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Providing Services for People with Dementia Who Live Alone

Issue Brief

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EXECUTIVE SUMMARY

As many as one third of community-dwelling people with Alzheimer's disease and other dementias live alone. Like other older adults who live alone, many people with Alzheimer's and other dementias want to remain independent and prefer living alone to the other options available to them. On the other hand, the symptoms of Alzheimer's and other dementias, such as impairments in memory, judgment, and ability to plan and carry out activities—symptoms that affect all people with these conditions—create obvious risks for individuals who live alone. Available research shows that they are at high risk for self-neglect, malnutrition, injury, medication errors, financial exploitation, unmet care needs, and nursing home placement.

Much less information is available about people with Alzheimer's and other dementias who live alone than about people with these conditions who live with others in the community. For this issue brief, the National Resource Center for the Administration on Aging's Alzheimer's Disease Supportive Services Program (ADSSP) reviewed the available literature and conducted interviews with people with Alzheimer's and other dementias who live alone, caregivers, and health care and social service professionals to obtain their views about the needs of these people and potentially effective ways to meet those needs. It also describes programs that have been tested by community agencies to reach and help people with Alzheimer's and other dementias who live alone and discusses related public policy and practice implications.

The issue brief is intended to assist state officials, program administrators, health care and social service professionals, and community-service agencies in planning and providing services for the large segment of the Alzheimer's and dementia population that lives alone.

Characteristics of People With Alzheimer's Disease and Other Dementias Who Live Alone

The typical person with Alzheimer's or another dementia who lives alone is an 83-year-old widow who has mild to moderate cognitive impairment and is able to bathe, dress, and use the toilet independently, but needs help with many daily activities, such as managing medications and money, using the telephone, and transportation. In comparison to people with Alzheimer's and other dementias who live with others in the community, people with these conditions who live alone are, on average, older, more likely to be female, and less likely to be

married. They have had Alzheimer's or another dementia for a somewhat shorter time, on average, and they are much less likely to have been diagnosed with the condition. They are also somewhat less cognitively and functionally impaired, although the differences are smaller than one might expect. Lastly, they have lower income, on average, and are more likely to be enrolled in Medicaid than people with Alzheimer's or another dementia who live with others in the community.

Many people with Alzheimer's or another dementia who live alone have a family member, friend, neighbor, paid aide, or other helper who sees them regularly, assists with tasks and activities, or at least calls regularly to check in with them. These individuals may not need additional help at any particular point in time, but Alzheimer's and most other dementias are progressive, and all individuals with these conditions will need more help over time. Relatives, friends, neighbors, and others who at least check in regularly with the person can help to monitor the person's condition and care needs, recognize when more care is needed, and provide or arrange for the provision of that care. People with Alzheimer's and other dementias who live alone and have no one who visits, helps, or even checks in regularly are most likely to fall through the cracks. The extent of their unmet needs often becomes apparent only when they have a medical or other care-related crisis, and an emergency response from health care, law enforcement, or Adult Protective Services (APS) agencies is required.

Care Issues for People With Alzheimer's and Other Dementias Who Live Alone

People with Alzheimer's and other dementias who live alone have unique care needs that will vary depending on factors such as the extent of their cognitive and functional impairments, availability of a caregiver, access to adequate care and services, and coordination of care. The most common unmet needs for people with dementia living alone include evaluation of eyesight and hearing, medication management, management of psychotic symptoms, companionship, daytime activities, mobility, self-care, abuse/neglect, accidental self-harm, looking after the home, nutrition, and in-home care. In addition, persons with dementia living alone receive inadequate support and supervision and they are more likely to receive social services. Other predictors of formal service use included the involvement of a caseworker, Medicaid eligibility, and mild dementia.

Alzheimer's and other dementias cause impairments that can reduce an individual's ability to remain safe at home, such as impairments in balance and mobility, judgment, sense of time and place, orientation and recognition of environmental cues, and changes in vision or hearing. The issue brief addresses safety issues related to falls, home safety, wandering, driving, and ability to respond in emergency situations.

The professionals interviewed for this study consistently cited falls as one of the most common risks to health and safety of persons with dementia living alone in the community. Home safety is an important consideration and the issue brief describes ways to adapt the home to make it safer for an individual with dementia. Wandering is a serious safety risk for people with dementia living alone because the likelihood of a person returning home safely largely depends on recognize that the person is missing or that something is unusual and to report it to the appropriate authorities. Driving is a difficult issue for almost all people with dementia, but it is likely to be more difficult for those who live alone, especially when there is no one to regularly monitor for changes in the person's driving ability. Living alone with dementia increases the risk of mortality associated with accidental injuries because of impaired insight and problem solving ability, and because of the absence of a caregiver at the scene and delayed medical help.

The professionals in this study identified self-neglect as one of the primary reasons for their involvement with people with dementia who live alone. Compulsive hoarding or extreme clutter and debris in the home can contribute to an individual's inability to manage his or her own daily activities and self-care. Financial exploitation is one of the most common reported types of elder abuse in people with dementia living alone.

The people with dementia interviewed for this study stated that they would like to have someone in the home to do certain things such as managing money and paying bills, reminding them of appointments, checking the mail, and advocating for them. Social activities and connection with others including the intimacy that one has with a spouse or a partner were identified as important. If there is no one in the home to observe changes in the person's cognitive and functional abilities, the gradual decline associated with Alzheimer's or a related dementia may go unnoticed until it is a problem.

Considerations When Developing Services for People With Dementia Who Live Alone

There are some areas for consideration when developing services for people with dementia who live alone. The paper addresses the importance of recognizing the signs and symptoms of a possible cognitive impairment, gaining an understanding of a person's capacity to manage daily activities, and determining effective approaches for intervention. Assistive technology and community-based interventions can provide innovative ways for meeting the needs of people with dementia who live alone.

Physicians often have less access to knowledgeable informants for persons who live alone and they are more likely to rely on patient self-reports which may not be accurate. Alzheimer's and other dementias will eventually impact health care decision-making and the management of daily activities. According to a report by the American Bar Association Commission on Law and Aging, the legal framework to support elders in the community who are unable to make decisions regarding their treatment and who have no legal alternative mechanism in place is not sufficient in most states.

The professionals interviewed for this paper stated that the biggest barrier to serving people with dementia who live alone is reluctance to accept help by the individual with dementia. Barriers to intervening include obtaining access to the person's home initially, establishing a trusting relationship, assisting the person to understand and accept services, monitoring for safety issues, and encouraging quality of life. Other barriers include lack of identification of a dementia and connection to the formal service system.

When considering the use of an assistive technology for people with dementia and their caregivers living at home, it is important to match a technology to a person's needs, abilities, and preferences, and to regularly monitor for usability of the technology because of the progressive decline that comes with a dementia diagnosis. There are important ethical and practical considerations concerning use of technology with people who have dementia living alone including individual consent and respect for autonomy, the individual's ability to use the device, cost of the device, maintenance, use of stored data and authorizing access to it, changes in the person's ability to manage the technology, and training of care providers on the technology.

Programs That Have Been Tested By Community Agencies

Over the past 30 years, some community agencies in the United States have developed innovative programs to reach and help people with Alzheimer's and other dementias who live alone. The programs have focused on various objectives, such as identifying individuals who live alone and are unable or unwilling to contact anyone for help; increasing community awareness of these people and implementing either specific services or a community-wide plan to address their needs; and creating "teams" of friends, neighbors, and others to assist those who live alone and have no family to help them. Most of these programs have been difficult to put in place and sustain, but they have been successful in reaching and serving at least some people with Alzheimer's and other dementias who live alone. Interestingly, most have involved Area Agencies on Aging, and some have been implemented with Administration on Aging funding, including ADSSP grants.

Conclusion

This issue brief describes the major care issues and considerations in developing services for people with Alzheimer's and other dementias who live alone from the perspective of the persons themselves, as well as caregivers, care managers, community service providers, and medical and adult protective services personnel. It also identifies components of a system of care that would allow them to continue living alone safely for as long as possible. Those components include better identification and diagnosis, assessment, ongoing monitoring ("checking on") of the person, individualized services, and for some persons early in the disease process, assistive technologies may be an option. In addition to ensuring safety, it is important to recognize the need for independence, the ability to participate in decision making, and opportunities for meaningful social interaction.

Many factors contribute to the difficulty of effective provision of services for people with Alzheimer's and other dementias who live alone. Programs intended to address these factors will require communication and care coordination from professionals representing various community and government agencies, and at times, nontraditional service providers (mail carriers, bank personnel, apartment managers) who can help with identification and monitoring. Persons with dementia who do not have a caregiver or anyone to monitor them will require

specialized assistance from a trained multidisciplinary team. As the prevalence of Alzheimer's and other dementias continues to rise, community and government agencies and other service providers should begin to create and test such programs in their communities, and share lessons learned with others in the aging services network in an effort to more effectively identify and meet the unique needs of people with Alzheimer's or other dementias living alone.

