

Promising Programs and Services for People Living Alone with Dementia



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The National Alzheimer's and Dementia Resource Center (NADRC) developed this resource at the request of the Administration on Aging within the Administration for Community Living (ACL). ACL funds the NADRC to provide expert technical assistance to ACL and its grantees. Through the NADRC, ACL makes Alzheimer's disease and related dementias (ADRD) program information, tools, and trainings available to the Alzheimer's Disease Programs Initiative (ADPI) grantee community and the general public. This resource is intended to support the work of ACL's ADPI grantees and others who are dedicated to developing and delivering programs and services for people living alone with dementia (PLAWD) to support people living with ADRD and their caregivers. The NADRC's full array of dementia-related information, resources, and tools can be found at <https://nadrc.acl.gov/>.

Background

As the U.S. population ages, the number of PLAWD will increase. ACL reported in the *2021 Profile of Older Americans* that 27% of persons age 65 and older, some 15.2 million older adults, were living alone in the community. Additional data in the *2021 Profile of Older American* indicate that 28% of those age 65 and older reported they had difficulty with remembering and concentration (i.e., cognition; ACL, 2021). Living alone, as an older adult, is documented as a risk factor for developing dementia (Shaw et al., 2022). Thirty percent of white older adults live alone, as do 28% of Black older adults, 20% of Latinx older adults, and 14% of Asian older adults, indicating that living alone is widespread across many racial and ethnic groups (Portacolone et al., 2022).

It is vital that ways to support PLAWD's ability to remain safely in their homes and communities be identified. Engaging people in discussions on decisions about present and future treatments and life planning, while they are able to engage, will support both their well-being and that of their caregivers and the communities within which they reside. PLAWD often view their home as their connection to their life and identity (Fæø et al., 2019). Most PLAWD will try to "carry on as normal" (Bronner et al., 2016, p. 1) using various coping strategies to continue living in their home even as their cognitive impairment forces them to adapt and change the routines and rhythms of their lives (Fæø et al., 2019). A recent study found the priority of staying in one's own home, for a PLAWD, reinforces the role the home played within a larger foundation of their life—as a place for memories, habits, and relationships (Fæø et al., 2019). These findings imply a need to understand what is important to people and how these factors interact to provide support for their special needs to support their living in their own homes, safely, as long as possible (Association for Frontotemporal Degeneration, 2021; Fæø et al., 2019).

People who live alone might interpret getting a formal diagnosis of dementia as a threat to their way of life and the first step to losing their independence and home. It is also possible that a person may just be unaware of the degree to which their cognition is impaired and not see a need to seek a diagnosis for cognitive loss (Portacolone et al., 2019). These attitudes present a challenge to health care professionals who must balance institutional or societal safety concerns against a PLAWD's sense of independence and home as a place of safety (Duane et al., 2013). Opportunities for early intervention

and treatment are lost if the PLAWD is not engaged in services as early as possible. Support systems that seek to serve this unique population must be flexible and innovative in their approaches to provide crucial, specialized, and adaptable services. Services and supports must be tailored to meet the changing needs of the PLAWD (Portacolone et al., 2019).

PLAWD face increased risks to their health and safety as their cognitive impairment progresses. A study examining characteristics and risks to PLAWD found that they may have an increased risk for injury to self or others through self-neglect resulting from the symptoms of their cognitive impairment. Most PLAWD were older, widowed women who were not diagnosed with Alzheimer's or dementia but screened positive for cognitive decline (Gibson & Richardson, 2017). This lack of formal diagnosis makes it difficult for PLAWD to plan and make decisions regarding the treatment of their condition or to prepare for the future (Portacolone et al., 2018). Even if they have noticed a difference in their cognitive abilities, PLAWD may not have the will or ability to arrange for outside help when the need arises. It is understood that "some PLAWD distrust and avoid healthcare providers (e.g., physicians, social workers, nurses) whom they believe do not understand their priorities" (Portacolone et al., 2018, p. 2).

