiencing moderate growth, primarily within the community and private sector. More research and policy development is required to ensure that this form of housing provision can support a diverse aged population.

3 POPULATION AND HOUSING PROFILE OF OLDER AUSTRALIANS AND PEOPLE WITH DEMENTIA

In Chapter 3, we examine available secondary data on the housing circumstances of older Australians and PwD. In Section 3.1 we provide an overview of the population and housing profile of older Australians, including: estimates and projections of older Australians, a profile of the housing circumstances of older Australians, estimates of older people living in low cost and marginal housing and experiencing housing stress, and older Australian's future demand for public and private rental housing. In Section 3.2 we focus on the available secondary data on the population and housing profile of PwD living in the community, including population projections by housing type, a profile of the housing circumstances of PwD, estimates of PwD living in housing stress, and other relevant housing data on residency, severity of condition, living arrangements and available assistance.

3.1 Population and housing profile of older Australians

3.1.1 Estimates and projections of older Australians, 2011 to 2041

Australia's population is ageing due to declining fertility rates and increased longevity, which in turn is contributing to increases in the prevalence of a range of health conditions associated with ageing, such as dementia (AIHW 2007). The AIHW's (2007) publication, *Older Australians* at a Glance, provides an overview of the demographic profile and housing circumstances of older Australians. While the report draws on 2006 census data, key tables have been updated using 2011 census data. This recent data is reported here.

Table 1 below provides two estimates of the number and proportion of older Australians. In 2011, there were approximately 3.1 million people aged 65 years and over, which comprised 13.7 per cent of the total population. In 2011, there were approximately 5 700 894 million people aged 55 years and over, which comprised 25.2 per cent of the total population.

Table 1: Estimated resident population for Australia, 30 June 2011

	Number	Per cent of total population
0–44	13,854,872	61.2
45–54	3,064,788	13.5
55–64	2,597,365	11.5
65–74	1,683,829	7.4
75–84	1,004,273	4.4
85–94	383,924	1.7
95+	31,503	0.1
Total persons 65+	3,103,529	13.7
Total persons 55+	5,700,894	25.2
Total persons	*22,620,554*	*100.0*

Source: ABS 2011a

Table 2 below provides an overview of the cultural diversity of older Australians. It highlights that 64.2 per cent of older people were born in Australia and 35.8 per cent were born overseas. The majority of older Australians are non-Indigenous Australian-born (63.6%, 1 913 797), 22.1 per cent of older Australians have migrated from English-speaking countries (n=666 251), 13.6 per cent of older Australians have migrated from non-English speaking countries (n=409 210) and 0.6 per cent of older Australians are Indigenous (n=18 809).

Table 2: Estimated residential population by cultural diversity, 30 June 2011

		No. 65 years and over	% 65 years and over
Australian born	Indigenous	18,809	0.6
	Non-Indigenous	1,913,797	63.6
	Total Australian born	1,932,606	64.2
Overseas born	English speaking countries	666,251	22.1
	Other countries	409,210	13.6
	Total Overseas born	1,075,461	35.8
Total Population		*3,008,067*	*100.0*

Source: ABS 2011a

The AIHW's (2007) publication, *Older Australians at a Glance*, also provides projections of the aged population. Table 3 below provides projections of the 65 and over and 55 and over population for the next 30 years. Table 3 indicates that the number of people aged 65 years and over is expected to increase from 3 103 500 in 2011 to 6 759 000 in 2041 and that the proportion of people aged 65 years and over is expected to increase from 13.7 per cent in 2011 to 21.4 per cent in 2041. In regards to people aged 55 years and over, the number is expected to increase from 5 700 900 in 2011 to 10 309 000 in 2041 and the proportion of people aged 55 years and over is expected to increase from 25.2 per cent in 2011 to 32.6 per cent in 2041.

Table 3: Projections of estimated resident population, 55+ and 65+ years, 2011 to 2041

Persons	2011[a]	2021[b]	2031[b]	2041[b]
55–64	2,597,400	3,010,000	3,231,000	3,550,000
65–74	1,683,800	2,448,000	2,863,000	3,084,000
75–84	1,004,300	1,386,000	2,046,000	2,422,000
85–94	383,900	499,000	737,000	1,110,000
95+	31,500	62,000	85,000	143,000
Total persons 65+	*3,103,500*	*4,395,000*	*5,732,000*	*6,759,000*
	13.72	*17.16*	*19.91*	*21.38*
Total persons 55+	*5,700,900*	*7,405,000*	*8,963,000*	*10,309,000*
	25.20	*28.91*	*31.14*	*32.61*
Total persons	*22,620,600*	*25,617,000*	*28,786,000*	*31,609,000*

