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Dementia-Capable States and Communities: the Basics

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Dementia-capable States and Communities: the Basics

Introduction

Dementia, including Alzheimer's disease, touches almost everyone's life. People may have dementia or know or care for someone who has it. Others may fear getting it as they age. Many of us interact with people who have dementia or their families as we provide services, or meet them socially. We may not even know that a person has it.

If a person has some type of dementia, they have a loss of brain function that leads to problems in at least two areas that are severe enough to affect their daily lives. For example, a person may have memory and language problems.

People with dementia experience losses over time, which may involve cognitive problems like difficulty with learning, thinking, and remembering. People also can have physical symptoms such as difficulty walking, talking, and eating. Some dementias involve troubling behavior changes. All of these problems interfere with their normal activities and relationships and generally get worse over time. The result is dependence on others.

Certain brain diseases and conditions cause dementia. Alzheimer's disease, which is progressive and fatal, is the most common form of dementia. Alzheimer's is only one type of dementia. A few causes of dementia are reversible, such as normal pressure hydrocephalus and cerebral vasculitis.¹ Symptoms of other conditions, such as depression, delirium, alcohol misuse, and brain tumors can resemble dementia. So can the effects of certain drugs and medicine interactions.

As dementia progresses, people depend more on others for help with activities ranging from managing finances to the most personal tasks such as eating and bathing. At some point, people cannot manage their lives on their own. Caregivers, who are family or friends, generally help without pay out of a feeling of love or duty. Eventually, the demands of caring for someone with dementia may become more than caregivers can manage without help. Then, people with dementia and their families rely on paid caregivers in the home and community, or in institutions like nursing homes.

The Secretary of Health and Human Services' (HHS) leads the ***National Plan to Address Alzheimer's Disease***, which deals with many of these issues. The Plan provides a national strategy for strengthening research, medical care, and long-term services and supports for those living with dementias, including Alzheimer's disease. It contains actions for federal agencies, states, and communities related to dealing with the unique needs of people with dementia, and their families. The Plan, which the 2011 National Alzheimer's Project Act requires, has 5 goals:

1. Prevent and effectively treat Alzheimer's disease by 2025.
2. Optimize care quality and efficiency.
3. Expand supports for people with Alzheimer's disease and their families.

4. Enhance public awareness and engagement.
5. Track progress and drive improvement.

Using these goals as guidance, we discuss how states and communities can become **dementia-capable**, that is, able to help people with dementia and their caregivers. To show how this can be done, we provide examples from the United States and some other countries. We begin by explaining why dementia-capability is so important for families, their communities, states, and the nation.

The Impact of Dementia

Individuals, their families, communities, and states face a number of challenges in dealing with dementia. These include the impact of the diseases that cause dementia on individuals and families, the number of people with the condition, and the cost of care.

While dementia results from the loss of brain cells and the connections among cells, symptoms can vary by type of dementia. For example, in frontotemporal disorders, dementia symptoms can include changes in personality, behavior, language, and movement. Symptoms in the early stages of Alzheimer's disease include a declining memory and difficulty managing finances and health care. People with Alzheimer's may also have behavioral symptoms,² such as agitation and depression. Wandering away from home is a common and serious safety issue. As dementia progresses, people typically need help with bathing, dressing, eating, and other basic daily activities. In the final stages of dementia, people can barely communicate, fail to recognize family members, and need constant care. Given these losses, it is surprising that among people 71 years and older, 17 percent of people with severe dementia and 25 percent of people with moderate dementia live alone.³

In addition to relying more on family, people with dementia can lose their savings when they lose their jobs or need to pay for additional services. Another risk is that people with dementia are vulnerable to elder abuse, including financial exploitation. As a result, many people end up relying on Medicaid and other public programs to help finance their services and supports.

As dementia progresses, caregivers can experience more stress as they provide more services and supports, such as supervision and personal care.⁴ Caring for people with dementia is particularly difficult because of the way it affects abilities and behavior. Caregivers of people with dementia are more likely than caregivers of other older people to help with all daily activities, including getting out of bed, using the toilet and eating.⁵ The resulting strain causes many caregivers to have high levels of stress, become depressed, and have financial worries. These worries may come from time lost at work or even job loss as caregiving time increases.^{6 7}

Estimates of the number of people with dementia vary, but studies suggest that as many as 5 million Americans 65 years and older and about 200,000 individuals under age 65

may have the disease.⁸ Since age is a major risk factor for dementia, researchers expect that the number of people with the condition will grow as the U.S. population ages. States that use the cognitive impairment module of the Behavioral Risk Factor Surveillance System (BRFSS) from the Centers for Disease Control and Prevention can develop their own estimates of the number of people with cognitive disabilities.

Information about the BRFSS can be found at:

<http://www.cdc.gov/aging/healthybrain/surveillance.htm> .

