Dementia Capable States and Communities: Lessons Learned from Administration on Aging Grantees

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Introduction

Dementia affects various aspects of a person's life and can also impact the lives of family members and friends. Family and friends, rather than paid care providers, deliver most of the care and support, helping with household tasks, medical condition management, and addressing behavioral symptoms (e.g., aggression, wandering). More than health care is needed to sustain people living with dementia in the community, but there are gaps in the availability of and access to services and the capability of providers, staff, and community to provide effective services (Lin & Lewis, 2015).

To address gaps in dementia services and capability, the Administration on Aging (AoA)/Administration for Community Living (ACL) encourages "dementia capability" through grants to states and local communities. Dementia capability means being skilled in identifying people with possible dementia, working effectively with individuals and caregivers, knowing what kinds of services are needed, and referring to agencies and individuals able to provide such services (Tilly et al., 2011).

The development of dementia-capable systems requires attention to (1) increasing knowledge and skills among staff, volunteers, and community members who may interact with people with Alzheimer's disease and other dementias and their caregivers; (2) identifying and addressing service gaps, particularly where more specialized services are needed; and (3) ensuring that long-term services and supports (LTSS) fulfill a person's needs and improve their quality of life. Success in achieving all of these goals is best supported by addressing workforce training, across a wide range of professions, on identifying and addressing needs, and in supporting the creation of dementia-friendly communities to promote both safety and continued independence for people living with dementia and their caregivers. Dementia-capable and friendly communities ensure that training, awareness, and willingness to support extends beyond traditional health and community support providers to include, but not limited to, staff in transportation, supermarkets, places of worship, financial institutions, and law enforcement.

This paper builds on the 2011 issue brief Making the Long-term Services and Supports System Work for People with Dementia and their Caregivers (Tilly et al., 2011) and the 2014 paper Dementia-Capable States and Communities: The Basics (Tilly et al., 2014), authored by the National Alzheimer's and Dementia Resource Center and AoA/ACL. The purpose of this paper is to provide background on dementia-capable states and

communities by presenting the need for dementia capability and outlining its evolution. This paper provides snapshots of dementia-capable programs across the United States resulting from the ACL-funded dementia grants. This is not a comprehensive review of all work conducted by ACL grants but provides illustrative examples of dementia capability efforts. The paper guides readers through the need for dementia capability, the development of dementia-capable systems, and examples of dementia-capable practices at both state and community levels.

Dementia

Prevalence of Dementia in Community-Dwelling Older Adults

Alzheimer's disease and other dementias have been identified as the sixth leading cause of death in the United States. On average, individuals over the age of 65 survive 4-8 years once they have a diagnosis, but it is not uncommon for individuals to survive up to 20 years with a dementia diagnosis (Alzheimer's Association, 2019). Because of the long duration of dementia, there are growing concerns about the cost of care (financial and personal) and the health impacts on family caregivers (Xu et al., 2017).

In 2015, the United States had 4 million older adults with dementia, of whom 3.4 million lived in community settings (Chi et al., 2019) and only a small proportion lived in nursing homes. Among people with dementia who live in the community, 32% live alone and about half of these people live in supportive settings where medication, self-care, and meal services are available (Chi et al., 2019). Dementia prevalence increases with age, from 2% of adults age 65-69 to 15% of adults age 80-84 to 33% of adults age 90+ living with dementia (Chi et al., 2019).

> 3.4 million out of 4 million people with dementia live in the community (85%)

Impact on the Person Living with Dementia

Numerous aspects of a person's life are profoundly impacted by Alzheimer's disease and other dementias. Dementia is characterized by a progressive loss of cognitive functions such as memory, language skills, visual perception, problem solving, self-management, and the ability to concentrate and pay attention. The vast majority of people living with dementia (80%-90%) experience behavioral and psychological symptoms such as hallucinations, agitation, sleep disturbance, and wandering (Black et al., 2013; Karon et al., 2015). Other symptoms can include information processing challenges (e.g., noisy

environments), impaired motor control affecting balance and falls risk (LBDA, 2018), and a decline in socially appropriate behavior (AFTD, 2018). When severe enough, these symptoms interfere with a person's ability to plan, organize, and follow through with daily activities and personal care needs (NIH, 2017).

Approximately 20% to 40% of people with dementia have a disorder other than Alzheimer's disease (NIH, 2013; Plassman et al., 2007). The most common of these other disorders are cerebrovascular disease (5%-10%), Lewy body disease (5%-10%), and frontotemporal lobar degeneration (<10%; Alzheimer's Association, 2019). Differences in age of onset, symptoms, dementia progression, comorbid conditions, and the lack of knowledge of medical professionals can all contribute to distinct challenges in obtaining an accurate diagnosis, accessing appropriate care and services and for some, continuing to work (Hughes et al., 2017).

Relationships with others and emotional intimacy are greatly impacted as dementia progresses. For people living with dementia, the roles or responsibilities they once held within a relationship may be taken on by others. They may also fear burdening others with care or other daily activities they once managed. Communication difficulties and memory loss can make it increasingly difficult to share experiences and memories with others. People living with dementia are less likely than others to recognize their own limitations and therefore are unlikely to seek the help they need (Wattmo et al., 2014). Even when they do identify a need, the symptoms of dementia make it difficult to initiate contact or understand how to navigate the complex medical and LTSS systems.

Impact on the Caregiver

The majority of people with dementia live in the community (between 70% and 81%) and, for approximately 75% of these individuals, care is provided by family and friends. About 16.1 million adult family caregivers care for someone who has Alzheimer's disease or other dementia (Alzheimer's Association, 2018). These caregivers provide on average 1-4 years more care than for someone with an illness other than dementia. People living with dementia generally require high levels of care, and without caregivers, people living with dementia have a poorer quality of life and need institutional care more quickly (Family Caregiver Alliance, 2016).