Note: (a) Preliminary estimated resident populations, 30 June 2011;
(b) 2008 population projections based on the 2006 Australian census data.
Sources: ABS 2008; ABS 2011a

3.1.2 Housing circumstances of older Australians

The AIHW's (2007) report provides a profile of the housing tenure of older Australians compared with all households. Table 4 below highlights that older households are substantially more likely to own their own home, with 78.1 per cent of older households owning their own home outright compared with 32.6 per cent of all households. In contrast, the proportion of older households renting their home is considerably smaller, 12.1 per cent compared with 28.7 per cent of all households.

Table 4: Housing tenure profile of older households (65+), 2009–10

Housing tenure type	No. of older households (65+)	% of older households (65+)	All households	All households
Owner without a mortgage	1,380,771	78.1	2,733,712	32.6
Owner with a mortgage	114,888	6.5	3,040,257	36.2
State/territory housing authority	85,017	4.8	326,702	3.9
Private renter	111,529	6.3	1,993,804	23.7
Other landlord	16,438	0.9	89,864	1.1
Total renters	213,161	12.1	2,410,370	28.7
Other tenure type	58,328	3.3	212,482	2.5
Total households	*1,767,500*	*100.0*	*8,398,500*	*100.0*

Note: (a) For a definition of Reference person see the glossary for the *Household and Income Distribution Survey* on the ABS website.
Source: ABS 2011b

The AIHW's more recent report, *Housing Assistance in Australia 2013* (2013b, pp.36–37), provides further insight into the housing circumstances of older Australians. Table 5 below indicates differences in home ownership rate according to household composition, with the overall home ownership rate for older couples living in private dwellings in 2011–12 at 90 per cent compared with a 77 per cent home ownership rate for older lone person households. In contrast, older lone person households are more likely to be private or public tenants compared with older couple households. Almost 1 in 5 single people aged over 65 was a renter compared with 1 in 15 couples (AIHW 2013b, p.36).

Table 5: Tenure of older Australians and all households, 2011–12 (per cent)

Tenure	Couple only, reference person aged 65 and over	Lone person aged 65 and over	All households
Owner	*90.3*	*76.7*	*67.5*
Owner without a mortgage	82.1	71.9	30.9
Owner with a mortgage	8.2	4.8	36.6
Renter^(a)	*7.9*	*19.3*	*30.3*
Renting from state or territory housing authority	2.6	7.2	3.9
Renting from private landlord	3.9	9.3	25.1

Note: (a) Renter includes 'Other landlords'.

Source: ABS 2013

Projections of older renter households over a 20-year period are outlined in the NHSC's (2010, p.142) *2nd State of Supply* report and are reproduced here. As noted in the report, the projections indicate that 'underlying demand for rental from older households is likely to increase by 120 per cent to 2028, with consequent pressures on both private and public rental markets' (NHSC 2010, p.143). Table 6 below shows that private rental demand is projected to increase from 146 200 in 2008 to 321 400 in 2028 and public rental demand is projected to increase from 86 500 in 2008 to 189 800 in 2028.

Table 6: Projections of older renter households (65 years and over), 2008 to 2028

	2008	2013	2018	2023	2028
Reference person aged 65 years and over					
Private rental	146,200	178,200	219,000	265,900	321,400
Public rental	86,500	104,800	129,700	156,800	189,800
Total renters	*232,700*	*283,000*	*348,700*	*422,700*	*511,200*

Source: NHSC projections based on McDonald-Temple household growth scenarios.

3.1.3 Older Australians in low cost and marginal housing

In general, older Australians on average have relatively low housing costs due to high rates of home ownership. However, higher housing cost burdens are experienced by older people in private rental and older people who live alone. Table 7 below provides a comparison of the housing costs of couple households and lone person households. In 2011–12, 6.4 per cent of older couples spent more than 25 per cent of their gross income on housing costs, compared with 15 per cent of singles who spent more than 25 per cent of their gross income on housing costs.

Table 7: Housing costs of older Australians and all households, 2011–12 (per cent)

Housing costs as a proportion of gross income	Couple only, reference person aged 65 and over	Lone person aged 65 and over	All households
25% or less	93.6	85.0	75.0
More than 25% to 30%	0.9[(b)]	2.3	7.0
More than 30% to 50%	4.1	7.1	12.4
More than 50%	1.4[(b)]	5.6	5.6

Notes: (a) Excludes households with nil or negative income. (b) Estimate has a relative standard error greater than 50 per cent and is considered to unreliable for general use.