INTRODUCTION

As many as one third of community-dwelling people with Alzheimer's disease and other dementias live alone (Prescop et al., 1999). Many of these people have one or more caregivers. Some have family members, friends, or neighbors who visit them regularly and help with tasks and activities they can no longer manage on their own. Some have a paid companion or aide who stays with them for a specified number of hours a day, one or more days a week, and helps with tasks and activities, and others have a relative or friend who lives at a distance but calls regularly to check in and visits from time to time. Still others have no one who visits, helps, or checks in regularly.

People with Alzheimer's disease and other dementias who live alone are part of a large group of older adults who live alone. In 2008, 30 percent of Americans aged 65 and older lived alone, including 19 percent of men and 39 percent of women (U.S. Census, 2008). Among older adults, the proportions of men and women who live alone increase with age. In 2008, 16 percent of men and 29 percent of women aged 65–74 lived alone, compared with 32 percent of men and an astounding 61 percent of women aged 85 and older.

Like other older adults who live alone, many people with Alzheimer's disease and other dementias want to remain independent and prefer living alone to the other options available to them (DeWitt et al., 2009, 2010; Harris, 2006). On the other hand, the symptoms of Alzheimer's and other dementias—symptoms that affect all people with these conditions—create obvious risks for individuals who live alone. Cognitive symptoms, including impairments in short-term memory, judgment, and ability to plan and carry out activities, are common even in the early stages of Alzheimer's and other dementias (Kawas, 2003; Morris, 2005). Lack of awareness of these impairments is also common in people with these conditions and adds to their vulnerability (Lehmann et al., 2010; Wagner et al., 1997). Noncognitive symptoms that occur frequently in Alzheimer's and other diseases and conditions that cause dementia, such as impairments in vision, gait, and ability to speak coherently and understand spoken and written language compound vulnerability and risk. Moreover, because Alzheimer's and most other dementias are progressive, all these symptoms usually worsen over time.

Research shows that people with Alzheimer's and other dementias who live alone are at high risk for self-neglect, malnutrition, injury, medication errors, financial exploitation, unmet care needs, and nursing home placement (Abrams et al., 2002; Cooper et al., 2005; Edwards & Morris, 2007; Heath et al., 2005; Miranda-Castillo et al., 2010; Nourhashemi et al., 2005; Tierney et al., 2001, 2004; Yaffe et al., 2002). Much more is known about people with Alzheimer's and other dementias who live alone and have someone who visits, helps, or at least checks in regularly than about those who live alone and have no one. Anecdotal reports suggest, however, that people with Alzheimer's and other dementias who experience severe medical and other care-related crises requiring an emergency response from health care, law enforcement, and Adult Protective Services (APS) agencies are often those who live alone and have no one who visits, helps, or even checks in regularly (Newhouse et al., 2001; Soniat & Pollack, 1993).

This issue brief provides information about people with Alzheimer's and other dementias who live alone. It was prepared for the Administration on Aging by the Alzheimer's Disease Supportive Services Program (ADSSP) National Resource Center (a partnership between RTI International and the Alzheimer's Association) to assist state officials, program administrators, health care and social service professionals, and community-service agencies in planning and providing services for people with these conditions.

The available information about people with Alzheimer's and other dementias who live alone is limited. There are many published studies about people with these conditions and some published studies about older people who live alone, but very few studies have addressed the intersection of these groups, and it is especially difficult to find information about people with Alzheimer's and other dementias who live alone and lack an involved family member or other informant. Moreover, several of the best studies are quite old, reporting data from the mid to late 1990s. To supplement information available from published studies, the ADSSP National Resource Center conducted interviews with people with Alzheimer's and other dementias who live alone, caregivers, and health care and social service professionals, to obtain their views about the care needs of people with these conditions and potentially effective ways to meet those needs.

The first section of the issue brief summarizes available information about the proportion and characteristics of people with Alzheimer's and other dementias who live alone. Later sections discuss the results of the interviews and information from published studies that address issues raised by the interviewees. The issue brief also describes programs that have been developed and tested by community agencies to reach and help people with Alzheimer's and other dementias who live alone. It concludes by discussing public policy and practice implications.

PROJECT METHODOLOGY

This issue brief relies primarily on two sources of information. First, we conducted a research literature search to identify what is known about people with Alzheimer's and other dementias who live alone. Second, we interviewed persons with dementia who live alone, caregivers, and health care and social service professionals.

Literature Search

Project staff performed a literature search using the following search engines: PubMed, OVID Medline & SilverPlatter, and CINAHL. The following search terms were used singularly and in combination: Dementia; Social Isolation; Home Nursing; Social Support; Quality of Life; Social Environment; Lifestyle; Accidents/Mortality; and Aged. OVID SilverPlatter was also searched with the following natural language syntax queries: Dementia AND Live Alone; and Dementia AND Living Alone, Dementia AND Community-Dwelling. To access other grey literature, Google and Google Scholar were searched using the above natural language syntax queries along with the phrase "people with dementia living alone." A total of 79 articles were reviewed for this paper.

The literature review identified several issues related to people with dementia living alone including risk assessment and capacity to live alone, recognition and diagnosis of dementia, functional performance and unmet care needs, safety issues, self-neglect, relationships with others, barriers to getting help, assistive technologies, and programs focusing on people with dementia living alone.

Interviews

A discussion guide, including an informed consent process, was developed and approved by the RTI International Institutional Review Board. Interviews were conducted by the ADSSP National Resource Center in June–August 2010. A total of 13 persons were interviewed, including persons with dementia who live alone, a family caregiver, a professional caregiver, geriatrics medicine professionals, adult protective services personnel, geriatric care managers, home care providers, an adult day care provider, and an expert on hoarding. The individuals interviewed reside in California; Idaho; Illinois; Massachusetts; Nebraska; Texas; and Washington, DC. Professional interviewees represent for-profit and not-for-profit organizations and serve diverse, low- to high-income communities in rural, suburban, and urban areas.

The interviews covered the following topics:

- Functional abilities of people living alone
- Unmet needs, service use, and services needed
- Support system
- Barriers to accessing services
- Role of assistive technology
- Future health and long-term care planning
- Home safety
- Challenges with living alone

BACKGROUND

Proportion of People With Alzheimer’s Disease and Other Dementias Who Live Alone

Findings from population-based studies in the United States, Canada, and several European countries indicate that about one third of community-dwelling people with Alzheimer’s and other dementias live alone. Results from other studies vary, depending on the source of the study sample.

Only one U.S. study provides information about the proportion of people with Alzheimer’s and other dementias who live alone based on data from a representative, population-

based sample (Prescop et al., 1999). Using a stratified random sample of community-dwelling people aged 65 and older with Alzheimer's and other dementias in 23 communities in southwestern Pennsylvania, this study found that about one-third (35%) were living alone.

Five other U.S. studies report findings on the proportion of people with Alzheimer's and other dementias who live alone in study samples drawn from medical, research, and community care settings. One study that used a sample from specialized Alzheimer's disease and dementia diagnostic and medical treatment centers in California found that 19 percent of the study subjects lived alone (Webber et al., 1994). Another study that used a sample from a large medical care system in Washington State found that 14 percent of the study subjects lived alone (Logsdon et al., 1998), and a third study that used a sample drawn from previous epidemiologic research conducted in Maryland found that 28 percent of the study subjects lived alone (Lehmann et al., 2010). In contrast, two studies that used samples from a specialized Alzheimer's and dementia diagnostic and care program located in an Area Agency on Aging (AAA) in St. Louis found that larger proportions of the study subjects lived alone (46% and 49%, respectively) (Edwards & Morris, 2007; Wilkins et al., 2007). The inconsistency in findings from the five studies is probably more a result of differences in the study samples than true differences in the proportion of people with Alzheimer's and other dementias who live alone in the four geographic areas. The findings from the AAA in St. Louis suggest, however, that program officials and others who are responsible for planning and providing services for older people in community care settings could expect that a substantial proportion of their clients with Alzheimer's and other dementias live alone.

The Canadian Study of Health and Aging, a large-scale survey of a nationally representative, population-based sample of people aged 65 and older living in urban areas in all 10 Canadian provinces, found that almost one-third (32%) of those who had Alzheimer's or another dementia and were living in the community lived alone (Ebly et al., 1999). A second study of a population-based sample of community-dwelling people aged 75 and older in Sweden found that 45 percent of those who had Alzheimer's or other dementias lived alone (Holmen et al., 2000), and a third study of a population-based sample of community-dwelling people aged 57 and older in the Netherlands found that 37 percent lived alone (van der Roest et al., 2009). Other studies conducted in medical, research, and community care settings in Canada and

Europe have found various proportions of people with Alzheimer's and other dementia living alone. As in the U.S. studies, Canadian and European studies that used samples drawn from medical settings (e.g., Nourhashemi et al., 2005; Sibley et al., 2002) found somewhat lower proportions of people with Alzheimer's and other dementias living alone, and studies that used samples drawn from community care settings (e.g., Gilmour et al., 2003; Gordon et al., 1997; Tuokko et al., 1999) found higher proportions living alone.