Family members and friends who care for someone with dementia often experience more complex care situations than other caregivers (NAC & AARP, 2015). In addition, the

care needs of people living with dementia change over time, thereby requiring caregivers to modify the assistance they provide (Shuman et al., 2017a). The stresses of caring for a person with dementia may result in increased caregiver depression and anxiety, decreased self-efficacy, and poor physical health (NAC & AARP, 2015; Karon et al., 2015). Caregiver well-being can have a direct impact on the person living with dementia, and lack of coping skills could result in more behavioral or psychological symptoms (Lepore et al., 2017).

Accessing Medical Care and Long-Term Services and Supports

Many people living with dementia and their families have great difficulty finding the medical and LTSS help they need. This section explores the care needs and challenges faced by individuals and caregivers and resources to address the challenges.

Needs and Challenges

People living with dementia experience frequent care transitions such as from hospital to home or to a long-term care setting. An individual may experience transitions in care when moving in with a family member because of changes in health care providers and relocation to different health care settings. Such disruptions and engagement with new health care professionals present greater risk for medical errors, poor health outcomes, increased caregiver burden, and higher costs of care (Callahan et al., 2015).

People living with dementia have double the number of hospital stays per year compared to people who do not have dementia (Alzheimer's Association, 2019). An individual may not accurately convey or even remember crucial health information during care transitions, which increases the risk for frequent hospitalizations and uncoordinated care (LaMantia et al., 2010). There are challenges associated with transportation to appointments, knowing where to receive needed help, accessing professionals who understand and are skilled in supporting persons with cognitive impairments, and navigating a range of community-based LTSS. Medical and social service professionals may not have the necessary knowledge or experience with dementia to recognize caregiving challenges.

> People living with dementia have double the number of hospital stays per year compared to people who do not have dementia.

Resources

Despite challenges of accessing medical and LTSS, people living with dementia can benefit from more integrated LTSS and medical care systems, increased cross-agency/provider coordination, evidence-based services, and single-entry points for information and assistance. To support families, providers can take person- and family-centered approaches to address the most pressing needs of the person living with dementia. (Hirschman & Hodgson, 2018).

The No Wrong Door (NWD) system supports families and individuals who need access to medical care and LTSS, regardless of condition. An initiative of the ACL, the Centers for Medicare & Medicaid Services (CMS), and the Veterans Health Administration, a NWD system centralizes access to LTSS for older adults, persons with disabilities, and family members; this eases the burden of needing to access multiple other services for which a person might be eligible. An NWD system places a strong emphasis on taking into account a person's and a family's strengths, preferences, needs, and values as LTSS decisions are made (Bowen & Fox-Grage, 2017). Benefits of a NWD system include helping families know their options and plan early and training professionals in the skills needed to practice in a person- and family-centered way (Bowen & Fox-Grage, 2017).

AoA/ACL's Role in Ensuring That Supports are Dementia-Capable

AoA/ACL has taken a lead role in ensuring that supportive services are dementia-capable. For example, AoA/ACL participates in the development and implementation of the recommendations of the National Plan to Address Alzheimer's Disease. The recommendations include enhancing care for people living with dementia; expanding support for people living with dementia and their families; and enhancing public awareness to help address the special needs of people living with dementia and their caregivers (ASPE, 2019). ACL's dementia grant programs are cited in National Plan updates as examples of successful initiatives focused on improving dementia-capable care. The ACL dementia grant programs support state and local initiatives to develop dementia-capable LTSS systems. They have increased dementia-

> Dementia capability means being skilled in identifying people with possible dementia, working effectively with individuals and caregivers, knowing what kinds of services are needed, and referring to agencies and individuals able to provide such services.

capable services provided through Aging Network programs and advanced integrated care across settings to help people with dementia remain in their homes and communities. Through ACL funded programs, many community organizations, such as Area Agencies on Aging (AAAs) and Aging and Disability Resource Centers (ADRCs), assist people living with dementia and their caregivers to identify, choose, and obtain services and supports (Gould & Wiener, 2017).

One method of increasing dementia-capable services is by translating and delivering evidence-based interventions—that have shown positive outcomes for people living with dementia and caregivers—to community settings. AoA/ACL is one of the few funders, along with the U.S. Department of Veterans Affairs and the Rosalynn Carter Institute for Caregiving (RCI), that have awarded translation studies of dementia care interventions (Maslow, 2012; Shuman et al., 2017b). Translation studies help to determine if evidence-based interventions deemed effective in a research setting can show similar results in communities. Since 2008, AoA/ACL grant projects have produced a great deal of practical information about how to translate existing evidence-based dementia interventions into effective supportive service programs at the community level and how to reduce problems that interfere with successful implementation (Gould et al., 2017).

Dementia-Capable System Components and Grantee Examples

What makes a system dementia-capable?

States and communities have many people at risk of or living with dementia. They live alone or with family and they use the full range of public and private service systems. People living with dementia rely on others to live successfully in the community including their families, faith communities, grocery stores and banks, and health and LTSS systems. The long, slow progression of most dementias means that the needs of people with the condition and their caregivers change and become more intense over time.

This section outlines the components of a model dementia-capable system. Given the impact of dementia on people and communities, service systems that wish to be dementia-capable should consider adopting components of the model that apply to their mission. Development of this model was based on two sets of information: research on

dementia progression and supportive services and an evaluation of ACL grantee experience in developing dementia-capable systems.