Source: ABS 2013

Despite high rates of home ownership, there are a substantial number of older Australians living in low cost and marginal housing, including boarding houses and caravan parks, and it is anticipated that demand for low cost housing will increase over the next decade. Table 8 below provides recent data on the total number of older people (65 years and over) who are living in public housing, the total number of older people living in state-owned and managed Indigenous housing, and CRA recipients (AIHW 2013b, p.38). Notably CRA recipients includes people living in low cost private rental and other marginal housing types such as boarding houses and caravan parks. Table 8 below indicates that currently 392 627 older people (that is, 12.7% of all people aged 65 years and over) receive some form of government housing assistance, with the majority (69.2%) of these receiving CRA, 30.4 per cent living in public housing and a further 0.4 per cent living in state-owned and managed Indigenous housing.

Table 8: Older recipients of housing assistance, by type of assistance, 30 June 2012

	Type of housing assistance			Total
	Public housing	SOMIH	CRA	
No. of people aged 65 and older living in households	119,331	1,488	271,808	392,627
Older people as a proportion of all people (%)	18.6	5.2	11.3	12.8
Total no. of people living in households	*640,445*	*28,589*	*2,402,748*	*3,071,782*

Notes: CRA data are as at 1 June 2012. CRA counts include persons with missing or incomplete state data.

Source: AIHW analysis of Australian Government Housing Data Set, June 2012. AIHW National Housing Assistance Data.

Housing costs as a proportion of gross income varies across different rental categories, with Table 9 below indicating that those living in private rental are more likely to be experiencing housing stress (i.e. paying above 30% of their income on housing costs) than those living in other marginal housing types such as boarding houses and caravan parks. While low income elderly households living in marginal housing may have reduced housing cost burdens, they are likely to be living in housing of lower quality, which is less appropriate to their health and care needs.

Table 9: CRA recipients aged 65 years and over, proportion of income (including CRA) spent on rent by rent type, June 2011

Rent type	Less than 25%	25% to < 30%	30% to < 50%	50% and more	Total	Total recipients aged 65 years and over
Private	49.6	13.6	28.6	8.3	100.0	159,748
Board and lodging	57.9	14.6	25.6	2.0	100.0	18,013
Lodging only	68.3	11.2	17.8	2.7	100.0	14,964
Site and mooring fees	95.5	2.0	2.2	0.3	100.0	39,662
Maintenance and other fees	84.3	1.9	6.8	7.0	100.0	12,334
Other	88.0	4.1	5.5	2.3	100.0	10,536
Total 65+	61.6	10.7	21.6	6.0	100.0	255,257

Source: AIHW analysis of Commonwealth Rental Assistance data.

3.2 Population and housing profile of people with dementia

3.2.1 Estimates and projections of people with dementia, 2011 to 2050

Access Economics (2011) report, *Dementia Across Australia: 2011–2050*, provides current and projected dementia prevalence estimates until 2050. Access Economics (2011, p.15) estimates that there are 266 574 PwD in Australia in 2011. This is projected to increase to 553 285 people by 2030 and 942 624 by 2050.The underlying population data used to calculate the number of PwD in Australia in 2011 to 2050 was estimated using an in-house demographic model based on the 2006 national census undertaken by the Australian Bureau of Statistics (Access Economics 2011, p.14).

Table 10: Total Australian prevalence projections, by age

	2011	2012	2013	2014	2015	2020	2030	2040	2050
0–59	4,992	5,058	5,122	5,189	5,256	5,585	6,209	6,850	7,459
60–64	11,337	11,317	11,487	11,698	11,899	13,304	14,491	15,737	20,100
65–69	14,541	15,873	16,994	17,774	18,480	20,104	24,175	26,244	30,554
70–74	25,157	26,212	27,215	28,679	30,269	40,606	48,981	53,321	57,908
75–79	34,043	35,235	36,526	38,526	39,820	50,045	72,574	88,187	96,753
80–84	56,440	56,860	57,168	57,526	57,958	70,033	117,440	144,635	160,416
85–89	65,471	68,035	70,640	72,878	75,054	80,217	122,727	181,647	225,898
90–94	39,240	43,277	47,280	51,148	54,334	67,087	89,521	152,771	195,992
95+	15,353	16,841	18,247	19,974	22,893	37,415	57,168	90,739	147.544
Total	*266,574*	*278,707*	*290,679*	*302,962*	*315,963*	*384,396*	*553,285*	*760,131*	*942,624*

Source: Table reproduced from Access Economics (2011, p.15).