A 2009 telephone survey of a nationally representative sample of Americans aged 18 and older who identified themselves as caregivers found that 28 percent of caregivers of community-dwelling people with Alzheimer's and other dementias said the person was living alone (NAC/AARP, 2010). In contrast, only 25 percent said the person was living with the caregiver. The remaining caregivers said their care recipient was living with other relatives or friends. People with Alzheimer's and other dementias who do not have a caregiver are not represented in the survey findings and would have to be added to determine the total proportion of community-dwelling people with these conditions who live alone.

Characteristics of People With Alzheimer's and Other Dementias Who Live Alone

The typical person with Alzheimer's or another dementia who lives alone is an 83-year-old widow who has mild to moderate cognitive impairment and is able to bathe, dress, and use the toilet independently, but needs help with many daily activities, such as managing medications and money, using the telephone, making medical appointments, shopping, housekeeping, and transportation. In contrast, the typical person with Alzheimer's or another dementia who lives with others in the community is slightly younger, much more likely to be male and married and to have moderate cognitive impairment, and somewhat more likely to need help with bathing, dressing, toileting, and other daily activities. The differences are smaller than one might expect, however. Four studies conducted in the United States are summarized below.

- *Age.* On average, people with Alzheimer's and other dementias who live alone are older than people with these conditions who live with others in the community (average age 83 versus age 81 [Prescop et al., 1999]). In response to the 2009 survey of a nationally representative sample of caregivers, 75 percent of the caregivers who said their care recipient had Alzheimer's or another dementia and was living alone reported that the person was aged 75

or older, including 39 percent who reported that the person was aged 85 or older. In contrast, a slightly smaller proportion of caregivers who said their care recipient was living with them (70%) reported that the person was aged 75 or older, including 34 percent who reported that the person was aged 85 or older (NAC/AARP, 2010).

- *Gender.* People with Alzheimer's and other dementias who live alone are much more likely to be female than people with these conditions who live with others in the community (76% versus 44% in one study [Prescop et al., 1999] and 87% versus 67% in another study [Edwards & Morris, 2007]).
- *Marital status.* People with Alzheimer's and other dementias who live alone are much less likely to be married than people with these conditions who live with others in the community (3% versus 73% in one study [Prescop et al., 1999] and 3% versus 46% in another study [Edwards & Morris, 2007]). The findings for gender and marital status are related and reflect the demographics of age, marital status, and living arrangements in the older U.S. population. Specifically, older women are much less likely than older men to be married, primarily because they have outlived their husbands, and older people who are married are much less likely to live alone.
- *Duration of dementia.* On average, people with Alzheimer's and other dementias who live alone have had the condition for a somewhat shorter time than people with these conditions who live with others in the community (2.9 years versus 4.2 years in one study [Prescop et al., 1999] and 4.3 years versus 4.9 years in another study [Webber et al., 1994]).
- *Diagnosis of dementia.* People with Alzheimer's and other dementias who live alone are much less likely than people with these conditions who live with others in the community to have been diagnosed with the condition. One study found that only 24 percent of people who lived alone and received a diagnosis of Alzheimer's or another dementia as part of the study had a prior diagnosis of the condition in their primary care medical record or on a Medicare claim form or their caregiver reported that a doctor had said the person had Alzheimer's or dementia (Lehmann et al., 2010). In contrast, 39 percent of the study subjects who lived with others in the community had a prior diagnosis of the condition. Another study found that 34 percent of people who lived alone and received a diagnosis of Alzheimer's or another dementia as part of the study had a prior diagnosis of the condition from their primary care

physician, compared with 53 percent of study subjects who lived with others (Wilkins et al., 2007).

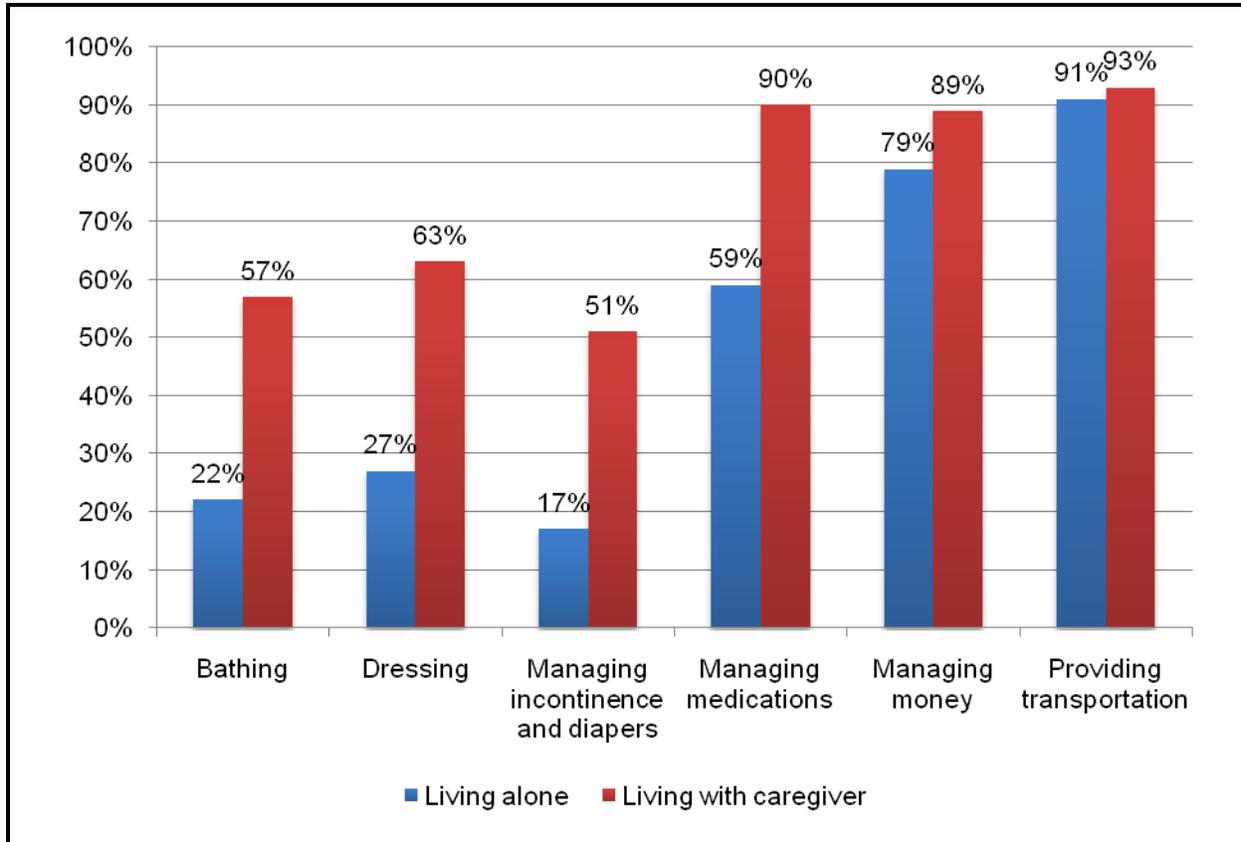
- *Level of cognitive impairment.* On average, people with Alzheimer's and other dementias who live alone are somewhat less cognitively impaired than people with these conditions who live with others in the community. Findings from three studies show a 3- to 5-point difference in the average score on the 30-point Mini Mental State Examination (MMSE) between those who live alone and those who live with others (Edwards & Morris, 2007; Lehmann et al., 2010; Webber et al., 1994). The average MMSE score for those who lived alone was 18 or 19, where a score of 17 or below indicates severe cognitive impairment and a score of 18 to 23 indicates mild cognitive impairment (Tombaugh & McIntyre, 1992). Using a different staging procedure, one study (Edwards & Morris, 2007) found that 36 percent of people in their sample had "mild consistent forgetfulness"; 53 percent had moderate memory loss sufficient to interfere with daily activities; 10 percent had severe memory loss and quickly forgot any new information; and 1 percent had severe memory loss and only retained fragments of information.
- *Level of functional impairment.* On average, people with Alzheimer's and other dementias who live alone are somewhat less functionally impaired than people with these conditions who live with others in the community. One study found that those who lived alone were impaired in an average of 0.5 activities of daily living (ADLs) (e.g., bathing, dressing and using the toilet), compared with 1.5 ADLs for those who lived with others (Lehmann et al., 2010). Likewise, those who lived alone were impaired in an average of 1.9 instrumental activities of daily living (IADLs) (e.g., managing medications and money, using the telephone, and shopping), compared with 3.1 IADLs for those who lived with others.
- *Use of social services and medical care.* People with Alzheimer's and other dementias who live alone are more likely than people with these conditions who live with others in the community to use social services, such as home-delivered meals, homemaker services, and case management (Edwards & Morris, 2007; Webber et al., 1994). One study found that those who lived alone were just as likely as those who lived with others to have a primary care physician (78% versus 75%, respectively) (Edwards & Morris, 2007), but another study found that people with these conditions who lived alone were significantly less likely than those who lived with others to use physician and hospital services (Webber et al., 1994).