Even though they live alone, research reveals that most PLAWD rely on adult children and paid professionals as their primary caregivers (Gibson & Richardson, 2017). Caregivers who reside in different households may not know that the person they care for has a dementia diagnosis or how well the PLAWD is functioning. PLAWD may forget receiving a diagnosis, or they may be reluctant to tell the caregiver in an effort to protect their independence (Portacolone et al., 2018). Caregivers from a different household may have an unrealistic view of the PLAWD's ability to live alone safely or may be unaware of the need for cognitive screening and possible dementia diagnosis that would support enrollment in supportive services (Gould et al., 2017).

Most PLAWD want to remain in their homes (Portacolone et al., 2019); however, given the gradual onset and variable nature of most dementias, they often do not recognize when they need more support to thrive in the community. A limited social support network and poor access to services places a person at greater risk of dementia or a rapid increase in dementia symptoms and impacts the PLAWD's psychological well-being (Desai et al., 2020; Poey et al., 2017; Rote et al., 2021). Without someone in the home to identify changes in cognition and unmet needs, a PLAWD's access to paid long-term services and supports (LTSS) or those supports provided by family caregivers may be delayed (Portacolone et al., 2022).

Studies indicate that people are at greater risk of institutionalization if they do not receive the services they need in the community. Despite the benefits of accessing services, research indicates that health care providers are reluctant to engage in the difficult conversation of getting additional supports in the home or transitioning to institutional settings to receive needed care (Cantu et al., 2022; Portacolone, et al., 2019; Rosenwohl-Mack et al., 2021). Inadequate advance care planning, especially with PLAWD, can lead to unnecessary distress, emergency care, or hospitalizations and increased safety risks (Portacolone et al., 2022).

Unmet Needs

PLAWD have higher unmet needs and are more susceptible to abuse and self-neglect than people with cognitive impairment who live with others (Lichtenberg et al., 2021; Portacolone, 2018). The most common unmet needs include assistance with basic activities of daily living, nutrition, medications, money management, and mobility (Edwards et al., 2020; Yang et al., 2022). Women report more difficulty getting their needs met than men, and Black and Latina women are more likely to report more difficulty getting their needs met than white women (Edwards et al., 2020).

PLAWD have an average of four or more care providers, which is significantly higher than people living with a caregiver. Rather than immediate family members, distant relatives and friends are more likely to be the primary care providers for PLAWD. However, these distant relatives and friends are often less willing to assist if tasks are time-consuming or if the person for whom they are caring stops acknowledging the support (Edwards & Morris, 2007). PLAWD are more likely to receive care from paid professionals than their counterparts living with others, even though they have fewer financial resources (Gibson & Richardson, 2017; Portacolone et al., 2019; Yang et al., 2022).

Changes in memory and decision-making can increase the vulnerability to abuse of people living with dementia. Even though abuse by family members and close friends is most common, PLAWD are significantly more susceptible to abuse and financial exploitation by strangers, and this abuse is less likely to be noticed (Gould et al., 2018). Financial exploitation is one of the most reported types of elder abuse in PLAWD. Examples of ways in which PLAWD can be financially exploited include check writing and cashing, leaving money or account information around the house, or talking to strangers about their finances (Gould et al., 2018; Lichtenberg et al., 2021).

A person is at risk for self-neglect when they cannot provide for their own basic needs and their health, safety, or well-being is in jeopardy. Self-neglect is one of the most frequent categories of abuse investigated and substantiated by Adult Protective Services. Unfortunately, it is difficult to intervene in cases of self-neglect when the PLAWD resists help or denies or underestimates the severity of their cognitive decline and related care needs (Gould et al., 2018).

Managing Health Conditions

Overall, PLAWD have poorer health outcomes than people with dementia living with others (Portacolone et al., 2018). Compared to people with dementia living with others, PLAWD are less likely to use health care services or seek a diagnosis for their cognitive impairment. PLAWD have a greater propensity for distrust and avoid health care providers who they feel do not understand their priorities (Portacolone et al., 2018). Living alone means that there is no one else in the house to recognize health changes and to facilitate follow-up with a physician.

