



Living Arrangements of People with Alzheimer’s Disease and Related Dementias: Implications for Services and Supports

Issue Brief

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Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.

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Issue Brief

Research Summit on Dementia Care: Building Evidence for Services and Supports

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Introduction

People with Alzheimer’s disease and other dementias (PWD) live in various settings that affect the quality of their lives and their health and well-being. This issue brief provides an overview of where PWD live and reviews use of services, quality of care, hospital and emergency department (ED) use, costs of care for PWD, and end-of-life care in various living arrangements. The issue brief concludes with some possible research agendas.

In 2017, there were an estimated 5.5 million PWD in the United States (Alzheimer’s Association, 2017). As shown in **Table 1**, PWD live at home, with caregivers and alone; in residential care settings (RCSs) such as assisted living; and in nursing homes. In addition, PWD live in veteran-specific settings such as State Veteran Homes, prisons, mental hospitals, and unlicensed care homes. Most people with dementia live in the community, but nearly a fifth live in either RCSs or nursing homes. Of people living in the community, most live with others, but a significant portion live alone—indeed, more than the total PWD who live in RCSs or nursing homes.

Table 1. Estimated Distribution of People with Dementia by Living Arrangement, 2017

Prevalence	Total living in the community	Living in the community with others	Living alone in the community	Living in residential care settings	Living in nursing homes	Total
Estimated number of people with dementia (thousands)	4,479	3,135	1,344	331	690	5,500
Percent of people with dementia	81	57	24	6	13	100

Source: Authors’ estimates based on Alzheimer’s Association, 2017; Harris-Kojetin et al., 2016; and Okura et al., 2011. People living in the community were calculated by subtracting number of people living in RCSs and nursing homes. People living alone were calculated as 30 percent of people living in the community.

Home-Based Living Arrangements for PWD

Home-based living arrangements for PWD include single-family homes, apartments, and other private residences (e.g., condominiums, mobile homes). The majority of PWD, like most older people, live in their own homes. Although estimates vary, the National Health and Aging Trends Study (NHATS) data indicate that 9.7 percent of the U.S. population age 65 and older who were not in nursing homes had probable dementia in 2011 (Kasper, Freedman & Spillman, 2014).

Most PWD who live at home reside with others, typically spouses or other family members.

- People with dementia generally need more support from their caregivers than those with other illnesses (Pinquart & Sorensen, 2003; Spector & Kemper, 1994). In addition to arranging health care visits, participating in medical decision making, and coordinating support services, caregivers of people with dementia must take steps to keep the person safe and to address the behavioral and psychological symptoms experienced by 80–90 percent of people with dementia (Black et al., 2013; Lyketsos et al., 2002). Dementia caregivers also experience challenges in performing nursing tasks and helping the person with dementia with activities of daily living, such as eating, bathing, and meal preparation (National Alliance for Caregiving [NAC]/[AARP], 2015).
- The overwhelming majority of help provided to people with dementia comes from family members, friends, or other unpaid caregivers (Schulz & Martire, 2004). Data from NHATS suggest that of the approximately 7.7 million older adults who received care from unpaid caregivers in 2011, 45.5 percent (approximately 3.5 million) were people with Alzheimer’s disease and other dementias) (Wolff, Spillman, Freedman, & Kasper, 2016).
- More than half of dementia caregivers provide more than 21 hours of care per week (NAC/AARP, 2015). About two-thirds of caregivers are women (Kasper, Freedman, & Spillman, 2014). The same study reports that about one-third of dementia caregivers are 65 or older, about two-thirds live with the person with dementia, and one-quarter are “sandwich” caregivers who take care of both a parent and children under 18 (Alzheimer’s Association, 2014). Current trends toward smaller families, more divorce, and more geographic dispersion mean that the number of available family caregivers is expected to decrease over time, while the number of people with dementia is increasing (Roth, Fredman, & Haley, 2015).
- Caring for someone with dementia appears to create a greater burden than caring for persons with other illnesses—for example, rates of depression are twice as high among caregivers of people with dementia as they are for other caregivers (Black et al., 2013; Family Caregiver Alliance, 2016). Caregivers’ physical health is often affected as well, with higher medical costs, more doctor visits, and greater medication use (Zhu et al., 2015).
- The financial impact of caregiving can also be significant. The 2014 Alzheimer’s Association survey found that 15 percent of caregivers had to take a leave of absence from their jobs, 13 percent went from full-time to part-time work, and 9 percent had to quit their jobs. The same survey found that many caregivers reduced the amount of money they saved, used money from their own retirement accounts, and decreased spending on their children’s education to fund care for the person with dementia (Alzheimer’s Association, 2014).
- Just as the needs of the person with dementia affect the caregiver, caregiver well-being also affects the care recipient. Lack of caregiver coping skills may result in more behavioral symptoms in the person with dementia, including increased irritability, agitation, and wandering. When the caregiver is angry or frustrated, the person with dementia is more likely to become similarly upset (Yuhas et al., 2006).