The report (Access Economics 2011, p.16) also provides dementia prevalence projections by jurisdiction (see Table 11 below). Variation in the growth of prevalence across jurisdictions reflects the age structure and growth of the population. Both the two jurisdictions selected for this study, South Australia (SA) and Tasmania, have ageing populations with constrained population growth. In SA, there are 23 710 PwD in 2011 and this is projected to increase to 44 236 people by 2030 and 69 620 by 2050. In Tasmania, there are 6732 PwD in 2011 and this is projected to increase to 13 544 by 2030 and 20 653 by 2050.

Table 11: Total Australian dementia prevalence projections, by jurisdiction

	2011	2015	2020	2030	2040	2050
NSW	91,038	107037	128,238	182,331	248,139	303,673
Vic	68,397	8,117	98,123	141,161	195,459	245,813
QLD	48,674	58,509	3,470	114,800	166,032	215,272
SA	23,710	27353	32,062	44,236	59,053	69,620
WA	23,931	29,041	36,500	46,332	57,781	68,708
Tas	6,732	7,818	9,362	13,544	18,043	20,653
NT*	838	1,049	1,473	2,700	3,992	4,916
ACT	3,254	4,040	5,167	8,181	11,632	13,970
Total	*266,574*	*315,963*	*384,396*	*553,285*	*760,131*	*942,624*

*Note that NT figures are likely to significantly underestimate the true prevalence of dementia.

Source: Table reproduced from Access Economics (2011, p.16).

The dementia prevalence projections presented in the tables above have been calculated by applying age and gender dementia prevalence rates to population projections. These dementia prevalence rates are presented in Figure 1 below. They are not simply based on the number of people diagnosed with, or reporting, the condition, but rather estimates are based on a combination of published epidemiological studies and meta-analyses to the population (Access Economics 2011, p.14). Figure 1 below clearly illustrates that increased risk of developing dementia is associated with age. It shows that dementia rates are relatively low until the age of 70 years and then incidence rates increase rapidly.
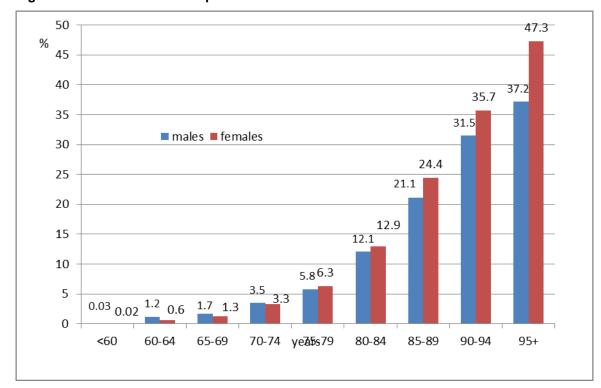
Figure 1: Estimated dementia prevalence rates in Australia 2010

Source: Chart reproduced from Access Economics (2011, p.14).

3.2.2 Housing circumstances of people with dementia

The projections of older PwD by tenure type presented in Table 12 below are based on integration of the ABS (2009–10) *Household Income and Distribution survey* and the population projections available from Access Economics (2011), excluding those living in residential care. Notably, these projections are based on several assumptions. First, that the proportion of PwD living in the community will remain constant. This may not necessarily be the case. For example, in-home care packages and support may be expanded to enable a greater proportion of PwD to live in the community for extended periods. Alternatively, there may be reduced capacity for informal family care and co-resident carers in part due to an increase in lone person households. Second, the projections assume that PwD are present across all tenure types and that there are no contributing factors that might result in PwD being concentrated in one particular tenure type. This assumption is made based on the absence of any evidence available to counter this claim. Third, we have assigned each person with dementia to a separate household and therefore we assume that there are no households that include two or more PwD. While this may not be the case, it is anticipated that the number of households with two or more PwD would be very low due to the substantial challenges that such a living arrangement would propose.

To estimate the housing circumstances of PwD, our first step was to derive an estimate of the proportion of PwD who live in the community. Data on dementia by residency is available in the AIHW (2012) report, *Dementia in Australia*. The report notes that there is no one data source available.Instead, the estimates are derived from data collected through the Aged Care Funding Instrument (ACFI) and ABS's 2009 Survey of Disability and Carers (SDAC). The report estimates that of the 298 000 PwD in Australia in 2011, 30 per cent (n=90 000) live in cared accommodation and 70 per cent (n=208 000) live in the community. We then applied

these proportion estimates to the Access Economics population estimates and projections. Notably, the revised estimates provided by Access Economics (2011, p.15) of 266 574 PwD in Australia in 2011 are slightly lower than the AIHW figures.