Social Isolation and Loneliness

People living alone are more predisposed to social isolation and loneliness, and they are less involved in clubs or other organized activities than people living with others. PLAWD may want social

interactions but are not able to participate because of health or limitations in activities of daily living (Gibson & Richardson, 2017). Apathy, a dementia symptom, can impact a PLAWD's motivation to engage with others, and the PLAWD may rely on others to encourage participation in activities.

Social isolation can be a risk factor for dementia. A recent study indicates that socially isolated older adults have a 27% greater chance of developing dementia than older adults who are not socially isolated (Huang et al., 2023). Reduced social interactions can contribute to decreased cognitive reserve, increased risk of cognitive decline, and decreased quality of life in PLAWD (Gibson & Richardson, 2017; Rote et al., 2021; Yu et al., 2021).

Promising Practices

Framework for Solutions

The following sections outline promising practices to address the range of experiences and challenges for PLAWD. These promising practices were identified in peer-reviewed literature and from the Final Reports of ACL's ADPI grantees. Specifically, the promising practices acknowledge that PLAWD can benefit from different supports as their care needs evolve. Many PLAWD need immediate support with diagnosing and addressing ADRD, including any resulting care needs or safety challenges. As symptoms progress, the PLAWD may need an expansion of the care network to support care monitoring, care management, and socialization (Portacolone, 2018). As part of the 5-year "Living Alone with Cognitive Impairment" project, a policy advisory group composed of policymakers, health service administrators, advocates, and researchers from diverse organizations convened to identify the LTSS needs of PLAWD and reinforced the importance of a "wraparound" set of services to assist people across their ADRD experience (Portacolone et al., 2022). An important aspect of all these promising practices is the need for person-centered care versus a standardized or "one-size-fits-all" approach (Duane et al., 2013).

Identification

PLAWD are unlikely to self-identify or seek services for challenges related solely to their dementia—either because of lack of insight or reluctance to share out of concern of losing their independence. Generally, service providers will not know if a person is living alone unless they specifically ask about the person's living situation. It is also unrealistic to rely solely on the PLAWD sharing that they have unmet care needs and possible safety issues. As a result, some ADPI projects have piloted multiple strategies to identify and support PLAWD.

Identification/Referral

The most common path ADPI grantees used to identify people who live alone with or at high risk of developing dementia was to identify and partner with local service providers that serve people who live alone and ask them to refer people to new programs.

The University of Virginia (UVA) targeted its recruitment efforts at people with dementia who lived alone from within UVA's Memory and Aging Care Clinic (MACC). UVA's recruitment success can likely be attributed to participants' existing relationships with MACC and their clinicians (e.g., geriatrician, nurse practitioner) (Rector and Visitors of the University of Virginia, 2021).

Most grantees spent significant time collaborating with established community agencies that did not already offer dementia-specific services. The programs benefited from these agencies' existing relationships with PLAWD and people who were otherwise isolated. Agencies targeted for partnerships include home-delivered and congregate meal programs, transportation services, friendly visitor programs, senior residential communities, and adult day health or senior centers. Partnering with trusted organizations providing home and community-based services (HCBS) facilitated introductions to people with dementia and those at risk for dementia who live alone. These partnerships proved essential in identifying PLAWD who needed more assistance (Alzheimer's Orange County, 2021) and helped with trust-building between clients and staff delivering live alone-specific services (Alzheimer's Greater Los Angeles, 2017a).