A dementia-capable system should (Tilly et al., 2014):

1. **Identify people with possible dementia** and recommend that they see a physician for a timely, accurate diagnosis and to rule out reversible causes of dementia or conditions that resemble it.

2. **Ensure** that **program eligibility** and resource allocation take into account the impact of cognitive disabilities.

3. **Ensure** that **staff communicate effectively** with people with dementia and their caregivers and **provide services that are person- and family-centered**, offer self-direction of services, and are culturally appropriate.

4. **Educate workers** to identify possible dementia and understand the symptoms of dementia and appropriate services.

5. **Educate the public** about brain health, including information about the risk factors associated with developing dementia, first signs of cognitive problems, management of symptoms if individuals have dementia, support programs, and opportunities to participate in research.

6. Implement **quality assurance** systems that measure how effectively providers serve people with dementia and their caregivers.

7. Encourage development of **dementia-friendly communities**, which include key parts of dementia-capability.

How are ACL grantees making their states and communities dementia-capable?

Many states and communities are using ACL grant funds to put dementia-capable components into practice. This section reviews the components of a dementia-capable system and provides a snapshot of dementia-capable programs from across the United States resulting from the ACL grants.

Identification of People with Possible Dementia

Providing appropriate care to people living with dementia and their caregivers begins with service providers being able to identify people living with the condition. Individuals or caregivers might contact service providers to discuss memory problems, difficulty doing daily tasks such as managing finances or medications, or changes in behavior. Trained provider staff can recognize whether a person is describing signs of cognitive problems and refer for an accurate diagnosis.

Examples of three strategies for identifying people with possible dementia are shared: training; standard protocols for identification and referral; and partnering with programs that are most likely to connect with people who live alone with dementia (e.g., home-delivered meal providers).

> **Three Strategies for Increasing Identification of People with Possible Dementia**
> - Training
> - Standard Protocols
> - Partnerships

Training

Through an ACL grant, MaineHealth provides dementia-specific training for community-based service providers and health care professionals to identify persons with dementia more consistently, diagnose earlier, and refer patients and caregivers to specialists and supportive services in the community. The Illinois Department on Aging's grant from ACL includes the development and delivery of training to staff and volunteers in care coordination, community care, pre-admission screening, and independent service coordination. The training focuses on identifying people living alone with dementia and referring them to appropriate resources.

Standard Protocols

As part of the University of California at San Francisco's (UCSF) ACL grant, when a neurologist, advanced practice nurse, or care team navigator (CTN) encounters a dyad or person living with dementia, they are referred to the *Care Ecosystem* ⤢. The CTN conducts an intake assessment and determines immediate needs. If appropriate for the program, the CTN will continue working with the dyad or person living with dementia to develop a personalized care plan that addresses needs such as medication reconciliation and review, behavior management, safety, caregiver well-being, referrals and education, and advance care planning. CTNs provide emotional support, problem-solving, and linkages to community resources for people living with dementia and their caregivers.

Minnesota's Aging and Disability Resource Center, the Senior LinkAge Line®, adopted a protocol to identify people with dementia and caregivers of people living with dementia at initial contact. Training on dementia identification is part of the required training for all new staff including online periodic updates to reinforce learning.

The Maine Office on Aging and Disability Services developed standard protocols to identify people with dementia or a caregiver for use by NWD agencies and AAAs statewide. Data from standardized questions about memory loss were integrated into the statewide database, Social Assistance Management System and tracked for a two-part response from individuals who call or receive a AAA service and indicate concern for self or others.

- LEAD-IN STATEMENT: We receive a lot of questions about forgetfulness or memory loss, which can be a common part of aging.
- QUESTION: Do you have any concerns about your own memory or the memory of someone you care for?

As part of the ACL grant to the United Way in Tarrant County, Texas, the community partner (University of North Texas Health Science Center) provides screening and diagnostic services through their Geriatric Assessment Program and trains students and professionals who serve people with dementia. The ACL grantee in San Diego County, California, has a brief, bilingual, nonclinical Alzheimer's disease and related dementia screening tool for staff to identify people with possible dementia, and there is also a protocol to refer people for a diagnosis.

Partnerships
The United Way in Tarrant County, Texas, is working with Meals on Wheels of Tarrant County, Inc. to identify and provide services to persons living alone with dementia, especially those who have diabetes. The Meals on Wheels case managers assess clients for dementia and, when appropriate, refer them to dementia options counseling in the ADRC. The Southern Maine Agency on Aging supported an intervention that uses Meals on Wheels volunteers to identify and refer individuals living alone with dementia to care management services. Results of the intervention in Southern Maine found that 30.0% of the Meals on Wheels clients were noted to have some form of dementia or cognitive changes, and 16.6% of persons with dementia lived alone.

Program Eligibility

Publicly funded programs that support people in the community have eligibility criteria for deciding whether a person can receive home and community-based services. Eligibility criteria based on a person's ability to carry out daily activities also need to consider the cognitive ability of the person. People with dementia may be able to carry out daily activities such as bathing and dressing, but they likely need support or prompting to complete these activities. Because of the behavioral symptoms that can accompany dementia, there needs to be consideration of the need for supervision of the person with dementia to avoid harm to self or others. Dementia-capable service systems recognize that people living with dementia use more and different services than people living with physical disabilities, and people living with dementia rely on caregivers to remain in their communities.

The next sections highlight three promising approaches for acknowledging cognitive disabilities in program eligibility: health system partnerships; prioritizing hard to reach/underserved populations; and delivering community-based care coordination.