Caregiver depression is also associated with more behavioral symptoms in the person with dementia (Mausbach et al., 2006) and is a major predictor of institutionalization (Karon, Gould, Hughes, Piersol, Maier, Leopold & Wiener, 2015). Finally, the support that caregivers receive can directly affect their ability to help follow doctors' recommended care plans and to ensure the safety of the person with dementia (Black et al., 2013; Family Caregivers Alliance, 2006).

Despite the needs of PWD for supervision to ensure safety, national and regional data indicate that between about 25 and 30 percent of PWD in the community live alone (Gould et al., 2015; Alzheimer's Association, 2012; Okura et al., 2011; NAC/AARP, 2010). Likewise, a 2009 telephone survey of a nationally representative sample of Americans aged 18 and older who identified themselves as family caregivers showed that 28 percent of caregivers of community-dwelling people with dementia said the care recipient was living alone (NAC/AARP, 2010). If there is no one else living in the home who can observe changes in the individual's cognitive and functional abilities, the progressive decline associated with AD and other dementias may go unnoticed until an emergency occurs.

Long-Term Services and Supports Use in Home-Based Settings

PWD in home-based living arrangements have substantial unmet needs for care and services to help them cope with their cognitive impairment.

- In a cross-sectional study of 88 PWD who lived at home, most PWD had high fall risk, unmanaged behavioral symptoms, pain, sleep disturbances, environmental challenges, and multiple hazards (Gitlin, Hodgson, Piersol, Hess, & Hauck, 2014).
- In a study of 254 PWD who lived at home and had regularly engaged informal caregivers, 99 percent of PWD had one or more unmet needs and 42 percent had eight or more unmet needs; unmet needs in the domain of safety were most common (experienced by more than 90 percent of PWD), and unmet needs in the domains of general health and medical care were experienced by more than 60 percent of participants (Black et al., 2013).

Among both PWD who live alone and those who live with others, some people use paid care; however, most rely on unpaid family caregivers and do not use services, in part because they are expensive if the PWD is not eligible for Medicaid.

- Home health agencies and adult day service centers are used by many PWD. Approximately 31.4 percent of Medicare home health agency patients are PWD, as are 29.9 percent of adult day service center clients (Harris-Kojetin, Sengupta, & Park-Lee, 2016).
- Little is known about what proportion of PWD receive home and community-based (HCBS) long-term services and supports (LTSS) and how they are financed. In particular, little is known about the number, proportion, and expenditures of people

receiving Medicaid HCBS services. An analysis of the 2002 Health and Retirement Study (HRS) found that older people with cognitive impairment and severe disabilities used about twice as much paid and unpaid home care services as people with severe disabilities without cognitive impairment (Johnson & Wiener, 2006).

- While nonpharmacological interventions have been shown to have some positive effects, they are not widely available in communities across the country (Gould, Wiener, Hughes, Shuman, & Lyda-McDonald, 2017; National Academies of Sciences, Engineering and Medicine, 2016; Gitlin, Marx, Stanley, & Hodgson, 2015; Maslow, 2012).

Quality of Care in Home-Based Settings

Although federal and state policy promotes HCBS over institutional care, almost no data are available about the quality of these services, especially as they are provided to PWD and their caregivers (National Quality Forum, 2016). To the extent that local or state quality data are available, they do not specifically measure how care is provided to PWD (See, for example, the National Association of States United for Aging and Disabilities' [2017] National Core Indicators—Aging and Disabilities (NCI-AD) TM).