- *Income and Medicaid eligibility.* On average, people with Alzheimer's and other dementias who live alone have somewhat lower income and are more likely to be enrolled in Medicaid than people with these conditions who live with others in the community. One California study found that 22 percent of people with Alzheimer's and other dementias who lived alone were receiving Supplemental Security Income (SSI), compared with 14 percent of those who lived with others (Webber et al., 1994). Likewise, 23 percent of those who lived alone had MediCal (California's Medicaid program), compared with 16 percent of those who lived with others. The St. Louis study found that people with Alzheimer's and other dementias who lived alone had lower income and were more likely to have Medicaid than people who lived with others, but the differences were not statistically significant (Edwards & Morris, 2007).
- *Availability of a caregiver.* Study findings differ with respect to the proportion of people with Alzheimer's and other dementias who live alone and have a caregiver. Differences among the studies in the definition of the term "have a caregiver" and differences in the study samples probably account for these inconsistent findings. The population-based study of older people with Alzheimer's and other dementias who lived alone in southwestern Pennsylvania found that 50 percent had no one who either helped them with personal care or other activities or checked in on them at least once a week (Prescop et al., 1999). Studies conducted in California and Maryland found that 30 percent of people with Alzheimer's and other dementias who lived alone had no one who provided any regular assistance with personal care or other activities (Lehmann et al., 2010; Webber et al., 1994). In contrast, the study conducted in the St. Louis AAA used a broader definition of "having a caregiver," including anyone who had "any identifiable informal caregiver," and found that less than 1 percent of the study subjects who had Alzheimer's and other dementias and lived alone had no caregiver (Edwards & Morris, 2007).
- *Nonrelative caregivers.* People with Alzheimer's and other dementias who live alone are more likely than people with these conditions who live with others in the community to have caregivers who are not relatives. Various studies show that 11 to 19 percent of people with Alzheimer's and other dementias that live alone have a caregiver who is neighbor or friend compared with only 1 to 7 percent of those who live with others (Edwards & Morris, 2007; NAC/AARP, 2010; Webber et al., 1994).

- *Help provided by the caregiver.* The 2009 telephone survey of a nationally representative sample of caregivers found that caregivers of people with Alzheimer's and other dementias who lived alone were less likely than caregivers of people with these conditions who lived with the caregiver to be providing help with various personal care and other daily activities (NAC/AARP, 2010). Still, substantial proportions of caregivers of those who lived alone were providing help with the activities. Figure 1 shows the proportions of caregivers who said they provided help with six activities for people with Alzheimer's and other dementias who lived alone versus people with these conditions who lived with the caregiver.

In summary, although the available U.S. data on community-dwelling people with Alzheimer's and other dementias who live alone show that they are, on average, somewhat less cognitively and functionally impaired than people with these conditions who live with others, the fact that they live alone creates obvious risks. As shown above, many of these individuals are receiving help from family members, neighbors, and friends, and some may not need additional help at any particular point in time. On the other hand, Alzheimer's and most other dementias are progressive, and all individuals with these conditions will need more help over time. Family members, friends, and neighbors who visit or check in with the person regularly can monitor the person's increasing cognitive and functional impairments and may be able to provide or arrange for needed services. Impairments in judgment and ability to plan and carry out activities and lack of awareness of cognitive and functional impairments mean, however, that many people with Alzheimer's and other dementias will not be able to recognize their own increasing need for help or plan for or arrange needed services. Thus, those who live alone and have no one who visits or checks in on them regularly are at very high risk.

Figure 1. Proportion of Caregivers of People With Alzheimer’s Disease and Other Dementias Who Reported Helping the Person With Specified Activities by Living Arrangement, 2009



Source: NAC/AARP, 2010.

CARE ISSUES FOR PEOPLE WITH ALZHEIMER’S DISEASE AND OTHER DEMENTIAS WHO LIVE ALONE

People with Alzheimer’s and other dementias who live alone have unique care needs that will vary depending on factors such as the extent of their cognitive and functional impairments, availability of a caregiver, access to adequate care and services, and coordination of care. This section reviews the findings from the interviews conducted for the issue brief and related findings from published research studies that address some of the differences for those who live alone, compared with those who live with someone else. The section includes quotations from the interviews, which were lightly edited for grammar and readability.

Functional Performance and Unmet Care Needs

For individuals with dementia, the ability to live alone is dependent on their physical ability and cognitive capacity to independently perform daily activities. Edwards and Baum (1996) reported that individuals with dementia who lived alone were able to perform basic self-care activities, but the quality of this performance was low and complex tasks such as laundry and medication management were more severely affected. General risk factors for functional disability in people with dementia include increasing age; depression; severity of dementia; presence of sensory problems such as visual impairment; gait, balance, and mobility problems; and psychotic symptoms (De Ronchi et al., 2005; Perrault et al., 2002; Whitson et al., 2007).

Right now, I do my own cooking, cleaning, laundry, and shopping. I will do the checkbook and then my son will verify that it is correct. If I get goofed up, my friends and family don't give me a hard time. They understand.

—*Person with dementia*

Making decisions has become increasingly difficult. She needs help with picking clothes to wear and she doesn't know how to dress properly for the weather.

—*Professional caregiver*

A person with more advanced dementia will tend to focus on tasks that are not essential. They might be out in the yard watering the weeds, because at one time that garden was a priority and they see no reason to shift that focus.

—*Expert on hoarding*

Several studies assessed the unmet needs of people with dementia (Gaugler et al., 2005; Greaves et al., 2006; Miranda-Castillo, 2010; Van der Roest et al., 2009). Most of these studies used the Camberwell Assessment of Need for the Elderly (CANE), which covers 24 areas of need (Reynolds et al., 2000). The most common unmet needs for people with dementia living alone include evaluation of eyesight and hearing, medication management, management of psychotic symptoms, companionship, daytime activities, mobility, self-care, abuse/neglect, accidental self-harm, looking after the home, and in-home care (Miranda-Castillo, 2010). People

living alone with dementia are also at greater risk for malnutrition than those living with others (Nourhashemi et al., 2005).

Without my help, I know she wouldn't eat the right foods. She would probably go for something quick and easy like grabbing Froot Loops instead of oatmeal for breakfast.
—Professional caregiver

The most common problems of my clients who have dementia and live alone include not taking medications or not taking them properly, poor grooming/odor, not dressing for the season or the temperature, missing doctor's appointments, not seeing the doctor for a year or more, and suspected financial abuse.
—Home care professional

In a study of African American older adults with dementia living in the community, social workers rated 61 percent of the persons with dementia living alone as receiving inadequate support and supervision, compared with 25 percent of persons with dementia living with others. Formal service use was low for both African American adults with dementia living with a caregiver and African American adults with dementia living alone. The adults living alone were more likely to receive social services. Other predictors of formal service use included the involvement of a caseworker, Medicaid eligibility, and mild dementia (Edwards & Morris, 2007).

People with dementia generally report fewer unmet care needs than their caregivers, and the number of reported unmet care needs is related to the severity of their dementia and their living situation. The reasons for unmet needs in community-dwelling people with dementia including those living alone were lack of knowledge about existing services and that some of the services were insufficient and not customized to the person's needs or preferences (Van der Roest et al., 2009).

I am never sure when to step in. I don't want to rob her of her independence.
—Caregiving daughter

No transportation service is available in our community or if there is, it is a bus that the person needs to meet. This means that they will need to be there at a certain time and a certain place. You can't expect that of a person with dementia living alone with no one to

assist them in getting there. What they need is a door-to-door companion.
—Home care professional

Safety Issues

Alzheimer's and other dementias cause impairments that can reduce an individual's ability to remain safe at home, such as impairments in balance and mobility, judgment, sense of time and place, orientation and recognition of environmental cues, and changes in vision or hearing. This section addresses safety issues related to falls, home safety, wandering, driving, and ability to respond to emergency situations.

Falls. The professionals interviewed for this study consistently cited falls as one of the most common risks to health and safety of persons with dementia living alone in the community. Studies show an annual falls incidence as high as 60 percent among people with dementia (Shaw & Kenny, 1998) and as many as 400 falls per 100 persons with dementia (Edwards & Lee, 1998). Cognitive impairment increases the risk of falls by almost two-fold as a result of impaired judgment, visual and spatial perception deficits, and disorientation (Rubenstein & Josephson, 2006).

The most common reason my agency is contacted to help a person with dementia who lives alone is after a fall or hospitalization.
—Geriatric care manager

Home safety. As soon as a person is diagnosed with Alzheimer's or a related dementia, it is important to plan for home safety. Safety considerations and adaptations to the home include using appliances with automatic shut-off features, removing throw rugs that may be a trip hazard, placing latches on kitchen cabinets and drawers to keep knives and cleaning products out of reach, monitoring the temperature of the hot water for showering or bathing, rearranging or removing furniture, removing clutter and organizing areas of the home, installing a ramp, placing grab bars in the bathroom, and widening a doorway (Alzheimer's Association, 2009; Gitlin & Corcoran, 2000).