Our second step was to identify the distribution of tenure type among the older Australian population (65 years and over). Here we drew on ABS *Household Income and Distribution*, Australia (2009–10) which was available on the AIHW website as an attachment to the AIHW (2007) report on Older Australians.

Table 12 below outlines estimates and projections of households with a person with dementia. In 2011, there were approximately 157 864 PwD living in an owner-occupied home, with 145 735 living in a home that is owned outright and a further 12 129 living in a mortgaged home. In 2011, there were approximately 11 756 PwD living in private rental and 8957 PwD living in public housing.

Looking at the projections by tenure, Table 12 below highlights that the number of PwD living in public housing is expected to increase from 8957 people in 2011 to 12 916 in 2020 and 31 672 in 2050. The number of PwD living in private rental housing is expected to increase from 11 756 people in 2011 to 16 952 in 2020 and 41 570 in 2050.

Table 12: Projections of number of households with a person with dementia by tenure type, 2009–2050

Housing tenure type	% of older households (65+)	2011	2012	2013	2014	2015	2020	2030	2040	2050
Owner without a mortgage	78.1	145,735	152,369	158,914	165,629	172,737	210,149	302,481	415,564	515,333
Owner with a mortgage	6.5	12,129	12,681	13,226	13,785	14,376	17,490	25,174	34,586	42,889
State/territory housing authority	4.8	8,957	9,365	9,767	10,180	10,616	12,916	18,590	25,540	31,672
Private renter	6.3	11,756	12,291	12,819	13,361	13,934	16,952	24,400	33,522	41,570
Other landlord	0.9	1,679	1,756	1,831	1,909	1,991	2,422	3,486	4,789	5,939
Total renters	12.1	22,579	23,606	24,621	25,661	26,762	32,558	46,863	64,383	79,840
Other tenure type	3.3	6,158	6,438	6,715	6,998	7,299	8,880	12,781	17,559	21,775
Total households—people with dementia living in the community	100	186,602	195,095	203,475	212,073	221,174	269,077	387,300	532,092	659,837
Total Households—people with dementia		*266,574*	*278,707*	*290,679*	*302,962*	*315,963*	*384,396*	*553,285*	*760,131*	*942,624*

Source: Projections from Access Economics (2011, p.15); ABS (2011b); Calculations by AIHW using rates based on ADI (2009) and ABS SDAC (2009).

We have also calculated estimates of CRA recipients aged 55–64 years and 65 and over who have dementia and identify the number who are experiencing housing stress, that is paying more than 30 per cent of their income on housing costs. Drawing on the five-year cohort prevalence rates generated by Access Economics (2011) we assume a prevalence rate of 0.46 per cent for persons aged 55–64 years[2] and a prevalence rate of 2.1 per cent for people over 65 years[3].

Table 13 below provides estimates of the number of CRA recipients who have dementia by rent type in 2011 and estimates of the number of recipients with dementia who are experiencing housing stress. It is estimated that in 2011 there were 6003 CRA recipients aged 55 years and over who have dementia; 643 of these were aged 55–64 years and 5360 were aged 65 years and over. The majority of CRA recipients who have dementia are private rental tenants. It is estimated that in 2011 there were 3355 CRA recipients aged 65 years and over and a further 471 CRA recipients aged 55–64 years who were private rental tenants and who have dementia.

It is estimated that in 2011 there were 1742 CRA recipients aged 55 years and over who have dementia and who were experiencing housing stress; 262 of these were aged 55–64 years and 1480 were aged 65 years and over. Housing stress affects a higher proportion of private rental tenants compared with other tenure types such as boarding and lodging houses, with 48.6per cent of those aged 55–64 years and 36.9 per cent of those aged 65 years and over experiencing housing stress.

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[2] This rate was calculated by averaging the male and female prevalence rates for <60 years and 60–64 years. Based on the assumption of a prevalence rate of 0.025 per cent for people aged 55–59 and 0.9 per cent for people aged 60–64 years, we then averaged these rates to derive the rate of 0.46 per cent for people aged 55–64 years of age.

[3] This rate was calculated by averaging the male and female prevalence rates for people aged over 65 years. We then examined estimated population rates for people aged 65–74, 75–84, 85–94 and 95 and over and applied these proportions to the rates. This enabled us to estimate a single prevalence rate for people aged over 65 years that factored in the age structure of the population.