> **Promising Approaches to Address Cognitive Disabilities in Program Eligibility**
> - Health System Partnerships
> - Hard-to-Reach/Underserved Populations
> - Community-based Care Coordination

Health System Partnerships

Dementia Cal MediConnect, a project funded by ACL to the state of California in partnership with Alzheimer's Los Angeles, built on California's Financial Alignment Initiative demonstration by specifically focusing on better care coordination for people with dementia. The project engaged relevant state departments (e.g., aging, public health, Medicaid), health plans, and several community-based organizations. Dementia Cal MediConnect aimed to build the dementia-capable capacity within the health plans as they provided dementia care and partnered with the community-based Alzheimer's organizations (Cherry et al., 2017). One aspect of this project's success is that health plans are referring members to community-based Alzheimer's organizations for added education and support services. Dementia Cal MediConnect shared promising practices with federal and health industry leaders (e.g., CMS), which led to further action supporting the expansion of dementia care nationally. The California model is being replicated by another ACL grantee, the state of Texas.

With its grant from ACL, MaineHealth strengthened dementia-specific training for community-based service providers and health care professionals. MaineHealth is also

working to improve connections between the health system and community-based organizations like the AAAs and paramedicine/emergency medical technician professionals. In Minnesota, ACT on Alzheimer's sponsored two Alzheimer's Health Care Leadership Summits with the goals of (a) engaging health care systems to increase detection of Alzheimer's disease and improving ongoing care and support; and (b) sustaining caregivers by offering information, resources, and in-person support. As a result of the summits, three major health systems deepened their efforts to identify and support people with dementia and piloted the implementation of the ACT on Alzheimer's physician guidelines, spreading the guidelines systemwide through their electronic medical records system.

Hard-to-Reach/Underserved Populations

In California, *El Portal* originated as a collaboration between the state of California, Alzheimer's Los Angeles, and community-based organizations serving older Latinos. The collaborative created a dementia care network in East and Southeast Los Angeles, which are two predominantly Latino communities. This award-winning model is successful in increasing awareness about dementia in the Latino/Hispanic community and connecting families to culturally and linguistically appropriate services in their area. The El Portal model has been replicated with the African American and Asian-Pacific Islander communities in Los Angeles, and it has been implemented in other geographic regions including Puerto Rico, Seattle, New Mexico, San Diego, and the San Francisco Bay Area.

Greenville Health System implemented *GHS REACH* (Resources Enhancing Alzheimer's Caregiver Health), allowing for the expansion of nurse practitioner services for patients living with dementia and their caregivers in hard-to-reach rural areas. Wisconsin opened three new outreach offices in underserved, high-need areas (one urban African American community and two rural communities) to improve connections with the medical and social service providers serving people living with dementia.

Community-based Care Coordination

BakerRipley in Houston, Texas, provides dementia-specific case management to people living with dementia and their families with a goal of providing person-centered care that includes accurate diagnosis, medication management, support systems, and advance care planning. The program at BakerRipley combines care coordination, active management, and advocacy. Active management includes coordination of care among health professionals and lay caregivers, enabling the person to participate in meaningful

activities, opportunities to engage with others living with dementia, and to plan for the future.

The Hawaii Alzheimer's Disease Initiative is implementing the *Memory Care Navigators Program* to enhance LTSS for dementia, with a special emphasis on persons who live alone. The program has trained care coordinators, nurses, social workers, and elder care volunteers to assist their clients in accessing home and community-based support services and resources. Most recently, the project has trained state public health nurses to reach underserved, homebound, and frail adults in every community across the state.

In Kansas, community-based care coordinators were trained to provide resources and support to people living with dementia and their families. Based on this grant's success, Kansas passed legislation to address geriatric mental health and funded dementia-capable care coordinator positions across the state. The *[Virginia Collaborative Care Coordination Program](#)* uses an award-winning model of person-centered care coordination that includes a relationship between the University of Virginia's Memory and Aging Care Clinic and the Jefferson Area Board for Aging.

Effective Communication and Person-Centered Services

Model systems effectively communicate and offer information, person-centered planning, and opportunities for self-direction. Information about services and supports helps people living with dementia and their caregivers choose what they need from a variety of public and private agencies, including ADRCs, Centers for Independent Living, and AAAs. These local agencies can offer information, assistance, help with managing services, and access to publicly funded programs like Medicaid and the National Family Caregiver Support Program.

Person- and family-centered planning enables people with dementia and their caregivers to choose services that will best meet their unique needs. This approach identifies the person's strengths, goals, preferences, service needs, and desired outcomes. Model dementia-capable systems recognize and support the important role that caregivers play in helping people with dementia remain in the community by helping with decision-making about services and providing them.

AoA/ACL has supported several states and communities in efforts to ensure that staff communicate effectively with people living with dementia and their caregivers and provide services that are person- and family-centered. Between 2008 and 2018, 123 grants were funded to deliver evidence-based or evidence-informed interventions in states and communities, resulting in the implementation of 17 evidence-based and 11 evidence-informed interventions (Knowles et al., 2018). ACL grants have supported development and delivery of evidence-informed interventions; translation, expansion, and sustainability of evidence-based dementia interventions; and creation of innovative tools to support people living with dementia and caregivers. The next sections provide examples of grantee projects that encourage effective communication and person-centered dementia services.

> **Ways to Encourage Effective Communication and Person-Centered Dementia Services**
> - Evidence-informed Interventions
> - Evidence-based Interventions
> - Tools to Support People Living with Dementia
> - Innovative Approaches

Development of New Evidence-informed Interventions

Alzheimer's Los Angeles, along with an original program author, developed a three-session version of the Savvy Caregiver Program called *Savvy Caregiver Express*. Savvy Caregiver Express condenses the six 2-hour sessions into three 2-hour sessions. A recent pilot study showed that Savvy Caregiver Express attendees experienced similar outcomes to the original research study including significantly reduced depression and anxiety while improving their tolerance for challenging memory-related behavioral symptoms.