Estimates of the number of caregivers for people with dementia vary. An analysis of the 2011 National Health and Aging Trends Survey of Medicare beneficiaries 65 years and older shows that 5.8 million caregivers are helping people who probably have dementia.⁹ The number of caregivers of people with dementia is also likely to grow with the aging of the population.

Use of Medical and Long Term Services and Supports

Dementia complicates managing medical care. Those with the condition often have other chronic diseases, such as heart disease, diabetes, and arthritis¹⁰ and are more likely to have them compared to those without dementia.¹¹ Cognitive problems can lead to poor management of other diseases and increased risk of falls.^{12 13} For example, on average, people with dementia have three times as many hospital stays and three times the average Medicare expenditure of other older people.¹⁴ Recent studies of care designed to help people with cognitive disability and their caregivers move from medical settings to home appear to better meet their needs than usual care.¹⁵

Many people who need long-term services and supports (LTSS) have cognitive problems, which often come from dementia. Fifteen percent of older adults living in the community with at least one limitation in a daily activity have a cognitive disability and the percentage increases with severity of disability.¹⁶ As a result, people with dementia form a large percentage of people using LTSS. Over 40 percent of nursing home residents have a diagnosis of dementia, most often a result of Alzheimer's disease.¹⁷ The percentage is higher among nursing home residents who are eligible for both Medicare and Medicaid. Not surprisingly, people with cognitive disabilities are high users of home and community services. Approximately 24 percent of people of all ages who receive Medicare or Medicaid-funded home health care have moderate to severe cognitive disability.¹⁸ Similarly, more than a quarter of Medicare-Medicaid dual eligibles who receive home and community-based services through Medicaid waiver programs had Alzheimer's disease or other dementias.¹⁹

The large number of people with dementia makes it a costly condition for individuals, families and the Nation. Researchers estimate that dementia care for people 70 years and older in the U.S. cost between \$159 billion and \$215 billion in 2010, depending on how informal care costs are calculated.²⁰ Costs stem from supports and services, and from loss of paid employment for caregivers, among other causes. Costs would be even higher if people under age 70 were included in these estimates.

State and Community Dementia-Capability

States and communities have many people at risk of or living with dementia. They live alone or with family and they use all service systems, public and private. People with dementia rely on their families and faith communities, grocery stores and banks, and medical, health, and LTSS, among other services. The long, slow progress of most dementias means that the needs of people with the condition and their caregivers change and become more intense over time.

Below we describe a model dementia-capable system. Given the impact of the condition on people and communities, service systems that wish to be dementia-capable should consider adopting key aspects of the model that apply to their mission. We developed this model based on two sets of information: research on dementia progression and supportive services, and an evaluation of Administration for Community Living (ACL) grantee experience in developing dementia-capable systems.

A model system would:

1. Educate the public about brain health. This would include 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.
2. 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.
3. Ensure that program eligibility and resource allocation take into account the impact of cognitive disabilities.
4. Ensure that staff communicate effectively with people with dementia and their caregivers and provide services that:
 - a. Are person and family-centered
 - b. Offer self-direction of services
 - c. Are culturally appropriate
5. Educate workers to identify possible dementia, and understand the symptoms of dementia and appropriate services.
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.

Below we elaborate on how organizations might develop those aspects of a model system that apply to their mission, work, and communities. These aspects are for discussion purposes and could be adapted to an organization or community's individual situation.

1. Educate the public

States and communities have a role in educating the public about health. There are four general categories related to education about brain health and dementia, with free federal resources available:

- a) One way to discuss the possible risk factors associated with dementia with the public is in relation to brain health. Although we do not know how to prevent Alzheimer's disease, experts say that some actions that can help us maintain cognitive abilities, such as avoiding head injury, not smoking, and getting enough sleep. Physical exercise, managing chronic diseases like diabetes and hypertension, and social and mental engagement also can promote brain health and have been linked to lower risk of Alzheimer's. HHS' *Brain Health Resource* provides current, evidence-based information and resources that can help states and communities educate people about brain health. The Resource, which is available at http://www.acl.gov/Get_Help/BrainHealth/Index.aspx, contains a consumer fact sheet, presentation slides, educator guide, and list of resources that people can use.
- b) People need to know about signs of cognitive problems and how to follow up if there is concern. If someone receives a dementia diagnosis, the person and their caregivers need information about how to manage its difficult symptoms. Free consumer-friendly information about how to cope with symptoms can be found in two places:
 1. Alzheimer's Disease Education and Referral (ADEAR) Center website: <http://www.nia.nih.gov/alzheimers>. The National Institute on Aging/NIH sponsors this site, which offers current, research-based information and publications for families, caregivers and professionals on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to Alzheimer's disease and age-related cognitive change.
 2. The National Alzheimer's Call Center, which offers advice 24 hours/7 days a week to people who have questions and need advice about dementia. The phone number is 1.800.272.3900. ACL helps support the Alzheimer's Association's operation of this service.
- c) Staff can find out about evidence-based programs that serve people with dementia and their caregivers by consulting a white paper - *Translating Innovation to Impact: Evidence-based interventions to support people with Alzheimer's disease and their Caregivers at home and in their Communities*. This paper and its related webinar describe successful interventions that help people in the early stages of dementia, family caregivers, and those who coordinate health and long term services and supports for them. These resources are available at: http://aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx.
- d) The public needs to know about opportunities to participate in research. A great deal has been learned about dementia in recent years, and scientists continue to