An identification strategy implemented by traditional senior service agency grantees was to enhance organizational processes and procedures, such as formal intake and assessment, to include questions about living situations, cognition, and risk. The Southern Maine Agency on Aging (SMAA; 2017) was one of the earliest projects funded by the Administration on Aging with a direct focus on PLAWD. SMAA had a long-held objective to improve the effectiveness of the federal requirement for regular in-home assessments of Meals on Wheels (MOW) clients, which allows vulnerable clients to be observed in their own environment to determine unmet needs. SMAA wanted its MOW assessors to be able to recognize signs of cognitive changes and risks in those living alone. They modified their existing MOW assessment process to include a section on Memory Concerns. The *Meals on Wheels Expanded Assessment* improved capacity and ability to identify PLAWD who are receiving community services. To ensure fidelity, SMAA provided standardized training, continuously monitored the assessment process, reviewed information collected, and provided MOW ongoing support for assessors. An evaluation of the assessment tool found that 60.4% of MOW clients screened and 16.6% of those identified with dementia lived alone. In a subsequent grant, MaineHealth collaborated with SMAA on the development of an implementation manual for the *Meals on Wheels Expanded Assessment* (MaineHealth, 2019).

The United Way of Tarrant County (2019)/Area Agency on Aging of Tarrant County and Meals on Wheels Inc. of Tarrant County co-created the Model for Alzheimer's/Dementia Services protocol that built efficiency into the process of screening, identifying, and connecting with PLAWD. As the first point of contact, MOW case managers used clients' responses to questions related to independent decision-making and short-term memory capacity on the existing state-required Texas Home Delivered Meal Assessment to trigger a MOW-administered memory screening using the AD-8 (Texas Health and Human Services, 2021). Once they identified a potential PLAWD through screening, MOW case managers contacted a United Way Options Counselor to schedule a home visit to initiate dementia-specific

services through United Way. United Way found that having access to a PLAWD's primary support contact, also identified by the MOW assessment, was especially important in the process.

Several grantees used the "Gatekeeper Model," which involves training community members such as apartment managers, hairdressers, utility workers, and first responders to identify individuals with dementia who live alone. These programs recruit 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 (Gould et al., 2010). As implemented in ACL's Alzheimer programs, trained community "gatekeepers" make referrals to grantee programs focused on serving PLAWD.

Alzheimer's Orange County trained gatekeepers to identify people who may be living with dementia and connect them to support (Alzheimer's Orange County, 2021). Training included identifying common symptoms of dementia: short-term memory loss, repetition, lack of awareness with time and place, and changes to their personality. As a grantee partner, Alzheimer's San Diego also created a webpage dedicated to its gatekeeper program, complete with a prerecorded training video, links to pre- and post-training surveys, a referral form, and a contact form for additional questions (Alzheimer's Orange County, 2021). Referral submission was designed to be user-friendly, including a referral landing page on the organization's website available 24/7.

Houston's Amazing Place, Inc. reported that they initially assumed churches would have accurate, accessible information about their congregants who lived alone. However, they found this varied considerably by church. Smaller churches and churches with a minister for Senior Ministries were more likely than others to have this information. Even churches with accurate general information about their congregants had difficulty identifying those who lived alone or had dementia. They found that there was a high level of stigma about dementia within churches; families did not talk openly about dementia and people living with dementia could easily drop "out of view." Some churches provided the grantee with long lists of people over age 75, but cold calls to congregants did not yield results. Other churches felt that sharing congregants' names violated their privacy. In these cases, a clergy or staff member made an introductory call and got permission for the grantee's Faith Care Connection (FCC) program staff to make a home visit. Although clergy introductions resulted in fewer contacts, they greatly increased the likelihood that the people identified for the program would agree to a visit, meet the eligibility criteria, and enroll in FCC to develop personalized care plans (Amazing Place, Inc., 2020).

Promising Practice Example

"Even churches that had good general information about their congregants, had difficulty identifying those who lived alone and/or had dementia. We found that there was a high level of stigma about dementia within churches; families did not talk openly about dementia and older persons with dementia could easily drop 'out of view' ... We found that it was difficult for pastoral care clergy and staff to identify older congregants who met the criteria, so we created charts to help them in their decision making."