In partnership with the state of Texas, Alzheimer's Los Angeles piloted *Cuidando con Respeto*, a linguistically and culturally adapted program for Spanish-speaking family caregivers of people living with dementia. The intervention is derived from the Savvy Caregiver Program. Training components include Spanish language video vignettes, small group discussions, learning activity game and visualization/sensitivity exercises.

Savvy Advanced, a 4-week program for caregivers previously trained on Savvy Caregiver Program, was developed through a grant awarded to Maine. The program was developed as a response to Savvy Caregiver graduates requesting a "refresher" program as they experienced new caregiving challenges. Savvy Advanced, which helps caregivers refine their problem-solving and planning skills and enhance their sense of self-efficacy, is

well received and caregivers have experienced significant and sustained improvements in care competence and personal gain at 12 months (Samia et al., 2018).

RCI developed the *Dealing with Dementia* ⤴ program, which focuses on the behavioral component of the REACH II program. Using a train-the-trainer approach, family and professional caregivers attend a 4-hour workshop to learn strategies and best practices for effectively managing problem behaviors and handling caregiver stress and burnout. Participants receive a Dealing with Dementia guide with over 300 pages of information and solutions to problems caregivers face every day.

In Virginia, the *Effective Strategies Program* ⤴ is an educational and social program designed to support people living independently with dementia or cognitive impairment by teaching memory and concrete strategies. The program consists of 18 sessions over 9 weeks led by experts from a variety of fields (e.g., psychology, social work, speech therapy, occupational therapy, physical therapy, art therapy, music therapy) and education support from the Alzheimer's Association. Most participants indicated that they learned new strategies for coping with memory change and they would recommend the program to others.

In tribal communities across Minnesota, Montana, New Mexico, Oklahoma, Rhode Island, and Wisconsin, programs like Music & Memory use personalized music that is hand-selected based on individual preference. The primary aim of these programs is to increase quality of life and reduce behavioral symptoms for those living with dementia and to rekindle caregiver relationships.

Translation, Expansion, and Sustainability of Evidence-based Dementia Interventions
As a result of ACL-funded projects, delivery of some evidence-based interventions has been expanded statewide, such as Savvy Caregiver Program (California, Illinois, Michigan), BRI Care Consultation (Georgia), and New York University Caregiver Intervention (Minnesota). Additionally, the BRI Care Consultation information system software (CCIS) has been added to the list of software applications approved for implementation by any VA Medical Center in the US, which means any VA Medical Center can use the CCIS to implement BRI Care Consultation without additional administrative approvals. This eliminates a major barrier to possible future expansions of BRI Care Consultation within the VA healthcare system.

The Rosalynn Carter Institute Training Center for Excellence offers national training and certification for service providers interested in implementing BRI Care Consultation and RCI REACH along with intensive technical assistance (RCI, 2019). WellMed Charitable Foundation in San Antonio, Texas, offers national training on the Stress Busting Program for Family Caregivers (D. Billa, personal communication, June 24, 2019).

To date, the Illinois Department on Aging (IDoA) has funded delivery of the Savvy Caregiver Program statewide to over 900 caregivers. In addition to the caregivers trained via ACL-funded grant activities, thousands more have participated because of sustainability efforts from "train-the-trainer" sessions. IDoA, with community partners, sponsored train-the-trainer sessions for at least 45 organizations within the aging network and other entities who work with people with dementia and their caregivers (Roate, 2019).

The Michigan Commission on Services to the Aging approved *Creating Confident Caregivers*® as a service definition prior to the end of their ACL-funded project. Creating Confident Caregivers® is the name given to Savvy Caregiver Program in Michigan. In Michigan, Creating Confident Caregivers® is eligible for implementation using Older Americans Act Prevention and Health Promotions Services (Title III-D) and National Family Caregiver Support Program (Title III-E) funds, along with state or local caregiver funds.

Minnesota's implementation of REACH Community (aka REACH VA) activated 126 caregiver consultants across the state. With funding through Title III-E of the Older Americans Act and other sources, these caregiver consultants were certified to deliver REACH Community. This grant specifically focused on delivering REACH in the American Indian, African American, Hispanic, and Hmong communities.

In St. Louis, Memory Care Home Solutions (MCHS) and Perry County Memorial Hospital use ACL funding to provide a modified version of the evidence-based Care of People with Dementia in their Environment (COPE) to fill gaps in their established dementia-capable service system. MCHS is targeting delivery of COPE to 500 caregivers and 250 people with dementia, including persons living alone, people with moderate to severe dementia, and people aging with intellectual and developmental disabilities (IDD) and dementia. To ensure the sustainability of this work, MCHS has enrolled with CMS and commercial insurance providers to obtain reimbursement for the occupational therapy component of COPE.

Three Alzheimer's organizations in California—Alzheimer's Los Angeles, Alzheimer's Orange County and the Alzheimer's Association in Northern California— continue to offer the Savvy Caregiver Program intervention through the Aging Services Network. The organizations are sustaining the program through fee-for-service charges, private foundation grants, Older Americans Act Title III-E funds, use of volunteer trainers, and working with assisted living facilities to underwrite the costs.

Tools to Support People Living Alone with Dementia and Caregivers

The *Live Alone Dementia Safety Net Algorithm* developed by the Alzheimer's Association, Northern California and Northern Nevada Chapter, with ACL funding, provides guidance to social service providers and staff members of community-based organizations on how to provide dementia-informed care. Numerous ACL grant projects have adopted this tool for their work with individuals living alone with dementia.