seek volunteers, both with and without dementia, to help test promising interventions, from medications to lifestyle and behaviors. The National Institute on Aging at NIH sponsors the Alzheimer's Disease Research and Education Centers and the Alzheimer's Disease Cooperative Study, which conduct a number of studies. Connections to these research centers and other opportunities to participate in research are available at <http://www.nia.nih.gov/alzheimers/clinical-trials>. Another resource is the Alzheimer's Association TrialMatch located at www.alz.org/trialmatch. Both websites list opportunities that come from a wide variety of research facilities and trial sites across the U.S.

2. Identify people with possible dementia

Providing appropriate care to people with dementia and their caregivers will not happen unless service providers can identify people with the condition. Individuals or caregivers may contact service providers to discuss memory problems, trouble managing finances or medical care or behavior changes. Service provider staff can learn to recognize whether a person may be describing signs of cognitive problems and refer them for an accurate diagnosis.

Aging and Disability Resource Centers and Area Agencies on Aging (AAAs), which are the local agencies that people with disabilities often contact for public services, use five general strategies for identifying people with dementia and their caregivers.

- a. Agencies (such as MinnesotaHelp.Info) add dementia-specific questions to their information gathering and assessment forms.²¹ In Missouri, AAA staff use the AD8 assessment to screen for dementia and to refer people who appear to have problems to the Alzheimer's Association.²² In Washington State, AAAs use the TCARE[®] tool in their Family Caregiver Support Program to provide reliable screening and assessment, identify high-risk caregivers, ensure that available resources go to those most in need, and to determine whether services make a measurable difference to caregivers.²³
- b. Staff at local agencies receive training to recognize possible cognitive impairment in their conversations with callers and in other interactions and about how various ethnic groups regard dementia.²⁴
- c. Agencies, such as AAAs, create processes for referral of people with possible cognitive impairment for professional assessment.
- d. Agencies partner with organizations specializing in dementia. For example, staff of the local chapter of the Alzheimer's Association spend one day per month at the Aging and Disability Resource Center in Racine, Wisconsin, providing training for its staff and information and referral for callers and walk-in clients.²⁵
- e. Practitioners who see people concerned about cognitive problems need to understand the possible signs of dementia, which can be found at the following website: <http://www.nia.nih.gov/research/dn/alzheimers-diagnostic-guidelines>. If necessary, practitioners must be able to assess a person's cognition or refer them to a physician who can. There are many brief cognitive screening tools available to identify cognitive problems. The NIA provides a searchable database of them at <http://www.nia.nih.gov/research/cognitive-instrument>. The Alzheimer's

Association asked medical experts for their recommendations for screening tools for use in primary care. These can be found at <http://download.journals.elsevierhealth.com/pdfs/journals/1552-5260/PIIS1552526012025010.pdf> . In addition, ACL sponsored an assessment of cognitive screening tools that non-medical staff can use. This assessment can be found at http://www.adrc-tae.acl.gov/tiki-download_file.php?fileId=33535 .

If an assessment shows that a person has cognitive problems, it is important to find out the cause. A few causes of dementia are reversible and some other conditions can resemble it. In addition, while Alzheimer's disease is responsible for 60 to 80 percent of dementia, there are other diseases that cause dementia, like Parkinson's disease, Lewy body disease, and frontotemporal dementia. The Department of Health & Human Services (HHS) offers a free educational program on this topic for practitioners available through Medscape that provides continuing education units for those who complete it. This program is called *Case Challenges in Early Alzheimer's Disease*, which is available after a free registration at www.medscape.com .

3. Ensure Appropriate Eligibility Criteria and Resource Allocation

Most public programs offering home and community services have criteria for deciding whether a person can receive them. Those programs with eligibility criteria based on a person's ability to carry out daily activities need to take into account cognition. People with dementia may be physically able to carry out daily activities, but still need prompting to complete them. The behavioral symptoms that many people with dementia experience may mean that they need supervision to avoid being a danger to themselves or others.

A 2006 examination of Medicaid nursing home level-of-care criteria in six states found that some states weighted "hands-on" assistance more heavily than prompting even if the service time exceeded that for people with physical disabilities only.²⁶ In addition, state eligibility criteria sometimes do not include the need for supervision due to behavioral symptoms or poor judgment. Medicaid eligibility criteria that accurately measure the needs of people with dementia can promote equitable access to publicly-funded home and community services.