Hospitalizations and Emergency Department Use in Home-Based Settings

Policy initiatives to reduce costs and improve quality are increasingly focused on reducing hospitalizations and ED use. Research shows that PWD living in the community have higher use of these services than people living in the community without dementia, when controlling for other medical conditions. This suggests inadequacies with the existing primary care and outpatient specialty system.

- Analysis of 2000–2008 data from the HRS linked with Medicare claims showed community-dwelling PWD had higher rates of hospitalizations, potentially avoidable hospitalizations, and ED use than similar community-dwelling individuals without AD and other dementias, but these rates were lower for community-dwelling PWD than for PWD in nursing facilities (Feng, Coots, Kaganova, & Wiener, 2014). Using the same dataset, another study found similar results examining Medicare expenditures (Daras, Feng, Wiener, & Kaganova, 2017).
- In a study of individuals who lived alone, Ennis and colleagues (2014) compared hospitalization rates between those with and without dementia; when controlling for age, sex, comorbidity burden, physical function, and length of follow-up, dementia status had no effect on the association between living alone and hospitalizations.

Costs in Home-Based Settings

While there have been estimates of the cost of health care and LTSS for PWD and their caregivers, few studies have estimated the health care and LTSS costs for people living in the community.

- Unpaid caregivers such as family members provide an average of 21.9 hours of care per caregiver per week. At \$12.65 per hour, the value of this care was estimated at \$230.1 billion in the United States for 2016 (Alzheimer’s Association, 2017).
- In 2014, 25 percent of PWD use Medicare home health care each year, compared to 10 percent of adults older than age 65 without ADRD (Alzheimer’s Association, 2017). In 2011, the average spending per PWD for home health was \$2,461 per year for PWD, compared to \$357 for adults without dementia.
- In a study linking the HRS to Medicare claims data from 2000–2008, fee-for-service Medicare beneficiaries with dementia living in the community had substantially higher Medicare costs for hospitalization and ED use and potentially preventable hospitalizations and ED use than people without dementia with similar medical conditions (Daras et al., 2017).

End-of-Life Care in Home-Based Settings

Alzheimer’s disease is a terminal illness. The Medicare hospice benefit plays an increasing role for PWD and their caregivers, as well as for the rest of the population. Especially because of the loss of judgment and difficulty with communication that is characteristic of end-stage dementia, it is often difficult to provide care consistent with the wishes of PWD.

- In a large, electronic health record–based retrospective cohort study of approximately 85,000 hospice admissions from 2008 to 2012, Dougherty and colleagues (2015) compared people receiving hospice care at home to residents of assisted-living facilities receiving hospice and found the home hospice population was significantly less likely than the assisted-living population to have a diagnosis of dementia (4.7 percent vs. 23.5 percent in assisted living) (Dougherty et al., 2015). This lower proportion may reflect the high proportion of PWD in RCSs and nursing homes compared to people living in the community.
- In 2014, dementia was the top noncancer primary diagnosis for patients admitted to hospice (14.8 percent of admitted hospice patients had a primary diagnosis of dementia) (National Hospice and Palliative Care Organization [NHPCO], 2015). The percentage of hospice patients (unrestricted to PWD) who were at home in their private residences at the time of death was higher than other locations (i.e., nursing home, residential facility, hospice inpatient facility, and acute care hospitals).

Congregate Community-Based Living Arrangements for PWD

Congregate community-based living arrangements for people with ADRD include various types of RCSs, including assisted-living residences; board and care homes; congregate care; enriched housing programs; homes for the aged; personal care homes; and shared housing establishments that are licensed, registered, listed, certified, or otherwise regulated by a state (Khatutsky et al., 2016). Several studies have estimated the proportion of RCS residents who have dementia to be about 40 percent, but some RCSs only admit PWD (Harris-Kojetin et al., 2016; Khatutsky et al., 2016; Zimmerman, Sloane, & Reed, 2014).