— Amazing Place, Inc., 2020

Alzheimer's Greater Los Angeles worked with resident service coordinators at low-income senior housing communities to identify and support residents with cognitive impairment to continue to safely live alone. They anticipated referrals from the resident service coordinators, who have the most interaction with residents in the building, but this did not occur. Many resident service coordinators were reluctant to connect residents with the program because of misconceptions about it and its potential benefits. Initially, many resident service coordinators mistook other mental health concerns (such as substance abuse) and depression as dementia, resulting in inappropriate referrals. Grantee staff accepted all referrals and referred people to other community resources from which they could benefit (Alzheimer's Greater Los Angeles, 2017a).

Assessment of Risk/Safety

The need for providers to conduct formal, comprehensive assessments of PLAWD's functional and health status and their community support systems was a consistent theme in the ADPI grants. Assessments should determine whether an individual needs assistance with activities of daily living (e.g., eating, bathing, and dressing) or instrumental activities of daily living (e.g., housework, money management, and medication management) (Gould et al., 2017). In addition to acute safety risks, PLAWD have a high risk of comorbid conditions (e.g., high blood pressure, heart disease, depression), which can be challenging to manage independently. These comprehensive assessments are important because most PLAWD access few services until a "catastrophe" (e.g., falls, fires) occurs resulting in connections to additional services (Portacolone et al., 2022).

Assessment Tools

Grantees have adopted, adapted, and developed assessment tools for PLAWD. In addition to collaborating on the development of the *Meals on Wheels Expanded Assessment* to improve identification of people living alone with cognitive impairment, SMAA also implemented an initial home visit with an in-home fall-risk assessment and a 1-month follow-up with the administration of a *Revised Crisis to Thriving Scale* (adapted from the *Self-Sufficiency Matrix*). The SMAA scale included 13 domains measured on a scale from 1 to 10 with 1 = crisis (immediate help is needed; emergent risk of injury to self or others; immediate risk for hospitalization or Adult Protective Services referral) to 10 = thriving (independent or has a strong network to meet needs). In early implementation, SMAA found the greatest levels of crisis and vulnerability for PLAWD who completed the *Meals on Wheels Expanded Assessment* were in cognitive function, medication management, fall risk, unmet transportation needs, nutrition needs, and money management (Southern Maine Agency on Aging, 2017).

The Alzheimer's & Dementia Alliance of Wisconsin (ADAW) implemented the *Live Alone Risk Assessment* originally developed by the University of Iowa for home care nurses and other community-based providers to assess level of risk when visiting PLAWD (Hall et al., 2001). The assessment is used to categorize conditions that may indicate when a person with dementia is no longer safe to live alone or requires more services, assistance, or placement. The ADAW program evaluation found that, at baseline, most PLAWD had a high level of need, having at least one living condition that suggested the need for

immediate assistance or facility placement. The most common concerns identified during follow-up assessments were mental health conditions, driving, medication usage, repeated calls to others, and poor grooming (Alzheimer's & Dementia Alliance of Wisconsin, 2021).

Alzheimer's Greater Los Angeles and the Alzheimer's Association of Northern California/Northern Nevada partnered to develop and implement the *Live Alone Dementia Safety Net Algorithm (Algorithm)*, a tool designed to assess a person's safety, guide cognitive screening, direct medical referrals, assess needs, and generate community resources (Bonigut, 2017). The *Algorithm* also incorporates the *Live Alone Risk Assessment* (Hall et al., 2001) to assess a client for immediate danger or other conditions that may indicate when a PLAWD is no longer safe. Upon using the *Algorithm*, baseline assessments commonly identified the following areas of unmet needs: looking after the home, food availability and storage, self-care, caring for someone else, daytime activities, eyesight/hearing, inadvertent self-harm, money/budgeting, and benefits (Alzheimer's Los Angeles, 2017a). Use of the tool resulted in PLAWD being referred to intervention options that addressed areas of unmet needs.