Measuring cognitive ability is less standard than measurement of the physical ability to carry out daily activities. There are dozens of measures of cognitive impairment.²⁷ Studies find that one of the most widely used measures - the Mini-Mental Status Examination (MMSE) – has scores that are unrelated to the disability or service needs of people with dementia.²⁸ One approach that states use is to recognize that if a person needs prompting or supervision when carrying out daily activities, that person has a disability. For example, the Virginia Department of Health, Office of Licensure and Certification has guidelines on assessing activities of daily living that do this. They can be found at:

<http://www.vdh.state.va.us/OLC/Laws/documents/HomeCare/ADLs%20for%20HCOs.pdf>

Model dementia-capable service systems recognize that 1) people with dementia use more and different services than people with physical disabilities and 2) rely on caregivers to remain in their communities. Research using data from the Health and Retirement Study found that older people with cognitive disabilities who needed help with daily activities used twice as many hours of paid care on average as people who had physical disabilities only.²⁹ People with dementia often need constant supervision and special services due to memory and behavior symptoms. Some states have accommodated these needs. For example, in Tennessee, an Alzheimer's Disease Supportive Services Program (ADSSP) grantee found that partnering with adult day care centers enabled caregivers to participate in training because respite was available.³⁰ Massachusetts' Home Care program staff identified four services of particular value for people with Alzheimer's disease and related disorders: Alzheimer's Day Care, Supportive Home Care Aides,³¹ habilitation therapy,³² and occupational therapy.³³

4. Ensure effective communication and person and family-centered services

Model systems offer information, person-centered planning and opportunities for self-direction and address cultural differences. Information about services and supports helps people with dementia and their caregivers choose what they need. Information can be made available in several ways. People with dementia and their caregivers can get help in choosing services from a variety of public and private agencies, including Aging and Disability Resource Centers 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. Some states create websites with relevant information. For example, the Alabama Department of Mental Health and Mental Retardation sponsors a website (<http://alzbrain.org>) that provides information for caregivers, professionals, and people with memory loss.³⁴ Virginia's Alzheimer's Disease and Related Disorders Commission has a virtual Alzheimer's disease center (<http://www.alzpossible.org>) that offers information about the disease.³⁵

Person and family-centered planning enables beneficiaries and their caregivers to choose services that will best meet their unique needs. Person-centered planning is a process that the person with disabilities directs. This approach identifies the person's strengths, goals, preferences, service needs, and desired outcomes. Staff, family, and other multidisciplinary team members help the person to identify and access a unique mix of paid and unpaid services to meet their needs. The best person-centered planning helps people live better lives, with support to do the things most important to them.

Section 2402(a) of the Affordable Care Act requires the Secretary of HHS to help ensure that all states develop home and community care systems that respond to the changing needs of beneficiaries, maximize independence, and support self-direction. The Secretary recently offered guidance on person-centered planning and self-direction, which can be found at: <http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf>. The Secretary's guidance also has standards for self-direction. Self-direction allows a person to control services and choose providers, which may include

family or friends. It may allow the person to purchase goods and supports that traditional systems fail to offer.

People with dementia can participate in self-directed programs, often with the support of representatives. Despite the challenges people with dementia face, people with mild to moderate dementia are able to show preferences for their care. A study of 51 pairs of older adults with their caregivers living in the community found that individuals with mild to moderate cognitive disability were able to respond to questions about preferences for care and their involvement in making decisions consistently over time.³⁶ Almost all people with mild to moderate cognitive disability were able to identify someone they wished to make health and personal care decisions for them.³⁷ Almost three quarters of these individuals named their primary family caregiver as the person who should be making these decisions and most individuals preferred help from family and friends. Although people who do not have severe dementia can express preferences, they generally are not able to manage care on their own because of losses in decision-making ability and other cognitive problems. As a result, having the assistance of a representative who can act on behalf of the person with dementia is important.³⁸

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. States may offer caregiver training and education as a distinct service under a Medicaid home and community-based services waiver. Covered services may include home-based training, special classes and workshops, and arranging for substitute services when caregivers are learning outside the home. Medicaid rehabilitation services may cover caregiver training. In Kentucky, for example, rehabilitation covers home visits to assist family members and beneficiaries with serious mental health conditions to practice effective communication to cope better with stressful situations that occur at home.³⁹ Self-directed service budgets generally permit expenditures for caregiver training and education.