Some RCSs exclusively serve PWD, and some RCSs have special care units (SCUs) for PWD. These SCUs are supposed to provide care by staff trained in dementia care and sometimes are architecturally designed to address the needs of PWD. In 2010, among RCC residents with cognitive impairment or dementia, more than one-third (35 percent) lived in RCSs with dementia SCUs, but just 14 percent lived in SCUs, while 21 percent lived in a general care unit (Khatutsky et al., 2016). In addition, approximately 7 percent of all RCC residents with cognitive impairment or dementia lived in RCSs that exclusively served adults with dementia.

Financing in RCSs

Most people pay out of pocket for RCS care; almost half of RCSs participate in Medicaid, but overall about 15.1 percent of residents use Medicaid to pay for their care (Harris-Kojetin et al., 2016). Fewer PWD use Medicaid and are less likely to reside in facilities that participate in Medicaid. In 2010, analyses using the National Survey of Residential Care Facilities (NSRCF) found that about a third of Medicaid beneficiaries in RCSs had Alzheimer's disease or other dementias, and about two-fifths of non-Medicaid residents had these conditions.

Quality in RCSs

Little is known about the quality of care provided in RCSs, especially for PWD. Facilities are regulated at the state level and there are wide variations in regulatory requirements (Carder, O'Keeffe, & O'Keeffe, 2015). In addition, there are fewer inspections and almost no public reporting for RCSs (Harrington, Wiener, Ross, & Musumeci, in press).

- A systematic review of the literature from 2005 to 2012 on effective characteristics of residential long-term care settings for people with ADRD found few high-quality studies on this issue but also found that outcomes do not differ between RCSs and nursing homes for PWD, except when medical care is indicated (Zimmerman et al., 2013).
- Thus, most states rely on general RCS regulations to cover dementia care policies and practices rather than having dementia-specific regulations. In an analysis of 2015 state regulatory standing, 16 states license or certify SCUs within RCSs (Carder, 2017). All states had at least one dementia care requirement, though only 4 states had requirements in five important domains. Most states addressed administrator training, consumer disclosure, and physical environment; 17 states addressed staffing types and levels; and 14 addressed pre-admission assessment for dementia.

Hospitalizations and ED Use in RCSs

Few studies have examined hospitalizations and ED use in RCSs, in part because of the difficulty of accurately identifying people living in those settings using Medicare and Medicaid claims data.

- Using data from the 2010 NSRCF, one study found that severe cognitive impairment was a marginally significant negative predictor of any hospitalization or any ED use ($p < 0.10$) in RCSs. Similarly, severe cognitive impairment was also a marginally significant negative predictor ($p < 0.10$) of the number of ED visits among residents who had any ED visit (Wiener, Feng, Coots, & Johnson, 2014). This study also found that the primary impact of severe cognitive impairment on hospital and ED use was through PWD residing in dementia SCUs or in RCCs that exclusively served PWD.

Costs in RCSs

PWD account for most RCS charges to residents and, on average, pay substantially more than people without dementia.

- The estimated total annual charges for PWD in RCSs in 2010 totaled \$17 billion, approximately 61 percent of total industry charges. (Khatutsky et al., 2016).
- PWDs in RCSs are charged substantially more for their care than people without dementia. In 2010, The average monthly RCS charge per resident in 2010 was \$3,131, whereas in RCSs that exclusively served PWD, the average monthly charge was \$4,156; in RCSs with a dementia SCU, the average monthly charge was \$3,820 (Karon et al., 2016).

End-of-Life Care in RCSs

End-of-life care for PWD in RCSs has been changing over time, with increased use of Medicare hospice services.

- Although reliably identifying residential care is difficult, the percentage of people receiving hospice care who lived in RCSs was 8.7 percent in 2014 (NHPCO, 2015).
- Based on after-death interviews with staff who had cared for PWD in RCSs or nursing homes and family caregivers of PWD, Sloane and colleagues (2008) found end-of-life care for PWD in RCSs was similar in quality to that of care for persons without dementia in RCSs, and end-of-life care for PWD in RCSs was similar to that provided in nursing homes for PWD. However, PWD dying in RCSs tended to have more skin ulcers and poorer hygiene care than persons without dementia in RCSs. PWD in RCSs also tended to be restrained less often and to have family more satisfied with physician communication than did PWD in nursing homes, but emergency services were called more often on the day of death than for PWD in nursing homes.