Table 13: CRA recipients aged 55–64 and 65+, proportion of income (including CRA) spent on rent by rent type, June 2011

Rent type

55–64	Total CRA recipients	CRA recipients who have dementia	Paying over 30% on housing costs
Private	102,351	471	229
Board and lodging	8,315	38	11
Lodging only	10,411	48	13
Site and mooring fees	10,909	50	4
Maintenance and other fees	566	3	1
Other	7,319	34	4
Total 55–64	*139,871*	*643*	*262*
65 years and over			
Private	159,748	3,355	1,238
Board and lodging	18,013	378	104
Lodging only	14,964	314	64
Site and mooring fees	39,662	833	21
Maintenance and other fees	12,334	259	36
Other	10,536	221	17
Total 65+	*255,257*	*5,360*	*1,480*

Source: AIHW analysis of Commonwealth Rental Assistance data.

3.2.3 Residency and severity of condition

The AIHW (2012) report, *Dementia in Australia*, examines dementia prevalence by residency and severity. This analysis is based on data collected through the *Aged Care Funding Instrument* (ACFI) and the ABS 2009 *Survey of Disability Ageing and Carers* (SDAC).These estimates of prevalence by residency suggest that 30 per cent of PwD lived in cared accommodation in 2011, while 70 per cent lived in the community (AIHW 2012, p.16).

In relation to severity of dementia, the AIHW analysis finds that:

→ The majority (63%) of those with dementia in cared accommodation had moderate dementia, while the majority (76%) of those in the community had mild dementia.

→ Those with mild dementia living in the community accounted for just over half (53%) of all Australians with dementia.

→ Of the 44 700 people with severe dementia, more than 1 in 3 (37% of 16 500 people) were estimated to live in the community.

The estimates also suggest that there are some differences in patterns of residency and severity by sex. For instance, men with dementia were more likely to live in the community than women (77% and 65% respectively). 'Among those living in the community, almost 1 in 3 men (31%) with dementia were estimated to have moderate or severe dementia, compared with a smaller proportion (19%) of women' (AIHW 2012, p.18).

3.2.4 *Living arrangements of people with dementia and available assistance*

The AIHW (2012) report, *Dementia in Australia*, also provides information on the living arrangements of those with dementia who live in private dwellings (rather than other types of dwellings in the community such as self-care aged accommodation, hotels, boarding houses, etc.) and the assistance available to PwD who live in the community.

In relation to living arrangements, in 2009 almost 9 in 10 (88%) PwD who lived in private dwellings lived with others, while 12 per cent lived alone. Men were more likely than women to have been living with others (93% and 84% respectively) (AIHW 2012, p.41).

In relation to assistance, in 2009 three-quarters (75%) of PwD living in the community made use of a combination of formal and informal assistance to obtain help in the areas for which they needed assistance, while 22 per cent relied solely on informal assistance (AIHW 2012, p.32).

In 2009, about 9 in 10 (92%) of PwD living in the community were receiving care from one or more carers. Most PwD were being cared for by family, either their spouse/partner or their children. Around 42 per cent of main carers of a person with dementia were the spouse/partner of the care recipient and 44 per cent were the son or daughter. When only co-resident primary carers were considered, 57 per cent were the spouse/partner and 36 per cent were the son or daughter (AIHW 2012, p.117).

The SDAC collected information about whether respondents living in the community needed help with various activities, with a distinction made between 'core' and 'non-core' activities of daily living. Core activities relate to self-care, communication and mobility, and non-core activities relate to health care, cognitive or emotional tasks, household chores, property maintenance, meal preparation, reading and writing tasks, and transport. Of the three core activities, PwD living in the community were most likely to need assistance with mobility (80%), followed by self-care (62%). They were least likely (39%) to need help with communication (AIHW 2012, p.50).

3.3   Chapter summary

This chapter has provided an overview of available secondary data on older Australians and PwD and their housing circumstances. It has included: population estimates and projections of older Australians and PwD, including projections by tenure type, estimates of older Australians living in low cost and marginal housing, estimates of older Australians and PwD living in housing stress, and other relevant housing data on residency, severity of condition, living arrangements and available assistance for PwD who are living in the community.

Key findings emerging from this review of secondary data sources relating to older Australians include:

→ The number of people aged 65 years and over is expected to increase from 3 103 500 in 2011 to 6 758 000 in 2041 and that the proportion of people aged 65 years and over is expected to increase from or 13.7 per cent in 2011 to 21.4 per cent in 2041.

→ The number of people aged 55 years and over is expected to increase from 5 700 900 in 2011 to 10 309 000 in 2041 and the proportion of people aged 55 years and over is expected to increase from or 25.2 per cent in 2011 to 32.6 per cent in 2041.