Model dementia-capable systems also recognize and accommodate the cultural aspects of care, particularly since certain racial and ethnic groups have a higher risk of getting dementia and cultural aspects of dementia vary. For example, older African-Americans are about twice as likely to have Alzheimer's and other dementias as older whites⁴⁰ and Hispanics are about 1 1/2 times as likely to have Alzheimer's and other dementias as older whites.⁴¹ These groups tend to have different symptoms of dementia than whites.⁴² In addition, African Americans and Hispanics often have more than one generation living together⁴³ and faith communities are particularly important to them.⁴⁴ Cultural attitudes toward dementia also vary. Hispanics tend to see dementia as a natural part of aging⁴⁵ and many Asian communities tend to view dementia as something to hide from others.⁴⁶ Finally, lesbian, gay, bisexual, and transgender groups may experience poor treatment from families, faith communities, and certain parts of society. In addition, these groups can experience limitations on their ability to marry, which can complicate their care.⁴⁷

Resources are available related to help meet the varying needs of diverse groups. Please see: *Serving Diverse Communities: A Self-Assessment of Alzheimer's Disease Services Provided by the Aging Network and Its Partners* at www.adrc-tae.acl.gov/tiki-download_file.php?fileId=33539 for further information about dementia capability related to cultural issues and a tool to assess an organization's cultural dementia capability related to the communities they serve. There is a companion document that provides resources for those interested in improving their services to diverse communities - *Serving Diverse Populations with Alzheimer's Disease and Related Dementias: A Resource List* at http://www.adrc-tae.acl.gov/tiki-download_file.php?fileId=33540 .

People with certain intellectual disabilities, like Down syndrome, have higher rates of dementia. Six percent of adults with an intellectual disability will have dementia after the age of 60. At least 50 percent of those with Down syndrome will have it after the age of 60.⁴⁸ Two groups have addressed the special concerns of those with intellectual disabilities who have grown up and acquired community living skills but find that their skills deteriorate as dementia progresses. Resources, like an aging and Down syndrome guidebook, from the National Down Syndrome Society can be found at <http://www.ndss.org/Resources/Aging-Matters/Alzheimers-Disease> . The National Task Group on Intellectual Disabilities and Dementia Practice at <http://aadmd.org/ntg> has a number of resources ranging from recommendations for assessment to opportunities to join workgroups on health care practice.

5. Worker Training

Staff who provide health and long term services and supports to people with dementia need special training due to the unique needs of this group and their caregivers. However, dementia training is uncommon among direct care workers. Federal regulations require 75 hours of overall training for home health aides and certified nursing assistants. While there is no national rule for training for personal care aides, many states have varying training requirements for them.⁴⁹ The Institute of Medicine, in *Retooling for an Aging America* (2008), called for raising the minimum training standards for home health aides and certified nursing assistants to at least 120 hours and to consider minimum training standards for personal care aides.

Several sections of the Affordable Care Act address training direct care workers to serve people with dementia. Section 5305 of the Affordable Care Act authorizes \$10.8 million in grants to geriatric education centers to offer training courses to family caregivers and direct care providers at minimal cost that incorporate mental health and dementia "best practices" training into their courses. Section 6121 of the Affordable Care Act requires CMS to ensure that nurse aides receive regular training on how to care for residents with dementia and on preventing abuse. The Centers for Medicare and Medicaid Services and its team of experts created the *Hand-in-Hand* training, which is based on person-centered care, to address this requirement. The training, along with other tools and resources, is offered free to all nursing homes, regional offices and state survey agencies and is available at <https://www.cms.gov/Medicare/Provider-Enrollment->

[and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-12-44.pdf](#) .

Several states have developed dementia training programs for direct care workers. For example, Washington developed a comprehensive training program on dementia for service providers, which covers the basics of dementia, communication, behaviors, and providing assistance with daily activities. Massachusetts developed new standards for provider training and qualifications, hired a dementia trainer, and provided special training for Supportive Home Care Aides who specialize in serving people with dementia.⁵⁰ In Alabama, the Dementia Education and Training Act provides for training of caregivers and agencies about dementia.⁵¹ Because of the high turnover among LTSS workers, training needs are ongoing and many of the workers who are trained in a given year may leave the field a few years later.⁵²

State grantees in collaboration with ACL produced a toolkit for those interested in dementia-capability that includes links to trainings, knowledge tests, staff competencies, and information on state dementia training policies and state Alzheimer's disease plan recommendations. The toolkit can be found at:

http://aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/docs/Staff-Training-Toolkit_September_2013.pdf

6. Quality Assurance

Improvements in dementia capability may result in better quality care because staff become knowledgeable about the special needs of people with dementia and their caregivers. Quality assurance could have at least three components. First, quality measures would assess whether the LTSS system and individual providers are dementia-capable. Second, systematic and regular measurement of the experience of people with dementia and their caregivers would provide an assessment of how the service system is working from their perspectives. Third, a process of continuous quality improvement would feedback information about dementia service quality which could be used to continue to improve services. This implies that the measures are tracked over time so that comparisons in performance can be made. A special learning collaborative with ACL grantees developed a set of measures of a system's dementia capability related to LTSS. States using this set of measures will be able to track their progress in improving dementia capability. The measures can be found at

http://aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/docs/Learning_Collaborative_Quality_Assurance_Tool-FINAL.pdf

7. Dementia Friendly Communities

Certain communities in Europe and the U.S. are becoming dementia-friendly. In these communities, residents, agencies, businesses and service providers are learning about dementia through education and awareness efforts, and providing assistance to people with the condition and their caregivers as they go about their daily lives.