Future considerations for identifying and assessing PLAWD or persons at high risk of dementia include findings from post-COVID research into social isolation. Study findings indicate that actual risk for dementia may be best recognized by identifying not those who currently live alone, but rather those who have lived alone for an extended duration or who are at risk for long durations of solitary living (Shaw et al., 2022). Technology advances may also hold hope to detect signs of cognitive decline in people living alone. One recent study evaluated degradation of a person's communication skills and commands given to a voice assistant (e.g., Amazon Alexa) over time as a sign of dementia-related speech and language difficulties. The study suggests that it may be possible to use this technology for home-based cognitive assessments in the future (Liang et al., 2022).

Care Management and Monitoring

Care management and monitoring can support a PLAWD by identifying and addressing unmet needs that may affect a person's quality of life. The needs of PLAWD, including the types of supportive services, vary based on the individual's stage of disease. Grantees offering care management either provided services to PLAWD or referred them to supportive services. Common unmet needs and services provided are presented in Exhibit 1.

Exhibit 1. Common Unmet Needs of PLAWD and Services Provided

Unmet Need	Service Provided
Home safety	Arranged for home repairs and home modifications and completed fall risk screenings (Alzheimer's Greater Los Angeles, 2017a; Eddy Alzheimer's Services, 2020; Latino Alzheimer's and Memory Disorders Alliance [LAMDA], 2022).
Poor health conditions / medication management	Coordinated appointments with health care providers and administered memory and depression screens (Alzheimer's Greater Los Angeles, 2017a; Eddy Alzheimer's Services, 2020).
Nutrition	Arranged for grocery shopping assistance to deliver food to the home or provide home-delivered meals from MOW (Eddy Alzheimer's Services, 2020; LAMDA, 2022; ONEgeneration, 2021).
Self-care	Coordinated personal care assistance services (Eddy Alzheimer's Services, 2020; ONEgeneration, 2021).
Transportation	Connected individuals with transportation options in their community (LAMDA, 2022; ONEgeneration, 2021).
Accessing government-funded programs	Provided assistance in completing paperwork for fuel assistance, health insurance, etc. (MaineHealth, 2019; Rector and Visitors of the University of Virginia, 2021).
Advance planning	Provided guidance on how to complete an advance directive (Alzheimer's Greater Los Angeles, 2017a).

Delivery Methods

Support systems that serve this unique population must be flexible in their approaches in delivery of services tailored to meet the needs and preferences of PLAWD. Care coordination models were similar among grantees, with staff or volunteers being assigned to PLAWD. The staff or volunteer conducted an assessment, developed a person-centered plan of care, provided referrals or direct services, and monitored progress.

However, delivery methods varied among grantees, with in-person, telephone, and virtual service offerings. Services could be delivered in people's homes or at a community-based organization office. Care management service duration varied, depending on the individual's stage and impairment, ranging from 3 to 6 months to a year, with some extending to multiple years.

Promising Practice Example

"Grantee provided one initial home visit, monthly phone contacts, visits during clinic appointments and ad hoc contacts (in-person, phone, or email)."

—Rector and Visitors of the University of Virginia (2021)

Provider Types

Grantees used staff, interns, and volunteers from several disciplines to provide care management. Grantees also used master's-level social work interns, community health workers, volunteers, or friendly visitors to provide care management or to support staff delivering the service. Staff, interns, and volunteers all received advanced training in dementia and on the unique characteristics of PLAWD.

Socialization

People with dementia may find it difficult to initiate a conversation or an activity with others. Grantees offered specialized services to address socialization with PLAWD, offering services face to face, via phone, and virtually. Regular check-ins with a PLAWD provided opportunities for socialization. Alzheimer's Community Care in West Palm Beach, Florida, created a program that paired veterans living alone with dementia with "Veteran Care Buddies" to provide companionship and support (Alzheimer's Community Care, 2018). During the COVID-19 pandemic, FCC coordinators at Amazing Place (2020) made telephone calls, email contacts, and home visits (as suitable) to PLAWD. Also during the pandemic, LAMDA (2022) community health workers dropped off food and conducted phone calls with clients. During phone calls, LAMDA community health workers would ask questions about depression and social isolation and make referrals as needed.