I did some organizing around the house and got rid of a lot of clutter. I simplified my wardrobe to make it easier on myself. I put labels on the kitchen cupboard so that I am

able to find things easily. I try to keep it simple.

—Person with dementia

Wandering. Wandering is a serious safety risk for people with dementia living alone because the likelihood of a person returning home safely largely depends on others to recognize that the person is missing or that something is unusual and to report it to the appropriate authorities. Rowe and Glover (2001) define “unattended wandering” as forays into the community without the supervision of a caregiver. Dementia can impair a person’s ability to negotiate the way back home and in those instances, it is up to others to assist the person to get home safely. The study indicates that those at greatest risk are individuals with dementia living alone or living with a caregiver who leaves them alone while attending to other family or job responsibilities.

There have been a couple of occasions where she has gotten turned around and flustered. She was able to figure out where she was and got back safely on her own. The key is not to get too anxious so you can think clearly. She will sometimes ask for help and I always tell her to call me.

—Caregiving daughter

I take more precautions when I am not feeling physically well and I let people know if I am feeling disoriented.

—Person with dementia

When I travel, I contact the airline staff in advance to explain my situation and that I will be traveling alone. I talk to my family and arrange for someone to meet me.

—Person with dementia

Recently, there was a situation where a woman lost her purse and went to the next town over thinking it was her home town and couldn’t find the coffee shop where she left her purse. Someone in her home town went looking for her and brought her purse.

—Home care professional

Driving. Driving is a difficult issue for almost all people with dementia, but it is likely to be more difficult for those who live alone, especially when there is no one to regularly monitor

for changes in the person's driving ability. There is debate among experts about whether a driver with mild dementia should be allowed to drive and whether there should be restrictions. Dementia symptoms can cause hazardous driving such as disinhibited and agitated behaviors, prominent visuoperceptual and attention deficits, visual hallucinations, and fluctuating levels of alertness. In addition, persons with other medical conditions such as cardiovascular diseases, diseases affecting vision, and respiratory diseases may be a greater driver safety risk. It is important to take the necessary precautions, such as testing to identify impairments in traffic skills, discussing driving cessation, and planning for transportation alternatives. However, it should be noted that a diagnosis of dementia should not be the sole justification for revoking a driver's license because many people with mild dementia are able to continue to drive. There is no standardized method for determining driver fitness in people with a cognitive impairment and performance-based road tests may not be a sufficient measure. A comprehensive, interdisciplinary approach to driver safety assessment that includes counseling about alternative transportation options is recommended (Carr & Ott, 2010).

A person may continue to drive when family are trying to get them to stop. I remember one situation with a farmer who drove his tractor to where the car was "being repaired" and got into the car and drove away.

—Home care professional

There needs to be more of an objective measure for driving ability. A driving test by a qualified professional like an occupational therapist is not covered by insurance.

—Geriatric nurse practitioner

I haven't made any changes to my driving since the diagnosis. I took a road test with the DMV and I passed.

—Person with dementia

Individuals with dementia who were interviewed for this issue brief shared specific modifications they have made since their diagnosis, such as not driving at night, carpooling more often, using index cards with directions to frequently traveled places, allowing others to drive on long trips, and not listening to the radio to avoid unnecessary distractions.

I am driving less and I don't go into Boston as much.

—Person with dementia

I asked a trusted friend if she would go out with me regularly and watch how I am driving. When she says I need to make a change or stop driving altogether, I will.

—Person with dementia

Emergencies. Ability to respond to crisis situations in the home is another important safety issue. One study found that older people who die as a result of a fire are more likely to be living alone than other older people (Elder et al., 1996). Living alone with dementia also increases the risk of mortality associated with accidental injuries because of impaired insight and problem solving ability (Cooney et al., 2004) and because of the absence of a caregiver at the scene and delayed medical help (Kibayashi et al., 2007).

I have a special needs child and the local (suburban) fire department has a system for people with special needs like my daughter where you can put a red dot in the door way so when the door is opened, it is visible to fire personnel to know to look on the refrigerator for medical information in a plastic pouch. This is a quick and easy way for the emergency responders to get medications, illnesses, allergies, emergency contacts, etc.—especially when there is a lot of information (such as with an illness or disability). When I asked about something similar for my mom with the city fire department where she lives, I was told that there wasn't anything that met this need. A system similar to this could be very beneficial for a person with Alzheimer's, especially one who lives alone.

—Caregiving daughter

Self-Neglect, Hoarding, and Financial Exploitation

The service professionals interviewed for this issue brief spoke about the need for ongoing monitoring of suspected abuse and indicated that the majority of suspected elder abuse situations involving a person with dementia who lives alone are reported by a family member, friend, or neighbor. In some situations, it may be another member of the community who has regular contact with the person and misses seeing them. People such as the local grocer, the

housing manager, or the local police officer may function as “atypical gatekeepers” for people with dementia living alone; these individuals have detailed knowledge of a person with dementia’s well-being and functional ability (Ballard, 1999). Professionals may not consider these individuals as an ally when advising the person with dementia who lives alone to accept assistance. The professionals interviewed for this issue brief indicated that conducting a risk assessment on someone who has a dementia and lives alone is challenging and often requires a trained physician or mental health professional.

We are in a small rural community of 3500 people and people know our agency. We have gotten calls from the grocer saying, “Can you help this person?”

—Home care professional

People are more vulnerable when they live in their own homes and they need more protection. With all of the emphasis on home and community-based services waivers, we are not providing the protections necessary when we are cutting funding for Adult Protective Services. The reports are going up while staffing is going down.

—Adult Protective Services professional

Self-neglect. The professionals in this study identified self-neglect as one of the primary reasons for their involvement with people with dementia who live alone. Self-neglect is when a vulnerable adult is unable to provide food, clothing, shelter, and medical care; maintain physical health, mental health, emotional well-being, and general safety; or manage financial affairs. Signs of self-neglect include dehydration, malnutrition, untreated medical conditions, poor personal hygiene, unsafe or unsanitary living conditions, inappropriate or inadequate clothing, and inadequate housing or homelessness (National Center on Elder Abuse, 1998). Cases of self-neglect can be among the most difficult to address and manage. At times, a person will resist interventions, and the provider is presented with the ethical dilemma of balancing individual autonomy and safety. One study of people with dementia who lived alone found that impairments in recognition memory, executive functioning, and conceptualization were independent, and measurable, risk factors for self-neglect (Tierney et al., 2007). The authors recommend closer monitoring and that extra precautions be taken for individuals who score poorly in these three areas to prevent harm if they are living alone.

Meals on Wheels is a fantastic program but it doesn't work so well when the person won't open the door, or when they won't open the food, eat the food, or store the food that is delivered. We've gone into houses where food has sat on the counter because the person wasn't hungry or they didn't recognize that they were hungry, and now it is 2 days later and it is inedible, but it is being consumed anyway.

—Expert on hoarding

Hoarding. Compulsive hoarding or extreme clutter and debris in the home can contribute to an individual's inability to manage his or her own daily activities and self-care. Food preparation becomes difficult if the person cannot access cooking appliances or even cupboards where food is stored. A significantly cluttered environment can lead to unsanitary living conditions and poses safety risks such as fire or falls/trips hazards. The living conditions affect not only the individual and family members but neighbors and can become a public health concern (National Center on Elder Abuse, 2005). The professionals interviewed for this study indicated that the most successful interventions for people with dementia who live alone involve collaboration and service coordination across disciplines and agencies.

We worked with a man who had dementia and lived alone. He spent years after his parents died picking through the neighbors' garbage cans and bringing home their garbage until his townhouse was so completely filled on every level that he could no longer enter the home. He ended up living in his back yard and eventually he was placed into long-term care by the Public Guardian. Because it was a townhouse situation, the neighbors were directly affected by the rodent and insect infestation as well as the constant potential danger of a fire which could have cost lives as well as property.

—Expert on hoarding

Financial exploitation. Financial exploitation is one of the most common reported types of elder abuse in people with dementia living alone (National Elder Abuse Incidence Study, 1998). The perpetrators are often friends or family members who have a relationship of trust with the victim. The National Association of Adult Protective Services Administrators recommends that all professional financial service providers receive special training on identifying and

reporting financial exploitation (National Association of Adult Protective Services Administrators, 2003).

Community education and public awareness campaigns do not adequately address the issue of preventing financial loss through theft and fraud and yet those are some of the most prevalent cases we see in APS.

—Adult Protective Services professional

I had a client living alone with dementia who paid a family member \$30,000 to help clean out the house.

—Expert on hoarding

Undue influence is a huge problem and it is really not addressed in our current legislation regarding self-determination.