The Alzheimer's Association, Northern California and Northern Nevada Chapter developed *Alone but Not Forgotten: Supporting Those Living Alone with Memory Loss*, a booklet for individuals and those who care for them. The booklet provides information on getting a diagnosis, communicating with the doctor, planning for care, legal and financial considerations, and expanding the circle of support for an individual living alone with dementia.

The Southern Maine Agency on Aging adapted the Crisis to Thriving Scale for use with people living alone with dementia. Using the new [Dementia Crisis to Thriving Scale](#), the person's level of risk is rated on several domains such as food security, in-home care, and falls risk (Southern Maine Agency on Aging, 2016).

Innovative Approaches to Barriers to Service Use

In Sarasota, Florida, Jewish Family Children's Services Suncoast coordinated and hosted a National Task Group on Intellectual Disabilities and Dementia (NTG) training to better prepare and update the project partners, the dementia-service community, and the lead agency itself on IDD and dementia practices. As a result, JFCS partnered with local IDD organizations to provide up to date education to family members who care for individuals with IDD and dementia. Topics include Alzheimer's disease and IDD, aging with intellectual disabilities, planning for the future, guardianship advocacy, residential options, and saving for the future. The grantee adjusted presentation topics to suit those caring for a person living with IDD who do not consider themselves caregivers but rather as a parent or sibling with considerable knowledge of the daily needs of the individual in their care. Beyond the

grant period, the education series is offered through the IDD community partner organizations.

Florida Atlantic University uses a nurse-led model to improve health-related quality of life to underserved or unserved populations in southeastern Florida, such as Haitian Creoles, by providing home health services by gerontological nurse practitioners. The project overcame a language barrier in providing caregiver education by working with a neuropsychologist who spoke Haitian Kreyol.

West Virginia, a primarily rural state, opened a community grant application for communities to receive funding to complete a community needs assessment to guide the development and implementation of a unique community dementia capability work plan. Ultimately, the grantee awarded 17 community grants throughout the state. Community projects included Healthy Steps, an evidence-based exercise program; Savvy Caregiver Program, an evidence-based dementia intervention; Memory Cafes; and caregiver support groups where none were before.

Educate Workers

Training dementia care providers and volunteers is important for achieving dementia capability. Information and Referral/Assistance staff, options counselors, care managers, home care providers, other professionals, and volunteers can be trained on how to recognize, understand, and meet the unique needs of people with dementia and their caregivers. This type of training is less common among direct care workers such as home care aides, home health aides, and personal care aides. The following are highlights of the work of ACL grantees who developed training programs for a range of providers, including primary care providers, dementia care managers, and caregiver consultants.

Alzheimer's Los Angeles developed a curriculum for dementia care managers and dementia care specialists that is evidence-informed and suited to dementia care managers in health plans and health care organizations. The curriculum includes a facilitator guide, slide presentation, worksheets, and manual. The *Dementia Care Management Toolkit* is available online and contains a health risk assessment, tool for identifying informal or family caregivers, best practice care plans, and caregiver tip sheets.

The Virginia Department of Aging and Rehabilitation Services developed a series of online primary care provider microlearning modules available on the AlzPossible.org

website that cover topics such as demystifying dementia, sharing the diagnosis, communication, and medication management. Microlearning is an innovative way of delivering education content in small, very specific bursts of 5-7 minutes allowing the learner to apply new knowledge and skills quickly.

Over 100 caregiver consultants and county long-term care assessors and other providers have been trained throughout Minnesota through the Board on Aging 12-hour online dementia training program that includes best practices for early detection, assessment, communication, behavior enhancement, and care coordination approaches. The Minnesota Board on Aging online training series *Cultural Awareness in Dementia Care* takes cultural competence into account, providing examples of approaches for American Indian, African American, Hispanic, Hmong, and Somali cultural communities.

Eddy Alzheimer's Services in Upstate New York developed a 3-hour classroom-based IDD and dementia training, the *Foundations of Dementia Care for Individuals with IDD*. The training uses multiple modalities, including taking a visual walk through the brain; role playing promoting positive interactions between professionals and clients; and opportunities for problem solving around responding to behavioral symptoms. The Minnesota Department of Human Services developed an online training for case managers and certified assessors, *[Serving People with Intellectual or Developmental Disabilities and Dementia](#)*, to help them understand the impact that dementia has on those who have IDD; what is different; how to best support the person, their families, and caregivers; and best practices.

The Care Ecosystem through UCSF trains neurologists and neuropsychologists to provide appropriate care for people with IDD and dementia. Providers who have experience working with this population mentor the neurologists and neuropsychologists. UCSF staff provide education on dementia to care providers from the Arc of San Francisco, a lifelong learning and achievement center for individuals with developmental disabilities in San Francisco, San Mateo, and Marin counties.

In partnership with the Alzheimer's Association, Northern California and Northern Nevada Chapter, the City of San Francisco Department of Aging and Adult Services provides training and education for Chinese community service providers and caregivers and information and referral and care consultation services for Chinese community caregivers in Cantonese or Mandarin. The program includes Savvy Caregiver Program and an annual half-day education forum for caregivers.

Educate the Public

States and communities have a role in educating the public about brain health, risk factors associated with developing dementia, first signs of cognitive problems, dementia symptom management, support programs, and opportunities to participate in research. Community education and awareness sessions, workbooks, and resource guides are a few of the public education tools created by ACL grantees that are presented in the next section.