Grantees have implemented virtual and face-to-face approaches to engage and support PLAWD. Nevada Senior Services (2020) provides access to *Living Alone and Connected*, a moderated Facebook group for PLAWD that provides emotional support, peer guidance, and monthly Facebook Live events. Adult day programs offer in-person opportunities to socialize and participate in activities in a safe environment. Jewish Family Service of San Diego (2021) added a day of social and wellness programming to its adult day program for enhanced opportunities for PLAWD to socialize. WISE & Healthy Aging (2021) developed a program and training for Volunteer Casual Caregivers to provide weekly home visits.

Expanding the Circle of Care and Support

ACL grantees devised some innovative approaches for expanding people's "circles of care and support" that recognize the unique needs of PLAWD. Building trust with PLAWD takes time and may require multiple contacts and meetings before they will accept help.

The greatest unmet needs of PLAWD include activities of daily living, nutrition, medications, money management, home safety, and getting to medical appointments (Alzheimer's Association, 2012; Edwards et al., 2020; Yang et al., 2022). Although HCBS such as in-home support services, home-delivered meals, and transportation are available, these services often do not sufficiently meet the unique needs of PLAWD. For example, PLAWD may also need more support with individual tasks, such as someone to warm up the home-delivered meal or to be an escort while traveling. Expanding people's circles of support aids in addressing unanticipated needs that evolve over time.

Alzheimer's Greater Los Angeles' partner (2017a), Alzheimer's Association of Northern California and Northern Nevada chapter, developed "Alone but Not Forgotten" (Alzheimer's Greater Los Angeles, 2017b), a handbook for professionals who assist PLAWD to establish or create care circles of family, friends, out-of-state relatives, members of congregations and cultural centers, and medical and social service providers who can help provide support. The aim is to identify the people whom PLAWD can trust for support so they can remain engaged in the community and live safely in their own home. Project staff offered care consultation sessions with PLAWD that included assessing their service needs

and making referrals to additional services. The care consultant then identified potential care circle members and worked with PLAWD and their care circle for a period of 6 months to strengthen available support through home visits and telephone consultations.

HCBS providers may encounter PLAWD who are unable or unwilling to provide accurate information on next of kin or emergency contact information. In these circumstances, HCBS providers need to act as if they have no known supports until a circle of care can be put in place. Case managers at ONEgeneration in Southern California (2021) established working relationships with In-Home Supportive Services, Adult Protective Services, the Public Guardian, the police department, and the psychiatric emergency team to create a social service safety net for their most vulnerable clients. They also participated in monthly meetings with the local elder abuse prevention multidisciplinary team to discuss cases and leverage resources. Through their FCC project, staff at Amazing Place (2020) offered enhanced pastoral care to congregants living alone with dementia. On occasion, staff encountered clients who did not have available family and referred them to geriatric care managers or an alternative housing arrangement.

Discussion About Programmatic and Research Opportunities

Tools and Resources for Community-based Providers

The following is a selection of tools and resources developed by ACL grantees for use in programs serving PLAWD. These may be useful for replication or adaptation by community-based providers.

Identification

- [The Dementia Gatekeeper Program](#): Guide for Non-Traditional Gatekeepers
Training guide intended to provide guidance on the planning, development, and delivery of Dementia Gatekeeper Program trainings for local businesses and organizations. The program's purpose is to identify those most at risk or in need of dementia-specific services in the community. The guide includes a brief section on dementia basics: safety concerns and considerations for people with dementia who live alone (Alzheimer's Orange County, 2021).