Nursing Homes

Most nursing home residents have AD and other dementias and have severe or moderate cognitive impairment. In 2014, according to the Centers for Medicare & Medicaid Services (CMS, 2015):

- 36.6 percent of nursing home residents had severe cognitive impairment
- 24.8 percent of residents had moderate cognitive impairment
- 38.7 percent of residents had mild or no cognitive impairment

This distribution by severity was similar across nursing homes by type of ownership (for profit, nonprofit, and government) and by size (number of beds), but the reported distribution of nursing home residents with cognitive impairment differed across states. These differences may reflect variations in reporting practices, but they may also reflect the availability of RCS and other HCBS.

Special Care Units in Nursing Homes

In 2014, more than one-seventh of nursing homes (14.8 percent) had a dementia SCU on a specific unit, wing, or floor, and a few (0.4 percent) exclusively served people with AD/DRD (Harris-Kojetin et al., 2016). Findings have been mixed regarding the impact of nursing home–based dementia SCU on quality.

- Compared to non-SCU residents, one study in the Boston area found that SCU residents were more likely to receive treatment for dyspnea, had fewer hospitalizations, were less likely to be tube fed, and were more likely to have a do-not-hospitalize order, but non-SCU residents were more likely to be treated for pain, had fewer pressure ulcers, and had less frequent use of antipsychotic drugs (Cadigan, Grabowski, Givens, & Mitchell, 2012).
- Analyses of data on nearly all nursing homes (96 percent) in the nation showed that the introduction of dementia SCUs had no influence on key clinical outcomes, including the prevalence of physical restraints, feeding tubes, and psychotropic medications (Gruneir, Lapane, Miller, & Mor, 2008).
- In a sequential cohort study of PWD in 35 dementia SCUs and 9 nursing homes, SCU residents were younger and less functionally impaired than those in nursing homes and caused more behavioral disturbances, but they were less likely to be hospitalized or physically restrained and showed a higher rate of withdrawal from antipsychotics; however, no differences were found in mortality or falls (Nobili et al., 2008).
- Studies conducted in the 1990s and 2000s found several quality indicators were positively associated with SCU residence, including higher quality of life (Reimer et al., 2004), less frequent tube feeding (Lamberg, Person, Kiely, & Mitchell, 2005), better continence care, and fewer behavioral disturbances (Bellelli et al., 1998). On the other hand, a large study of SCUs in 1990s found no positive impacts of SCUs on reducing physically aggressive behaviors within 6 months of placement (Leon & Ory, 1999).

Quality of Care in Nursing Homes

Although nursing home quality has been a subject of voluminous studies, few projects have investigated the quality of care in nursing homes for PWD.

- While dementia is most commonly associated with a decline in memory, it can also cause changes in mood or personality, loss of communication, and, at times, agitation or aggression. To manage these behaviors, antipsychotic drugs are sometimes prescribed, which is a major concern because of the potential health risks, and many believe that prescribing rates for these drugs, particularly for nursing home residents with dementia, have been too high. According to the General Accountability Office (2015), approximately a third of older adult Medicare Part D enrollees with dementia who resided in a nursing home were prescribed antipsychotic drugs in 2012. CMS has launched initiatives to reduce use in nursing homes.
- Nationally, nursing home performance on measures of care quality differ by resident cognitive status (CMS, 2015; Konetzka, Brauner, Perrailon, & Werner, 2015). On many but not all measures, people with severe cognitive impairment did worse than people with moderate or mild cognitive impairment. Nationally, in 2014, of nursing home residents with severe cognitive impairment, 4.9 percent experienced pressure ulcers, 2.1 percent experienced restraint use, 52.8 percent had incontinence, 9.2 percent had feeding tubes, 6.1 percent had unintended weight loss, and 25.3 percent were using antipsychotics (CMS, 2015).
- Nationally, from 2000 to 2014, the proportion of nursing home residents with advanced dementia and eating dependency who received feeding tubes decreased by approximately 50 percent (Mitchell, Mor, Gozalo, Servadio, & Teno, 2016).
- After Nursing Home Compare public reporting was initiated, outcomes for nursing home residents with severe dementia did not consistently improve or worsen (Konetzka et al., 2015). The study found no evidence that individuals with severe dementia are being avoided by nursing homes, despite their potential negative impact on quality scores.