→ Older households are substantially more likely to own their own home, with 78.1 per cent of older households owning their own home outright compared with

32.6 per cent of all households. In contrast, the proportion of older households renting their home is considerably smaller, 12.1 per cent compared with 28.7 per cent of all households.

→ Older lone person households are more likely to be private or public tenants compared with older couple households. Almost 1 in 5 single people aged over 65 was a renter compared with 1 in 15 couples.

→ Private rental demand is projected to increase from 146 200 in 2008 to 321 400 in 2028 and public rental demand is projected to increase from 86 500 in 2008 to 189 800 in 2028.

→ In 2011–12, 6.4 per cent of older couples spent more than 25 per cent of their gross income on housing costs, compared with 15 per cent of singles who spent more than 25 per cent of their gross income on housing costs.

→ The majority of CRA recipients are private rental tenants. It is estimated that there are 3355 CRA recipients aged 65 years and over, with a further 471 CRA recipients aged 55–64 years who are private rental tenants and who have dementia. Housing stress affects a higher proportion of private rental tenants compared with other tenure types such as boarding and lodging houses, with 48.6 per cent of those aged 55–64 years and 36.9 per cent of those aged 65 years and over experiencing housing stress.

→ Currently 392 627 older people (that is, 12.7% of all people aged 65 years and over) receive some form of government housing assistance, with the majority (69.2%) of these receiving CRA, 30.4 per cent living in public housing and a further 0.4 per cent living in state-owned and managed Indigenous housing.

→ Older Australians living in private rental are more likely to be experiencing housing stress (i.e. paying above 30% of their income on housing costs) than those living in other marginal housing types such as boarding houses and caravan parks.

Key findings emerging from this review of secondary data sources relating to PwD include:

→ There were 266 574 PwD in Australia in 2011. This is projected to increase to 553 285 people by 2030 and 942 624 by 2050.

→ Dementia rates are relatively low until the age of 70 years and then incidence rates increase rapidly.

→ In 2011, there were approximately 157 864 PwD living in an owner-occupied home, with 145 735 living in a home that is owned outright and a further 12 129 living in a mortgaged home.

→ In 2011, there were approximately 11 756 PwD living in private rental and 8957 PwD living in public housing.

→ The number of PwD living in public housing is expected to increase from 8957 people in 2011 to 12 916 in 2020 and 31 672 in 2050.

→ The number of PwD living in private rental housing is expected to increase from 11 756 people in 2011 to 16 952 in 2020 and 41 570 in 2050.

→ It is estimated that in 2011 there were 6003 CRA recipients aged 55 years and over who have dementia; 643 of these were aged 55–64 years and 5360 were aged 65 years and over.

→ It is estimated that in 2011 there were 1742 CRA recipients aged 55 years and over who have dementia and who were experiencing housing stress; 262 of these were aged 55–64 years and 1480 were aged 65 years and over.

→ It is estimated that in 2011,30 per cent of PwD lived in cared accommodation, while 70 per cent lived in the community.

→ In relation to living arrangements, in 2009 almost 9 in 10 (88%) of PwD who lived in private dwellings lived with others, while 12 per cent lived alone. Men were more likely than women to have been living with others (93% and 84% respectively).

→ In 2009, about 9 in 10 (92%) of PwD living in the community were receiving care from one or more carers. Most PwD were being cared for by family, either their spouse/partner or their child/ren. Around 42 per cent of main carers of a person with dementia were the spouse/partner of the care recipient and 44 per cent were the son or daughter.

→ PwD living in the community were most likely to need assistance with mobility (80%), followed by self-care (62%). They were least likely (39%) to need help with communication.

4   RESEARCH PROGRAM

In Chapter 4 we provide an outline of the primary data collection stage of our project. This entails interviews conducted in two case sites, South Australia (SA) and Tasmania. The research team will conduct approximately 15 interviews with relevant stakeholders in each case site. Relevant stakeholders include housing managers, social workers and aged care service providers. The research team will then conduct approximately 10 interviews with PwD and their carers across a range of low cost housing settings, including low income owner-occupiers, private rental tenants and public and community housing tenants.

4.1   Evaluation of in-home support service for people with dementia

To answer to RQ3, RQ4 and RQ5, the team will conduct interviews in two case sites, South Australia (SA) and Tasmania. The reason for selecting these two case sites is that SA and Tasmania have the highest proportion of people aged 65 years and over (15.6% of the population in both SA and Tasmania in June 2010) of all states and territories.