—Adult Protective Services professional

Social Isolation and Loneliness

Relationships with others and having the support of family and friends are important to sustain people with dementia who live alone. In a qualitative study of 15 people with dementia who live alone, the participants indicated that having a strong social support network was the most important factor for helping them cope with living alone (Harris, 2006). The study participants were concerned about maintaining their independence, continuing to drive, and being involved in decision-making for as long as possible. Most were comfortable living alone but they did experience feelings of loneliness. The author suggests that services for people with dementia living alone need to be sensitive to the person's needs and wishes, and not just about responding to safety concerns.

The people with dementia interviewed for this study stated that they would like to have someone in the home to do certain things such as managing money and paying bills, reminding them of appointments, checking the mail, and advocating for them. Social activities and connection with others including the intimacy that one has with a spouse or a partner were identified as important.

Often the needs of my patients with dementia who live alone are less about their medical condition and more about being connected to others as a way to avoid further decline in physical and cognitive health.

—Geriatric nurse practitioner

The isolation of a person with dementia leads to increasing confusion and the person withdraws even more. They are more vulnerable to a scam artist or new “best friend.”

—Adult Protective Services professional

It is important to have an intimate connection to someone else. I miss the physical touch. It would be nice to have a date or go out some place. I can’t go on the Internet to meet someone because I wouldn’t be telling the truth about my diagnosis. The other person has a right to know especially if they are interested in a long-term relationship.

—Person with dementia

When asked about the challenges of living alone, the greatest need consistently identified by every person interviewed for this study was “having someone to check on the person with dementia.” If there is no one in the home to observe changes in the person’s cognitive and functional abilities, the progressive decline associated with Alzheimer’s or a related dementia may go unnoticed until it is a problem (Soniati, 2004).

I don’t really have anyone in my life who could check in on me regularly when I need more monitoring. I am interested in maybe getting something like a location management system and I also like the idea of a home check-in through the TV or a videophone by a care manager or a social worker.

—Person with dementia

My daughter lives nearby and she checks on me.

—Person with dementia

There is no one here to monitor changes with me.

—Person with dementia

It is important to have someone to monitor the living situation, not to be intrusive but to discover situations before they become so overwhelming and out of control that it becomes a hazard to the person and the neighborhood. It sometimes requires that the person be removed from the home they have lived in for 40–50 years and taken away from everything they know. To my mind, the less change, the better.

—Expert on hoarding

However, even when someone who lives alone gets support from family and friends, it may not be adequate. One study found that most of the help received by those with dementia living alone was from family and friends and that the assistance provided was inadequate (Miranda-Castillo, 2010). Persons with dementia living alone had significantly more unmet needs than those living with others in the areas of looking after home, nutrition, self-care, daytime activities, companionship, psychological distress, eyesight/hearing, and accidental self-harm. Another study that assessed African Americans with dementia living alone found that neighbors and friends were more often the primary care providers. Neighbors and friends were less likely to help with certain types of assistance especially when the task was time-consuming or required more intimate care compared to caregivers living with the person (Edwards & Morris, 2007).

Describing nontraditional support systems for individuals with dementia who live alone with no close family members to provide care and support, Soniat and Pollack (1994) refer to these as “makeshift networks of neighbors and agencies” that help individuals to continue to live in the community. However, those involved in helping a person stay in the community may have narrowly defined roles and the various members of the network may not even know each other or coordinate the care they provide. When there is no relationship history like there is with a family member or close friend, the support person may not have any particular emotional ties or commitment to the individual with dementia that keeps them involved in caregiving. The caregiving relationship may end when the support person gets frustrated and decides to move on.

People in our town will come to someone’s aid if they know that the person with dementia doesn’t have support from family or friends until they get tired of doing it.

—Home care professional

CONSIDERATIONS WHEN DEVELOPING SERVICES FOR PEOPLE WITH DEMENTIA WHO LIVE ALONE

There are some areas for consideration when developing services for people with dementia who live alone. This section of the paper addresses the importance of recognizing the signs and symptoms of a possible cognitive impairment, gaining an understanding of a person's capacity to manage daily activities, and determining effective approaches for intervention. Assistive technology and community-based interventions can provide innovative ways for meeting the needs of people with dementia who live alone.

Recognition and Diagnosis of Dementia

In general, people with dementia are less likely to seek medical care despite their health needs and their inability to manage their own care (Prince et al., 2007). The diagnostic process relies heavily on family members or close friends to bring concerns to the attention of the doctor and to report on changes in the individual's cognitive and functional abilities. Physicians often have less access to knowledgeable informants for persons who live alone and they are more likely to rely on patient self-reports which may not be accurate (Wilkins et al., 2007). Without an accurate diagnosis of dementia, a physician may incorrectly assume that a patient has the ability to manage his or her medical conditions and follow a prescribed regimen (Ouldred, 2004; Wilkins et al., 2007).

I thought I was doing everything right at work but then my boss called my son about concerns that he was having. I was having difficulty following instructions. A doctor friend of the family recommended an evaluation by the local Alzheimer's Disease Center.
—Person with dementia

People with dementia who are living alone are at greater risk of missing appointments or not seeing a doctor for long periods of time because there isn't anyone to monitor and remind the person. Unfortunately, the situation may not be recognized early on by the physician as an indicator that the person needs help.
—Geriatrician

Kobylarz and colleagues (2010) stress the importance of health literacy when working with patients with Alzheimer's disease for patient adherence to a medically prescribed regimen. They define health literacy as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (p. 34). The authors recommend that persons with Alzheimer's or other dementias receive supportive interventions that promote understanding of daily care and management of their health conditions.

Health Care Decision Making and Planning for the Future

Health care decision making is an important area of risk assessment for individuals with dementia living alone. According to a report by the American Bar Association Commission on Law and Aging, the legal framework to support these elders in the community who are unable to make decisions regarding their treatment and who have no legal alternative mechanism in place is not sufficient in most states (Karp & Wood, 2003).

I am most concerned about the person with dementia living alone who doesn't have family or other support. They fall through the cracks; they stop eating and stop taking their medications and, don't get in to see the doctor. As a result, their physical health deteriorates. They may not yet meet the requirements of guardianship and they are refusing your help. You just have to wait until it gets bad enough.

—Geriatrician

All of the people with dementia who were interviewed for this paper spoke about the need to take steps to prepare for the future including discussions with family and friends about health care wishes; completion of advance directives; consultation with financial planners or elder law attorneys; and review health, life, and long-term care insurance policies. According to the Adult Protective Services professionals and geriatric care managers interviewed, many of their clients with dementia living alone did not plan for future health and long-term care needs while they had decision-making capacity.

The “perfect storm” is when there is no plan, there is a crisis, the person lacks decision-making capacity, and the family doesn’t communicate.

—Adult Protective Services professional

Overcoming Barriers to Service Use

The professionals interviewed for this paper stated that the biggest barrier to serving people with dementia who live alone is reluctance to accept help by the individual with dementia. Barriers to intervening with people who have dementia and live alone include gaining access to the person’s home initially, establishing a trusting relationship, assisting the person to accept services, addressing ongoing safety issues, and promoting the person’s quality of life (Waugh, 2009).

The person with dementia living alone can be resistant to leaving what is familiar, so sometimes I am not able to convince the person to attend an outside program like an adult day center.

—Geriatric nurse practitioner

You need to take baby steps—you can’t do it all at once. Be a friend first, then check in once a day, maybe bring food to the person, offer to join them for a meal, maybe have them attend the adult day center for a couple of hours and then half a day and so on.

—Home care professional

In a study about adult day services in the community, 54 percent of people with dementia who lived alone would not attend adult day services (Durand et al., 2009). These individuals had misconceptions about adult day care that caused them not to use services and the authors also noted that the individuals may have had an undiagnosed depression.

Adult day care gives her the chance to interact with her peers and provides stimulating activities. I have observed that people with dementia who get more stimulation during the day decline less rapidly.

—Professional caregiver

Lack of identification of a dementia and connection to the formal service system can also be a significant barrier to getting services and certain cultural groups may be at greater risk. Many African Americans with dementia seem to be outside of the formal social service system suggesting that there needs to be improvement in service provision for older African Americans who have dementia and live alone (Edwards & Morris, 2007).

Barriers to getting help identified by people interviewed for this study include lack of coordination and communication among professionals from different disciplines or agencies, lack of adequate transportation for the person, geographic distance that makes travel cost-prohibitive for professional caregivers, insufficient personal finances, and lack of support for state-funded programs that keep the person at home.

Communication among members of the team is a huge obstacle. This means social work, police, and Adult Protective Services. Each has their own agenda, not the same ideas on priorities. We need to be able to work together.

—Adult Protective Services professional

If a client lives too far away, it is difficult to find a service provider that can travel that far. In some cases, it just doesn't make sense financially for a nursing assistant to travel a certain distance because of traveling expenses to get there.

—Geriatric care manager

I had a patient with dementia living alone in a rural community who needed to choose between milk and firewood. She couldn't afford both. Many of my low-income patients with dementia are forced to come off of their medications including cholinesterase inhibitors such as Aricept when they have hit the Medicare Part D donut hole.