Hospitalizations and ED Use among Nursing Home Residents

Rates of hospitalization and ED use among nursing home residents are high, but among PWD in nursing homes, the rates do not appear to differ substantially from those of people without dementia. Among residents with dementia, those with do-not-hospitalize orders appear to have lower hospital use than those without dementia. Comparing nursing home residents who had dementia with those who did not, Feng and colleagues (2014) found only small (not statistically significant) differences in hospitalizations (45.8 percent vs. 41.9 percent, respectively) and ED use (55.3 percent vs. 52.7 percent, respectively). Comparing nursing home residents who had dementia with those who did not, the study found only small differences in the rates of potentially avoidable hospitalizations (42.8 percent vs. 41.6 percent, respectively).

Costs

Nursing home care is expensive, creating a large financial burden on PWD and their caregivers. In 2017, the national median charge for a semiprivate room was \$85,776 per year (Genworth Financial, 2017).

- Hurd and colleagues (2013) distinguished costs for nursing home care between people with and without ADRD and found the additional yearly per person cost attributable to dementia for nursing home care was \$13,876 in 2010, after adjusting for demographic characteristics and coexisting conditions.
- Among Medicare fee-for-service beneficiaries, the presence of ADRD nearly quadruples the likelihood of expensive Medicare skilled nursing facility (SNF) stays. The average annual per person Medicare payment for SNF care is about 3 times greater when ADRD is present for the most common coexisting conditions, including coronary artery disease, diabetes, congestive heart failure, chronic kidney disease, chronic obstructive pulmonary disease, stroke, and cancer (Alzheimer's Association, 2017).

End-of-Life Care

Nursing homes are a prominent location of end-of-life care, where hospice care can support the dying resident, but quality of end-of-life differs for PWD within and across nursing homes.

- The proportion of nursing home decedents with advanced dementia who used hospice nearly tripled from 1999 to 2006 when it reached approximately 40 percent (Miller, Lima, & Mitchell, 2010).
- Among people with advanced dementia who died while residents of nursing homes in 2006, 40 percent had Medicare SNF care in the last 90 days of life, and outcomes differed between those with and without Medicare SNF care: individuals with Medicare SNF care used hospice less frequently (30 percent with Medicare SNF used hospice vs. 46 percent without SNF), more frequently had short (< 7 days) hospice stays (40 percent with Medicare SNF had short stays vs. 19 percent without SNF), and more frequently died in hospitals (14 percent with Medicare SNF died in hospitals vs. 9 percent without SNF) (Miller, Lima, Looze, & Mitchell, 2012).
- Among fee-for-service Medicare beneficiaries, researchers compared hospitalizations and ED use among nursing home decedents (i.e., people who died while nursing home residents) with and without dementia. Results showed no statistically significant difference in hospital or ED use between those who had dementia and those who did not. Comparing nursing home decedents who had dementia with those who did not, the study found only small differences in hospitalizations (65 percent vs. 74 percent, respectively) and ED use (69 percent vs. 75 percent) (Feng, Coots, Kaganova, & Wiener, 2014).

Other Living Arrangements

Veteran-Centered Settings

In 2014, an estimated 262,899 people diagnosed with ADRD were treated by the Department of Veterans Affairs (VA), with a portion of these living in veteran-centered settings (Karlin et al., 2016). Veteran-centered living arrangements that include supports for PWD include VA Community Living Centers (CLCs), Medical Foster Homes, and State Veteran Homes.

- In 2016, a total of 41,507 Veterans received care across 135 CLCs nationally, with active care integrated psychologists (VA, 2017). VA CLCs provide nursing-facility care, and some provide dementia care and other services, such as mental health rehabilitation, respite services, and palliative or hospice care (VA HealthCare, 2017a).
- State governments also manage facilities for aged or disabled veterans. In 2003, there were 114 state-run facilities serving 17,000 veterans (Department of Veterans Affairs, 2005). These facilities are generally known as State Veteran Homes and must be certified by the Department of Veterans Affairs (VA HealthCare, 2017b).
- VA also approves private homes where continuous care is provided for a few individuals, known as Medical Foster Homes. These homes are not administered by the VA, but some oversight for quality and caregiver training is provided. These homes may support veterans and nonveterans with a wide range of abilities and conditions (VA HealthCare, 2017c).