Assessment of Risk/Safety

- [First Responder Alzheimer's & Dementia Training 4: "House Call"](#)
A brief video for police officers demonstrating effective identification and response to PLAWD at risk created by grantee partner Alzheimer's Orange County (Alzheimer's San Diego, 2018).
- [Meals on Wheels Expanded Assessment Tool](#)
A manual of how to implement the assessment tool. Designed to improve the capacity and ability of home-delivered meals assessors to identify PLAWD; includes a section on Memory Concerns (MaineHealth, 2021).

- [Live Alone Dementia Safety Net Algorithm](#)
Tool assesses unmet diagnostic, medical, financial/legal, daily living, safety, quality of life, support system, or technology needs of PLAWD (Alzheimer's Greater Los Angeles, 2017a).

Care Management/Complex Care Management

- [Gatekeeper Program and Dementia Care Coordination Toolkit](#)
The toolkit is intended to provide guidance on planning, development, implementation, and evaluation of dementia training and care coordination services concerning PLAWD (Alzheimer's Orange County, 2021).
- [Care Management Manual](#)
Manual provides a guide for agencies considering implementation of a care management program. Focuses on serving PLAWD and people with moderate to severe dementia living with a caregiver (Eddy Alzheimer's Services, 2020).

Expanding the Circle of Care and Support

- [Care Circle Guide: Alone But Not Forgotten](#)
An educational booklet for Care Circle members about what planning needs to occur and how to work with physicians and identify issues that need to be addressed when supporting those living alone with memory loss. The guide provides information and tips for PLAWD and their friends and family. The guide includes checklists and areas where important information can be documented about the PLAWD, such as their health care team and other important contacts (Alzheimer's Greater Los Angeles, 2017a).

Further Research and Development

PLAWD are an often underserved and hidden population, and the opportunities to best serve them are many. Increased research on living alone with dementia is one step toward better services and programs. Although the current review highlighted promising practices in the areas of Regular Monitoring, Case Management, and Expanding the Circle of Care, there is little or no peer-reviewed literature on these practices. Future research might help identify the circumstances in which these practices might best support PLAWD.

We expected that there would be promising practices about Legal and Financial Services targeted to PLAWD; however, the reviewed literature and ADPI Final Report materials did not reveal any. The areas of advanced care planning and emergency preparedness are critical supports for everyone and can be especially useful for PLAWD (Gould et al., 2018; Gould & Stockdale, 2022). Guides or toolkits do exist for individuals, families, and professionals seeking to implement advanced planning in the areas of financial, health care, and overall care planning, and decision-making considerations in light of cognitive changes and dementia, but are not solely targeted to individuals living alone (Hughes et al., 2023a, b, c, d).

Another area for research that will inform development of promising practices is to identify the barriers and facilitators of services specifically for PLAWD. Ideally, PLAWD, their extended family and friends, and service providers will provide insight about the barriers and facilitators. Portacolone (2018) conducted an ethnographic study of a woman living alone with dementia, and this work provides an important firsthand account of the barriers and facilitators to care and support. Research involving more people and a broader perspective may yield innovative ideas for new practices.

The exploratory study by Duane and colleagues (2013) highlights the need for a person-centered approach to care:

Overwhelmingly, there was a perception that current care practices take a standardized, rather than individualized, approach to support. This approach did not match the needs expressed by participants (p. 132).

Practitioners developing new services or adapting existing services for PLAWD should bear in mind the need for strengths-based, person-centered services. Programs and services demonstrate the best results when they align with the experiences and needs of individual PLAWD.

Closing

Studies have estimated that 32% of the 6.7 million people who live with dementia live alone (Amjad et al., 2016; Rajan et al., 2021). Although PLAWD may experience the same dementia symptoms as other people living with dementia, they experience different risk factors and challenges connecting with the service system. These unique circumstances for PLAWD require specific support and consideration from providers. A strengths-based, person-centered approach is key when supporting PLAWD—recognizing their unique needs, circumstances, strengths, and preferences. The practices outlined here highlight selected examples that can be repeated or adapted for new settings. Researchers and providers are encouraged to engage PLAWD and families in the development and planning for new services, which may point to new areas for supporting this underserved population.

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