—Geriatrician

Lack of finances is a major barrier. There have been major cuts in state programs that keep the person at home. In my community, two are nursing home diversion programs and one is consumer-directed care.

—Geriatric care manager

Assistive Technologies

Assistive technologies may provide options for people with dementia living alone to remain at home. In a literature review on assistive technology for people with dementia and their caregivers living at home, O’Keeffe, Maier, and Freiman (2010) highlight the importance of matching a technology to a person’s needs, abilities, and preferences, and the necessity for ongoing monitoring for usability of the technology because of the progressive decline that comes with a dementia diagnosis. An assistive technology should be easy for the person with dementia to use and help the person with something they need or want. There are a variety of assistive technologies that can be used by people with dementia at home or in the community such as technologies that help find frequently misplaced items; help people remember when to take medications, ensure safety, monitor the environment, summon help, and monitor activity in the home; address wandering; and improve emotional state and decrease behavioral problems.

Some of the technologies being used by individuals in this study include medication reminders; emergency response systems; videophones; temperature monitors for the house and for the refrigerator; a robot for companionship; global positioning systems (GPS); and preprogrammed music, lighting, and temperature settings for difficult nighttime or sundown behaviors.

I took an indirect way home from the next town over and I got a little turned around. Now I keep a GPS in my car.

—Person with dementia

Monitors for the temperature of the house or the fridge will alert a person to go check and call. I had a female patient with dementia living alone who somehow had the heat turned off in her apartment during the winter and a neighbor discovered her shivering.

She was hypothermic!

—Geriatrician

These technologies, however, are of limited use when the person with dementia lacks the executive function to know what the prompts are designed to help them do. In a study on the use of assistive technologies by people with dementia living alone, the authors found no overall

resistance to using technology. Difficulties arise when familiar and unfamiliar technology is being used (Nygard, 2008). Another study noted that the ability to use a technology as basic as a telephone can deteriorate as a dementia progresses (Eccles et al., 1998). The barriers to using technology in the home by people with dementia include conditions related to the person, the context and the design of the device, limitations to the person's knowledge of the technology, and its potential, and difficulties in direct use and the person's use of instructions. Persons of similar age without a dementia experienced some of the same issues when using technology (Nygard & Starkhammer, 2007).

Those medication reminders don't always work—a person may hear a buzzer but not know what it is for.

—Home care professional

Some people with dementia may have difficulty learning a new gadget. Even hearing aids can sometimes be difficult to adjust and maintain.

—Geriatric nurse practitioner

Telemedicine still requires caregiver involvement and videophones are not yet HIPAA compliant—if using a wireless connection, a stranger may have access if it is not encrypted. Getting it all set up and getting it to work is a challenge.

—Geriatrician

In a study of people with dementia living alone, a monitoring system was used that captured a person's activity over a 24-hour period using small, wireless movement sensors placed in key rooms of the home (Smith et al., 2007). The findings suggest that monitoring systems may provide a more accurate picture of a person's abilities to manage activities of daily living than assessment by a professional coming to the home, which may allow for a more customized intervention.

There are important ethical and practical considerations concerning use of technology with people who have dementia living alone. These considerations include individual consent and respect for autonomy, the individual's ability to use the device, cost of the device, maintenance, use of stored data and authorizing access to it, changes in the person's ability to

manage the technology, and training of care providers on the technology (Martin et al., 2007; O’Keeffe et al., 2010; Price, 2007).

Programs That Have Been Tested by Community Agencies

Over the past 30 years, some community agencies in the United States have developed innovative programs to reach and help people with Alzheimer’s and other dementias who live alone. These programs have focused on four main objectives:

- to identify individuals who live alone and are unable or unwilling to contact anyone for help;
- to increase community awareness of people with Alzheimer’s and other dementias who live alone, develop a community-wide plan to address their needs, and mobilize community agencies to implement the plan;
- to provide specific services for people with Alzheimer’s and other dementias who live alone; and
- to develop “teams” of friends, neighbors, and others to help people with Alzheimer’s and other dementias who live alone and have no family to check in on them regularly or help with tasks and activities they can no longer manage on their own.

Most of the programs described below have been difficult to put in place and sustain, but they have been successful in reaching and serving at least some people with Alzheimer’s and other dementias who live alone. Most have involved AAAs and other aging network agencies, and some have been implemented with Administration on Aging funding, including ADSSP grants. The program descriptions in this section are intended to provide an overview of approaches that have been implemented by various community agencies to assist state officials, program administrators, health care and social service professionals, and community agencies that want to establish programs to serve this population.

Programs to identify individuals who live alone by community members and others. Several community agencies have implemented programs based on “the Gatekeeper Model” that was first used in Spokane, Washington, in 1978. Gatekeeper programs recruit mail carriers, utility meter readers, bank personnel, and other individuals who interact with many people in the course of their daily work and train them to identify isolated older people who may need assistance and refer those people to a central agency. The Gatekeeper program in Spokane has

been implemented by a community agency that provides aging and mental health services for people age 60 and older with funding from the AAA in eastern Washington State and the State Division of Mental Health (Florio & Raschko, 1998). A study of older adults referred to the community agency in 1994 and 1995, compared those referred through the Gatekeeper program and those referred by more traditional medical and social service sources, families, friends, and neighbors. Almost 60 percent of older adults referred through the Gatekeeper program had cognitive impairment consistent with dementia, and almost three quarters (74%) of those referred through the Gatekeeper program were people who lived alone, compared with less than half of those referred by other sources (Florio & Raschko, 1998; Florio et al., 1996, 1998; Raschko, 1997).

In 1986, a community mental health center in Cedar Rapids, Iowa, in cooperation with the local AAA, implemented a gatekeeper model program as part of the Iowa Rural Elderly Outreach Program (Buckwalter et al., 1991). The gatekeeper model program was one of five approaches used to identify adults aged 55 and older with physical, cognitive, and mental health needs that were not being met with existing services. A study conducted after the first 3 years of the program found that 43 percent of those identified by the five outreach approaches were people who lived alone, and large numbers of community members had participated as gatekeepers.

Programs to increase community awareness of people with Alzheimer's and other dementias who live alone and develop a community-wide plan to address their needs and mobilize community agencies to implement the plan. In 1998, the Alzheimer's Association Chapter in Sioux City, Iowa, convened a day-long meeting of state and local government officials, AAAs, other community service providers, police, Adult Protective Services staff, physicians, emergency department staff, other health care professionals, and clergy to talk about common problems in care for people with Alzheimer's and other dementias who live alone and develop a community-wide plan to address these problems (Newhouse et al., 2001). Meeting attendees were surprised to learn that many of their agencies were working with the same individuals, without realizing that the other agencies were also involved. They were even more surprised to hear the police chief talk about the amount of time spent by his officers just sitting in the homes of individuals with apparent dementia who lived alone and experienced an emergency

at night when there was no other place the officers could take them. After the meeting, several workgroups of community agency representatives were formed. One workgroup surveyed people who had not been at the meeting, concluded that a single point of contact was needed for crisis calls about people with Alzheimer's and other dementias who live alone, and established that point of contact at the Alzheimer's Association Chapter. A three-person team was created to respond to crisis calls, assess the situation within an hour, and determine next steps. The workgroup also discussed the need for a "safe house," where people could be taken temporarily if no other short-term shelter could be found, concluded that respite beds in residential care facilities could serve this function, and encouraged the use of this alternative for their community.

The 1998 meeting and resulting community-wide plan targeted the largely urban and suburban Sioux City area, but three Alzheimer's Association Chapters went on to establish a program called "First Contact," to respond to crises situations involving people with Alzheimer's and other dementias who live alone in rural communities in Iowa and Nebraska. Networks of local volunteers were established to respond to crisis calls in their communities. In 2000, the Iowa Department of Elder Affairs received an ADSSP grant that included a component "People Living Alone who Need Services (PLANS)" to replicate the model of community-wide planning and implementation in smaller Iowa communities (Newhouse et al., 2001).

Programs to provide specific services for people with Alzheimer's and other dementias who live alone. In 1992, the Washington, DC, Office on Aging received an ADSSP grant to establish "Standing in the Gap," an initiative intended to identify needs and provide services for people with Alzheimer's and other dementias and their families. When the Office on Aging surveyed the 30 agencies that were members of its Senior Care Network to obtain their views about the most important service needs for people with Alzheimer's and other dementias, the responses identified a need for in-home services for people with these conditions who lived alone and did not have a family caregiver. One community agency, AL-CARE, was already delivering in-home services that were funded by the DC Office on Aging and intended to provide respite care for family caregivers of people with Alzheimer's and other dementias (Kocin & Kendrick, 1998). It was decided that some of the ADSSP grant funds would be used to create a special program for people with these conditions who lived alone (Starns et al., 2002). The services provided through the AL-CARE live-alone program (e.g., personal care, meal preparation, and

medication management) are similar to in-home services provided by many agencies across the country for people with Alzheimer's and other dementias who have caregivers, but the live-alone program confronted unique obstacles, including general skepticism in the community about whether people with dementia can and should live alone, questions about provider liability when there is no relative to give consent for the provision of the services, and how to decide when it was no longer safe for the person to continue living alone. The home care aides who provided care for individuals living alone also needed specialized training about many of the care issues described earlier in this issue brief, such as how to gain access to the person's home, since program clients often forgot about scheduled visits and sometimes refused to let the aide in. In 1999, the average cost per live-alone client was approximately \$3,000 per year. In addition to providing low-cost services to a population that had few options, the live-alone program has also helped to increase awareness about this population and demonstrated that people with Alzheimer's and other dementia can live at home alone safely (Starns et al., 2002).