Unlicensed Care Homes

Unlicensed care homes are RCSs that are not licensed by the states where they are located—some are legally unlicensed and operate within guidelines provided by state agencies, but many are illegally unlicensed, are subject to little oversight, and create concerns for the safety of residents. Overall, they house a wide range of vulnerable people, including older adults, and some are criminal enterprises exploiting their vulnerable residents (Greene, Lepore, Lux, Porter, & Vreeland, 2015). Although it is difficult to estimate the population of PWD in unlicensed care homes, subject matter experts consistently report that many older adults reside in these homes (Greene et al., 2015), and reports indicate that at least some residents have ADRD (Williams, 2017).

Prisons

Although there is no national study estimating the prevalence of dementia among prisoners, the population of older adults in the correctional system is rising (Maschi, Kwak, Ko, & Morrissey, 2012). Given the prison environment and risk factors related to mental health, older adults aging within the prison system may be more likely to develop AD and other dementias. Some studies indicate that 44 percent of inmates may experience dementia in some

correctional settings, although there is likely a wide range of prevalence. Some groups, such as the Project for Older Prisoners, have campaigned for more comprehensive care for older adults in prison, but few dementia supports are currently available.

Homelessness

Many older adults are homeless and live in a variety of transient locations. According to a 2017 study of 350 homeless older adults in Oakland, California, 25.8 percent of the sample showed signs of cognitive impairment (Brown et al., 2017).

Conclusion

People with disabilities live in a variety of settings, including in their own homes, RCSs, nursing homes, veteran-centered settings, and other settings such as unlicensed care homes and prisons. Across all these settings, the majority of PWD live in their own homes, either alone or with other individuals that may serve as caregivers. A significant portion of PWD also live in nursing homes or RCSs and they make up about half of those residents. Given the data available, it is difficult to estimate the numbers of PWD living in veteran-centered settings and other settings.

PWD may have exceptionally variable experiences based on their living arrangements. Many of the settings covered in this paper, including nursing homes, RCSs, and veteran-centered settings, have created specialized settings to support PWD. These settings are designed to provide comprehensive training to their staff on caring for individuals with ADRD and increase the quality of care; however, their effectiveness, especially in RCSs, is not well established. Those caring for PWD living at home may experience increased difficulty obtaining the services and caregiving training needed, which may be reflected in the unmet needs of PWD. Studies have shown that PWD living at home experience more hospitalizations than those living at home without dementia, which suggests that the current system of primary care may not adequately meet the people with cognitive impairment.

In general, PWD pay more on average for health care and long-term care than those without dementia across settings. They have higher utilization rates for services such as home health care (Alzheimer's Association, 2017), which leads to higher spending on average. Dementia SCUs are significantly more expensive than nonspecialized RCSs and nursing home care. These increased costs may be difficult for PWD and their families to manage.

This brief review of the literature suggests several areas in which very little is known and where additional research could further our understanding. These include the following:

- *The use of paid home care services by PWD and how they compare with impaired people without cognitive impairment.* Little is known about the proportion of PWD living in the community who use paid services, how much is used, how they are

- financed, and what the financial burden is, especially compared to other people with disabilities.
- *The role of Medicaid in financing LTSS for PWD, by service type.* Medicaid is the primary source of financing for LTSS, but little is known about the role of Medicaid, specifically for people with cognitive impairment.
 - *The quality of care of home care and RCS, specifically for PWD.* Little is known overall about the quality of these services, and almost nothing is known about the services that people with cognitive impairment receive.
 - *The impact of various new delivery system innovations, such as patient-centered medical homes and accountable care organizations, on PWD.* Although CMS has sponsored large demonstrations of these innovations, evaluations have not singled out PWD for special attention.
 - *The accuracy of Medicare and Medicaid claims data in identifying people with dementia.* The underreporting of AD diagnoses is a barrier to using Medicare and Medicaid claims data to conduct research on PWD. Studies are needed to improve on existing algorithms commonly used to identify PWD. In addition, federal government agencies should provide more data that link surveys, such as the HRS, which have more detailed measures of cognitive impairment, with Medicare and Medicaid enrollment and claims data.

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