Through an ACL project, Alzheimer's Los Angeles created *IDEA!*, a simple three-step strategy designed to assist caregivers with understanding a specific behavior with individualized approaches for addressing it. "IDEA!" stands for IDentify the problem/challenging behavior, Explore the behavior, and Adjust your response. The project also developed a series of [plain language tip sheets](#) ⬈ for caregivers that complement the IDEA! strategy on various topics related to Alzheimer's and related disorders, in English, Spanish, Japanese, and Chinese. Topics include a range of issues such as bathing, communication, driving, hallucinations, medications, sundowning, and toileting.

The Early Memory Care Initiative in Minnesota created the first workbook of its kind for newly diagnosed early stage individuals called *[TAKING ACTION: A Personal and Practical Guide for Persons with Mild Cognitive Impairment (MCI) and Early Alzheimer's Disease](#)* ⬈. The workbook covers topics like understanding memory loss, partnering with your doctor, telling others about your diagnosis, strategies for daily living, coping with changes, legal and financial planning, and various resources.

The University of Hawaii encourages advance health care planning through a collaboration with the Hawaii Hospice and Palliative Care Organization through community education and public awareness to have the conversation early and complete advance directive forms.

Seven Hills Rhode Island created *[Intellectual Disability and Dementia: A Caregiver's Resource Guide](#)* ⬈ in collaboration with the National Task Group on Intellectual Disabilities and Dementia Practices. This document provides informal and formal caregivers with the foundation to begin the conversation in planning supports for the individuals under their care. The resource includes sections on becoming a health care advocate; learning about screening, assessment, and diagnosis; learning about dementia; working with the health care provider; providing care; and caregiver tips.

Quality Assurance

In 2012, with input of ACL and grantees, the Alzheimer's Disease Supportive Services Program National Resource Center (precursor to the National Alzheimer's and Dementia Resource Center [NADRC]) developed a tool to assess the dementia capability of states' LTSS systems. This initial version included 20 questions covering three key areas of dementia capability: (1) identification of people with possible cognitive impairment or dementia and their primary caregiver; (2) staff training about cognitive impairment, dementia, and dementia care; and (3) provision of specialized services for people with a cognitive impairment or dementia and their caregivers.

The *Dementia Capability Assessment* was revised in 2017 to (1) refine the content to incorporate components of a model dementia-capable system as defined in the collaborative paper between ACL and the NADRC, *Dementia-Capable States and Communities: The Basics* (Tilly et al., 2014); and (2) ensure that the assessment tool is useful to a broad audience of dementia service providers beyond AoA/ACL grantees. The revised assessment includes questions that capture the components of a dementia-capable system.

The usefulness of a tool like the *Dementia Capability Assessment* is largely based on the degree to which the data can inform understanding and decisions about the system and specific program activities. Currently, the NADRC focuses on two types of scores for each grant program that completes an assessment:

Dementia Capability Score	Dementia Capability Improvement Score
• A static reflection of the **overall level of dementia-capability** at any given point in time. It is reported as a percentage and reflects the proportion of possible dementia-capable activities that grantees and their partners are addressing.	• This score is intended to indicate the **amount of improvement in dementia-capability** that a given grant program is making over time, in comparison to what is possible. It is calculated by considering the total improvement that is possible from one year to the next, and then looking at how much actual improvement was achieved.

AoA/ACL and the NADRC can use *Dementia Capability Assessment* results to determine areas of dementia capability most in need of attention for future grants.

Grantees may obtain their project's raw assessment data and summary scores from the NADRC, and some grantees use the results from the assessment to inform their work. For example, one grantee noted that he is "putting together a project to better identify people with memory impairment as they contact the NWD network in Virginia, starting with the AAAs. These are areas that were identified from my completing the Dementia Capability QA tool last fall" (Personal communication, G. Worthington, April 23, 2019).

Dementia-Friendly Communities

A growing number of communities in the United States are becoming dementia-friendly. A dementia-friendly community is a village, town, city, or county that is informed about dementia; is organized to be safe and respectful of individuals living with dementia, their families and caregivers; and provides physical and other supports that will maintain and foster quality of life (Alzheimer's Disease International, 2019). In a dementia-friendly community, everyone is encouraged to support and empower people living with dementia and their caregivers and include them in all aspects of community life. Dementia-friendly communities go beyond the health care and LTSS systems to bring awareness to the general population, transportation providers, utility workers, members of faith-based organizations, community social workers, and more (Lin, 2017).

A dementia-friendly community culture emerges when there is involvement by all aspects of that community:

- **Businesses and banking** by ensuring that employees are trained and procedures exist to accommodate customers with cognitive impairment.
- **Law enforcement and first responders** by ensuring that they have been trained and their approach to individuals is guided by their ability to recognize signs of dementia and to respond accordingly.
- **Health care systems** by organizing their services to promote early diagnosis and provide dementia-related care including connections with community services.
- **Area Agencies on Aging** by operating as a resource center for other providers, for family caregivers, and for people living with dementia by offering information on helpful services, training business and other professionals about community resources, and working with health care and service providers to increase their dementia awareness and problem-solving.
- **Transportation providers** by ensuring that drivers are aware of signs and symptoms of cognitive concerns, offer supportive statements about upcoming

stops, respond patiently and prompt passengers for the information that they may need to help someone who is lost or confused.

- **Faith communities** by using specialized programs, services, and accommodations to genuinely welcome people with dementia.
- **Local governments** by actively considering the needs and views of people with dementia and their caregivers in planning housing, transportation, public spaces, and emergency response systems.
- **Community members** by ensuring that they are ready to interact sensitively and create networks of support.
- **Restaurants, grocery stores, and libraries** by promoting access and supporting independence.
- **Employers** by tailoring personnel policies to support employees who are caregivers.
- **Formal services** by maximizing independence and support ongoing community engagement.
- **Physical Environments** by supporting the needs of people living with dementia by being accessible and easy to use (Lin, 2017; McCallion & Janicki, 2002).