Another program that is providing a specific service for people with Alzheimer's and other dementias who live alone is the "Senior Watch Program" in Lake County, Florida. The program, which is implemented by the Lake County Sheriff's Office, is intended to monitor older people who are living alone and have no one to check on them daily, including people with dementia (https://www.lcso.org/public_html/seniorwatch.htm). The person must register and provide some personal details, such as age, medical conditions, and contact information for neighbors or relatives who live nearby. The person is supposed to contact the Senior Watch telephone operators every morning to report how they are feeling. If the operators do not hear from the person, they call the person, and if the person fails to answer the phone, they contact a neighbor or relative to check on the person. If timely contact cannot be made, a Deputy Sheriff is dispatched to the home. The program, which has been in operation for 10 years, also issues cell phones that only dial 911, free of charge to older people who live alone.

Programs to develop "teams" of friends, neighbors and others to help people with Alzheimer's and other dementias who live alone and are socially isolated. The "Vulnerable Isolated Persons (VIP) Project" in Boston attempted to create a team of friends, neighbors, service providers, and others to help isolated people with Alzheimer's and other dementias remain in the community safely and avoid nursing home placement (Drebing & Harden, 2006).

The project began in 2000, with funding from the Alzheimer's Association, and was a joint initiative of the Bedford Veterans Administration (VA) Medical Center, the Boston University School of Medicine, and the local Alzheimer's Association chapter. In its first 3 years, the project served 40 people with Alzheimer's and other dementia who were isolated and living alone. Project staff attempted to identify friends, neighbors, distant family members, and others who had any regular contact with the person and were willing to be involved in an organized team that would help the person. At an initial meeting of these individuals, information about the person and his or her condition and care needs was provided; a plan for meeting the needs was proposed, and meeting participants were asked to indicate which tasks and activities they would be willing to undertake. Project staff were available to consult with the "team" members and revise the plan as needed. Developing and sustaining the teams was time-consuming for the project staff, but the project was effective in avoiding or delaying nursing home placement for many of the people it served. The project evaluation found that very few of those individuals had been placed in a nursing home, whereas all of the individuals in a comparison group of isolated people with Alzheimer's and other dementias had been placed.

POLICY AND PRACTICE CONSIDERATIONS

Addressing the needs of people with dementia living alone requires changes in practice and policy and recognition of the complexities and difficulties experienced by people with dementia living alone. Based on the literature review and interviews for this paper, we provide two areas of policy and practice considerations that address improvement in the detection of a possible dementia in older people who live alone, and the delivery of personalized services to meet the unique needs of people with Alzheimer's or other dementia who live alone.

Improve Detection of Possible Dementia in Older People Who Live Alone

- Many older adults living alone have dementia that has not been detected or diagnosed because there are no family members or friends to identify that there is a problem. Health care and social service professionals should be aware of the possibility of dementia. In addition, public and private programs that provide services to this population should have routine procedures for detection of possible dementia and staff training to ensure that the condition is recognized and people are referred for a diagnostic evaluation when appropriate.

The new health reform law authorizes an “Annual Wellness Visit” for Medicare beneficiaries, and the U.S. Centers for Medicare & Medicaid Services has proposed that detection of cognitive impairment should be a required element of each “annual wellness visit” (*Federal Register*, July 13, 2010).

- Physicians and other health care professionals may not recognize persons with Alzheimer’s or other dementias who live alone who are at risk. It is important that a person’s living situation, support system, and functional performance be assessed for capacity to live alone. Missed doctor’s appointments may be a possible sign of cognitive impairment and the physician or other health care provider should be notified by office staff for follow-up.
- A person with dementia who lives alone may have inadequate or no support. It is important to reach out to “atypical gatekeepers” such as the local grocer, postal service worker, public transit drivers, financial services providers, and utility meter readers to identify and intervene with those persons with dementia living alone who may be at risk.
- Adult Protective Services personnel, geriatric care managers, and other community care professionals need effective tools for identifying persons with dementia living alone who are at risk and appropriate interventions. It is recommended that tools including neuropsychological testing be evaluated for use by community care professionals.
- A more standardized measure for assessing driving ability in someone who has a cognitive impairment should be developed.

Provide Personalized Services to Meet the Unique Needs and Preferences of People with Dementia Who Live Alone

- Services for older adults with dementia who live alone should be based on assessment of cognitive capacity as well as assessment of IADLs and ADLs, home safety, and risk for unsafe wandering.
- Since Alzheimer’s and other related dementias are progressive and fatal diseases of the brain, services for people with dementia living alone, such as Meals on Wheels, must be reassessed periodically for appropriateness based on changes in the person’s cognitive and physical capacity.

- A person with dementia living alone is unlikely to know about available home and community-based services. Care managers should work with people with dementia living alone to obtain needed services and to provide ongoing monitoring of services needs.
- People with dementia who live alone may not be able to maintain ongoing household repairs. Home repair and modification programs should include ongoing monitoring of persons with dementia living alone who are identified as lacking the capacity to recognize home maintenance needs.
- A person with dementia may not be able to navigate available public transportation or paratransit services without assistance. Transportation alternatives for persons with dementia who live alone that include door-to-door or companion services may be more useful for this population.
- Once a diagnosis has been made, the individual with dementia should be encouraged to talk to family and friends about their preferences for end-of-life care and to complete an advance directive when they have the decision-making capacity.
- Home and community-based services providers need to understand how to respond to the unique needs of someone with dementia who lives alone in an emergency. Emergency personnel at the time of a fire or other crisis situation should have access to concise, accurate information about the person's dementia, their medical conditions, medications and dosage, and other important information. Home and community-based services providers should be trained on working with first responders such as fire personnel or police to assist with finding the individual in an emergency situation, effective communication strategies for people with dementia, and effective approaches when the person resists offered assistance.
- Interdisciplinary/interagency teams should be established to encourage collaboration and service coordination across government agencies and community-based services providers to ensure quality care and cost-effective service delivery for people with dementia living alone.
- State or local government agencies involved in developing and implementing services for people with dementia may want to establish an advisory group of people with dementia who are living alone and family caregivers because of unique needs.

CONCLUSION

Despite the large proportion of people with Alzheimer's and other dementias who live alone—as many as one third of all community-dwelling people with these conditions according to data presented in this issue brief—the great majority of programs and services target people with dementia who live with their spouse, adult child, or other relative or friend. Very few programs and services target those who live alone.

Community-dwelling people with Alzheimer's and other dementias who live alone are, on average, somewhat less cognitively and functionally impaired than people with these conditions who live with others. Many of them receive help from relatives, neighbors, friends, and paid caregivers and may not need additional help at any particular point in time. Alzheimer's and most other dementias are progressive, however, and all individuals with these conditions need more help over time. Relatives, friends, neighbors, and others who check in regularly with a person with Alzheimer's or another dementia can monitor the person's condition and care needs, recognize when more care is needed and provide or arrange for the provision of that care. People with Alzheimer's and other dementias who live alone and have no one that checks in on them regularly are most likely to fall through the cracks. The extent of their unmet needs often becomes apparent only when they have a medical or other care-related crisis, and an emergency response is required.

This issue brief describes the major care issues and considerations in developing services for people with Alzheimer's and other dementias who live alone from the perspective of the persons themselves, as well as caregivers, care managers, community service providers, and medical and adult protective services personnel. It also identifies components of a system of care that would allow them to continue living alone safely for as long as possible. Those components include better identification and diagnosis, assessment, ongoing monitoring (“checking on”) of the person, individualized services, and for some persons early in the disease process, assistive technologies may be an option. In addition to ensuring safety, it is important to recognize the need for independence, the ability to participate in decision making, and opportunities for meaningful social interaction.

Many factors contribute to the difficulty of effective provision of services for people with Alzheimer's and other dementias who live alone. Programs intended to address these factors will require communication and care coordination from professionals representing various community and government agencies, and at times, nontraditional service providers (mail carriers, bank personnel, apartment managers) who can help with identification and monitoring. Persons with dementia who do not have a caregiver or anyone to monitor them will require specialized assistance from a trained multidisciplinary team. As the prevalence of Alzheimer's and other dementias continues to rise, community and government agencies and other service providers should begin to create and test such programs in their communities, and share lessons learned with others in the aging services network in an effort to more effectively identify and meet the unique needs of people with Alzheimer's or other dementias living alone.

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