These efforts go beyond developing dementia-capable health and long term services and supports. Dementia friendly communities involve improved customer service at

participating agencies and businesses, supportive faith or spiritual communities, emergency services that understand dementia, and suitable transportation and public spaces. One of the leading organizations promoting dementia-friendly communities in the U.S. is Minnesota's *ACT on Alzheimer's*, which involves over 50 partners. Its website – www.ACTonALZ.org has a number of tools to help communities explore how they might become dementia-friendly. The Alzheimer's Society in the United Kingdom has resources available about communities across the country at http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1843 and <https://dementiafriends.org.uk>. Communities in other European countries are becoming dementia-friendly.

Conclusions

Ensuring that state and local service systems are dementia-capable and friendly is critical. Many who seek assistance from these systems have dementia or may have cognitive disabilities resulting from other conditions. In addition, caregivers of people with dementia regularly contact these systems seeking assistance in coping with their loved ones' special needs. These needs relate to ever more dependence on others for help with daily activities, short-term memory loss, impaired decision-making capacity, and behavioral symptoms. The types of supports that people with dementia and their caregivers use include assistance with planning for service needs, identifying dementia-capable services, counseling about service options, and home and community services providers who understand dementia.

The model dementia-capable and dementia-friendly systems we describe identify those with dementia who contact them, ensure staff have special training and communication skills, and have public and private services tailored to the unique needs of those coping with dementia through the use of person and family-centered planning. To promote optimum quality of services, self-direction is a viable option for those with dementia and their caregivers and the quality assurance system measures progress toward dementia capability. A number of states have begun working toward dementia capability, and others are well along the path. And, many communities are becoming dementia-friendly by adopting key aspects of dementia-capability in public and private sector agencies and businesses. By taking these actions, states and communities can work to improve care and quality of life for people with dementia and their caregivers, who are among our most vulnerable citizens.

Endnotes

- ¹ National Institutes of Health .(2013). *The Dementias Hope through Research*. Bethesda, MD. National Institutes of Health.
- ² Alzheimer's Association. (2011). *2011 Alzheimer's disease facts and figures*. Chicago, IL: Alzheimer's Association.
- ³ Okura, T., Plassman, B. L., Steffens, D. C., Llewellyn, D. L., Potter, G. G., & Langa, K. M. (2011). Neuropsychiatric symptoms and the risk of institutionalization and death: The aging, demographics, and memory study. *Journal of the American Geriatrics Society*, 59, 473–481.
- ⁴ Alzheimer's Association. (2011). *2011 Alzheimer's disease facts and figures*. Chicago, IL: Alzheimer's Association.
- ⁵ Unpublished data from a 2009 National Alliance for Caregiving/AARP survey; data were prepared for the Alzheimer's Association under contract with Matthew Greenwald and Associates, 2009; and Alzheimer's Association. (2011). *2011 Alzheimer's disease facts and figures*. Chicago, IL: Alzheimer's Association.
- ⁶ Alzheimer's Association. (2010). *Women and Alzheimer's Poll*. Chicago, IL: Alzheimer's Association.
- ⁷ Yaffe, K., Fox, P., Newcomer, R., Sands, L., Lindquist, K. et al. (2002). Patient and caregiver characteristics and nursing home placement in patients with dementia. *Journal of the American Medical Association*, 287, 2090–2094; Taylor, D. H., Ezell, M., Kuchibhatia, M., Ostbye, T., & Clipp, E. C. (2008). Identifying the trajectories of depressive symptoms for women caring for their husbands with dementia. *Journal of the American Geriatrics Society*, 56(2), 322–327.
- ⁸ Herbert, L. E., Weuve, J., Scherr, P. A., Evans, D. A., (2013). Alzheimer disease in the United States (2010-20150) estimated using the 2010 Census. *Neurology*, 2013;80(19), 1178–1783. Cited in Alzheimer's Association. (2014). *2014 Alzheimer's disease facts and figures*. Chicago, IL: Alzheimer's Association.
- ⁹ Spillman, B.C. & Kasper, J.D., *Dementia and Informal Caregiving Analyses of the National Study of Caregiving*, presentation before the National Advisory Council on Alzheimer's Disease, Care and Services, July 21, 2014.
- ¹⁰ Bynum, J. (2009). *Characteristics, costs and health service use for Medicare beneficiaries with a dementia diagnosis: Report 1: Medicare current beneficiary survey*. Dartmouth, NH: Dartmouth Institute for Health Policy and Clinical Care, Center for Health Policy Research.
- ¹¹ Fields, S. D., MacKenzie, C. R., Charlson, M. E., & Sax, F. L. (1986). Cognitive impairment. Can it predict the course of hospitalized patients? *Journal of the American Geriatric Society*, 34(8), 579–585; Gutterman, E. M., Markowitz, J. S., Lewis, B., & Fillit, H. (1999). Cost of Alzheimer's disease and related dementia in managed-Medicare. *Journal of the American Geriatric Society*, 47(9), 1065–1071; Hill, J. W., Futterman, R., Dutttagupta, S., Mastey, V., Lloyd, J. R., & Fillit, H. (2002). Alzheimer's disease and related dementias increase costs of comorbidities in managed Medicare. *Neurology*, 58(1), 62–70; Lyketsos, C. G., Sheppard, J. M., & Rabins, P. V. (2000). Dementia in elderly people in a general hospital. *American Journal of Psychiatry*, 157(5), 704–707; and McCormick, W. C., Hardy, J., Kukull, W. A., Bowen, J. D., Teri, L., Zitzer, S., et al. (2001). Healthcare utilization and costs in managed care patients with Alzheimer's disease during the last few years of life. *Journal of the American Geriatric Society*, 49(9), 1156–1160.
- ¹² Doraiswamy, P. M., Leon, J., Cummings, J. L., Marin, D., & Neumann, P. J. (2002). Prevalence and impact of medical comorbidity in Alzheimer's disease. *Journal of Gerontology A Biological Sciences Medical Sciences*, 57(3), M173–177; McCormick, W. C., Kukull, W. A., van Belle, G., Bowen, J. D., Teri, L., & Larson, E. B. (1994). Symptom patterns and comorbidity in the early stages of Alzheimer's disease. *Journal of the American Geriatrics Society*, 42(5), 517–521; Sloan, F. A., Trogdon, J. G., Curtis, L. H., & Schulman, K. A. (2004). The effect of dementia on outcomes and process of care for Medicare beneficiaries admitted with acute myocardial infarction. *Journal of the American Geriatrics Society*, 52(2), 173–181; and Sullivan-Marx, E. M. (1994). Delirium and physical restraint in the hospitalized elderly. *Image Journal of Nursing Scholarship*, 26(4), 295–300.
- ¹³ Tilly, J., Riggs, J., Maslow, K., & Brown, K. (2006). *Medicaid managed long-term care for people with Alzheimer's disease and other dementias*. Washington, DC: The Alzheimer's Association.
- ¹⁴ Bynum, J. (2009). *Characteristics, costs and health service use for Medicare beneficiaries with a dementia diagnosis: Report 1: Medicare current beneficiary survey*. Dartmouth, NH: Dartmouth Institute