Dementia-friendly communities work to understand, respect, and support the unique needs of people living with dementia. They are places where people with dementia live as independently as possible and are respected and supported to engage in daily activities even as they become more difficult. A dementia-friendly community supports equity, inclusion, access, and awareness (Dementia Friendly America website accessed May 2, 2019). The following are examples from ACL grantees' work to advance dementia-friendly communities.

Minnesota ACT on Alzheimer's supported the development of dementia-friendly communities statewide (ACT on Alzheimer's, 2019). Two ACT Dementia-Friendly Cultural communities funded through ACL grants (i.e., Centro Latino Collaborative, Dr. Solomon Carter Fuller Collaborative) implemented a culturally focused community outreach and education plan. Another dementia friendly community in Sibley County delivered educational sessions on Alzheimer's to the Hispanic community and explored strategies to increase cultural acceptance of services as part of the ACL grant.

Other ACL grants have also taken broad approaches to establishing dementia-friendly communities. *Dementia-Friendly Wyoming* ⤢ has developed an extensive Dementia

Friends program targeting multiple sectors including business, banking, faith-based organizations, first responders, legal professionals, and human resource professionals. Champions from within these sectors deliver presentations and encourage involvement among their peers. The project has engaged with Home Depot to develop store displays showing home modifications that can help people with dementia remain safely in their homes.

The state of Nevada established, community action groups in targeted areas throughout the state to transform the culture of dementia in those communities, enabling conversation and participation by all citizens, especially those living with dementia. An ACL grantee in North Carolina implementing a dementia friendly business initiative _Dementia Friendly Orange County_ ⬈ provided training to county government workers and people employed in commercial businesses to increase their knowledge, skills, and attitudes about dementia. Over 850 individuals representing 97 organizations received this training. These activities have been sustained through establishment of a volunteer coalition.

In 2018, a community grant from the West Virginia Bureau of Senior Services funded the establishment of a community-based coalition comprised of business leaders, organizations, and Huntington residents, _Dementia Friendly Huntington_ (DFH). DFH has trained businesses on dementia friendly practices and hosted its first restaurant day on August 7, 2019. David Nisbet, DFH founder and a business owner, explained the model in a Washington Post article, "Make eye contact, smile and don't give them seven daily specials to choose from," he said. "Maybe give them two choices." Nisbet says if a customer with dementia says something offensive, never take it personally. "There's a guy I see every week who tells me, 'You need to lose weight,'" he said. "I just smile and say, 'You know what? You're right.' You can't get your feelings hurt. Just keep talking and give them a compliment" ([Washington Post, August 5, 2019](#) ⬈). DFH plans to hold similar events one day each month for breakfast, lunch and dinner.

Because of the potential behavioral and medical issues that can arise for people with dementia, increased efforts are being made to ensure that first responders, such as police officers, firefighters, and emergency medical services, have increased dementia knowledge (Hughes et al., 2018). Alzheimer's San Diego and Alzheimer's Orange County provided 57 in-person trainings to 1,633 first responders over the course of their grant project. These trainings provided first responders with basic information about Alzheimer's disease, tips for interacting with someone living with the disease, and how to support a family member

who may be overwhelmed. As a result of the trainings, Alzheimer's San Diego has received several referrals from law enforcement for families needing additional support.

On July 12, 2019, the governor of California, Gavin Newsome, approved an act to amend Sections 1797.170, 1797.171, and 1797.172 of the Health and Safety Code, relating to emergency medical services. The bill was sponsored by Alzheimer's Orange County, Alzheimer's Los Angeles, and Alzheimer's San Diego that requires all EMT's in the state be required to take dementia capability training. The amendment reads as follows:

> *"Under existing law, the Emergency Medical Services System and the Prehospital Emergency Medical Care Personnel Act, the Emergency Medical Services Authority is responsible for establishing minimum standards and promulgating regulations for the training and scope of practice for an Emergency Medical Technician-I (EMT-I), Emergency Medical Technician-II (EMT-II), and Emergency Medical Technician-Paramedic (EMT-P). This bill would require EMT-I, EMT-II, and EMT-P standards established pursuant to the above provision to include a training component on how to interact effectively with persons with dementia and their caregivers."*
> https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201920200AB453

The *Alzheimer's Poetry Project Initiative* in Washington, DC, uses art as a communication tool for people living with dementia. The District of Columbia Department of Aging and Community Living, is training DC's Senior Service Network providers to conduct Alzheimer's Poetry Project sessions, scheduling Memory Arts Cafe Events with faith-based organizations, and developing a Poetry for Life curriculum to train middle and high school students to interact and work with persons living with dementia at a local senior day care center.

Conclusion

Ensuring that state and local service systems are dementia-capable is critical. Many who seek assistance from these systems have dementia or may have cognitive changes resulting from other conditions. Caregivers of people living with dementia regularly contact these systems seeking assistance in coping with addressing the special needs of their loved ones. AoA/ACL has taken a lead role in ensuring that systems and supports are

dementia-capable. AoA/ACL dementia grant programs support state and local initiatives to develop dementia-capable LTSS systems, which continue to increase dementia-capable services provided through the Aging Network programs (Gould & Wiener, 2017).

The model dementia-capable services and programs described in this paper identify people living with dementia, ensure that staff have special training and communication skills, and have public and private services tailored to the unique needs of those living with dementia through the use of person- and family-centered planning. Many states and communities are working toward improved dementia capability and dementia friendliness. By adopting the model system components outlined in this paper, states and communities can work to improve care and quality of life for people living with dementia and their caregivers.

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