The team will conduct group and individual interviews with housing managers, social workers and service providers delivering Community Aged Care Packages (CACP) and the Extended Aged Care at Home Dementia (EACHD) program in the two case sites. It is anticipated that around 15 interviews will be conducted in each case site (30 in total). This number is sufficient to ensure that a range of perspectives are captured, including insights that relate to each point in the trajectory of care. The interviews will examine the role housing plays in enabling PwD to retain independence and identify challenges associated with people's particular household circumstances, in particular, low cost and insecure housing situations. The interviews will question managers about the problems experienced in assisting PwD to date and how these can be addressed. The interviews will also identify strategies that can facilitate early diagnoses and intervention, assist PwD to maintain independence, improve in-home support, and assist PwD and their carers to manage transitions into residential care.

4.2   People with dementia's perspectives on living at home and in-home support

The team will also seek participation from people with mild to moderate cognitive decline who are clients of in-home support services, as well as their families and carers. Despite their cognitive impairments, people with mild to moderate dementia can retain the capacity to provide helpful insights into factors that impact on their quality of life and are often eager to do so (Wilkinson 2002). It is also an ethical and methodological imperative to offer PwD the opportunity to contribute to research that could affect them and others with the disease. Direct participation in research acknowledges the unique personhood of PwD and can produce more reliable information into their preferences than the use of proxies. In the absence of the capacity for informed consent in the person with dementia, however, and with specific regard to carer services, the perspectives of carers and family members are also valuable (Livingston et al. 2010).

It is anticipated that 10 cases will be described in each case site as this will enable the team to capture the experience of PwD and carers across a range of low cost housing settings. The number of interviews will vary by case, with family and carers being invited to participate in a separate interview in order to shed further light on the circumstances of an individual. The purpose of these interviews is to understand the

factors that influence quality care outcomes including the significance of maintaining independence, the value attached to the home environment, the neighbourhood and public spaces, capacity and mobility around the home, availability of family and support networks, geographic location, planning and processes of decision-making around in-home support and the transition into residential care, and financial resources. While PwD may not be able to recall specific reasons for decisions, the study aims to uncover the factors that most influence their thinking around service help. The interviews with family and carers will assist with corroboration and detailing of insights provided by PwD about their housing circumstances, as well as providing the interviewer with insight into the specific views and concerns of carers.

The team will aim to recruit people living in a variety of household and tenure types, and their family and carers. The team will engage service providers to assist with the dissemination of information about the research project. Clients and their families and carers can then choose if they want to be involved in the project. They will be offered remuneration for their time and assistance.

4.3   Data analysis

The interviews will be transcribed and analysed using NVIVO. Key themes for analysis include: evaluation of equity, efficiency and effectiveness of existing services; community service coordination; the role and responsibilities of housing managers and landlords; interaction between family carers, service providers and PwD; independence, capacity and mobility around the home; home modification; attachment to home and connection to place; social isolation; housing costs and financial management; housing pathways and care trajectories; and decision-making and transitions into residential care.

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APPENDIX

Search strategy for future housing and support needs of people with dementia

The literature and policy search strategy entailed three key steps:

1. Integration of existing literature and policy review material which had previously been collated by research team. Lloyd and Stirling contributed citations collected as part of a project on people with dementia who live alone. Gabriel and Faulkner contributed citations collected as part of a range of low cost housing and housing for an ageing population.

2. Conducting database searches to locate relevant peer-reviewed research and grey literature.

3. Conducting specific searches for relevant materials cited in collected journal articles and reports and key references provided by experts in the field.

In relation to the database review, the specific parameters of the search were:
→ International
→ Research completed between 1990–2012.

The electronic databases searched included:
→ Medline
→ Cumulative Index to Nursing and Allied Health
→ Web of Science (Social Sciences Citations Index)
→ Cochrane Library
→ Sociological abstracts.

Combined search terms included:
→ 'dementia' and 'housing'/'home'/'residential care'
→ 'dementia' and ''living alone'/'isolation'
→ 'dementia' and 'social housing'/'public housing'/'low income'
→ 'dementia' and 'housing' and 'care'
→ 'dementia' and 'supported housing'/'assisted living'.

Key websites searched included theAustralian Government Department of Health,MyAgedCare,Australia Institute of Health and Welfare, Alzheimer's Australia, Dementia Care Australia, Health Direct Australia, Australian Indigenous HealthInfoNet,Dementia UK, Alzheimer's Society UK,Department of Health UK,Housing Learning and Improvement Network (Housing Lin),Social Care Institute Dementia Gateway,NationalCenter for Assisted Living US, and AHURI.

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