for Health Policy and Clinical Care, Center for Health Policy Research. Feng, Z., Coots, L.A., Kaganova, Y., and Wiener, J.M. (2014). Hospital and ED use among Medicare beneficiaries with dementia varies by setting and proximity to death. *Health Affairs*, 33(4): 683-690; Feng, Z., Coots, L. A., Kaganova, Y. M., & Wiener, J. M. (2013, August). *Hospital and emergency department use by people with Alzheimer's disease and related disorders: Final report*. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services. Available from: <http://aspe.hhs.gov/daltcp/reports/2013/addrhdhed.shtml>.

¹⁵ Naylor, M. D., Stephens, C., Bowles, K. H., & Bixby, M. B. (2005). Cognitively impaired older adults: From hospital to home. *American Journal of Nursing*, 105(2), 52–61; Naylor, M. D., Hirschman, K. B., Bowles, K. H., Bixby, M. B., Konick-McMahan, J., & Stephens, C. (2007). Care coordination for cognitively impaired older adults and their carers. *Home Health Services Quarterly*, 26(4), 57–78.

¹⁶ Johnson, R. W., & Wiener, J. M. (2006). *A profile of frail older Americans and Their carers*. Washington, DC: The Urban Institute. Available at http://www.urban.org/UploadedPDF/311284_older_americans.pdf.

¹⁷ Bernstein, A. B., & Resmburg, R. E. (2007). Estimated prevalence of people with cognitive impairment: Results from nationally representative community and institutional surveys. *Gerontologist*, 47(3). 350–354.

¹⁸ U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. (No date). Unpublished data from rollup summary reports, case mix means and episode counts, national values for the 12-month period from March 2003–February 2004, Baltimore MD.

¹⁹ Walsh, E. G., Freiman, M., Haber, S., Bragg, A., Ouslander, J., & Wiener, J. M. (2010). *Cost drivers for dually eligible beneficiaries: Potentially avoidable hospitalizations from nursing facility, skilled nursing facility, and home and community-based services waiver programs: Final task 2 report*. Waltham, MA: RTI International. Available at <https://www.cms.gov/reports/downloads/costdriverstask2.pdf>.

²⁰ Hurd et al., "Monetary Costs of Dementia in the United States," *New England Journal of Medicine* (368);14: 1326 org April 4, 2013.

²¹ Brown, D., & Wiener, J. M. (2007). *Alzheimer's Disease Demonstration Grants to States: Minnesota*. Research Triangle Park: RTI International. Available at http://www.aoa.gov/AoA_Programs/HPW/Alz_Grants/docs/Minnesota_CaseStudy.pdf.

²² G. Meachum-Cain, Aging Program Specialist, Missouri Department of Health and Senior Services, personal communication, June 15, 2011

²³ Korte, L. (2011). *Washington state dementia partnerships project: Final report*. Olympia, WA: Washington Department of Social and Health Services.

²⁴ Grey, H., Jimenez, D. E., Cucciare, M. A., Tong, H-Q., & Gallagher-Thompson, D. (2009). Ethnic differences in beliefs regarding Alzheimer disease among dementia family carers. *American Journal of Geriatric Psychiatry*, 17(11), 925–933; Wiener, J. M., & Mitchell, N. (2007). *Alzheimer's Disease Demonstration Grants to States Program: Cross-state report on initiatives targeting limited-English-speaking populations and African American communities*. Washington, DC: RTI International. Available at http://www.alz.org/national/documents/aoagrnt_cs_crossstate_07.pdf.

²⁵ K. Scheel, Program Director, Alzheimer's Association, Southeastern WI chapter, personal communication, October 4, 2011

²⁶ O'Keeffe, J., Tilly, J., & Lucas, C., (2006). *Medicaid eligibility criteria for long-term care services: Access for people with Alzheimer's disease and other dementias*. Chicago, IL: Alzheimer's Association.

²⁷ For a small selection of available measures, see: Galvin, J. E., Roe, C. M., Powlishta, K. K. et al. (2005). The AD8: A brief informant interview to detect dementia. *Neurology*, 65, 559–564; Clark, C. M., & Ewbank, D. C. (1996). Performance of the Dementia Severity Rating Scale: A caregiver questionnaire for rating severity in Alzheimer disease. *Alzheimer Disease and Associated Disorders*, 10(1), 31–39; Hill, J., McVay, J. M., Walter-Ginzburg, A., et al. (2005). Validation of a brief screen for cognitive impairment (BSCI) administered by telephone for use in the medicare population. *Disease Management*, 8, 223–234; Nishiwaki, Y., Breeze, E., Smeeth, L., Bulpitt, C. J, Peters, R., & Fletcher, A. E. (2004). Validity of the Clock-Drawing Test as a screening tool for cognitive impairment in the elderly. *American Journal of Epidemiology*, 160, 797–807; Mitchell, A. J. (2009). A meta-analysis of the accuracy of the mini-mental state examination in the detection of dementia and mild cognitive impairment. *Journal of Psychiatric Research*, 43, 411–431; Brigidi, B. D., Achenbach, T. M., Dumenci, L., & Newhouse, P. A. (2010). Broad spectrum assessment of psychopathology and adaptive functioning with the Older Adult Behavior

Checklist: A validation and diagnostic discrimination study. *International Journal of Geriatric Psychiatry*, 25, 1177–1185.

²⁸ Royall, D. R. (1994). Precise of executive dyscontrol as a cause of problem behavior in dementia. *Experimental Aging Research*, 20(2), 73–94; Nelson, A., Fogel, B., & Faust, D. (1986). Bedside screening instruments: A critical assessment. *The Journal of Nervous and Mental Disease*, 174(2), 73–83; Royall, D. R. (1997). Use of the mini-mental status examination to categorize dementia. *Nursing Home Medicine*, 5(11), 11A–13A. Letter to the editor.; Royall, D. R., Mahurin, R. K., & Gray, K. F. (1992). Bedside assessment of executive cognitive impairment: The Executive Interview. *Journal of the American Geriatric Society*, 40, 1221–1226; Fogel, B., Brock, D., Goldscheider, F., & Royall, D. (1994). *Cognitive dysfunction and the need for long-term care: Implications for public policy*. Washington, DC: AARP Public Policy Institute.

²⁹ Johnson, R. W., & Wiener, J. M. (2006). *A profile of frail older Americans and their carers*. Washington, DC: The Urban Institute.

³⁰ Gould, E., Hughes, S., O’Keeffe, C. and Wiener, J. *The Alzheimer’s Disease Supportive Services Program: Report on Completed Grants*. Prepared by the ADSSP National Resource Center for the U.S. Administration on Aging at the Administration for Community Living, September 2014.

³¹ Supportive Home Care Aides (SHCAs) provide personal care or homemaking services by workers who have received specialized training and are better able to provide emotional support and socialization for consumers with ADRD or emotional or behavioral problems. SHCAs also receive enhanced supervision and support, which increases the cost of this service above usual rates for personal care and homemaker.

³² Habilitation therapy for people with ADRD, developed by Dr. Paul Raia of the Alzheimer’s Association, Massachusetts Chapter, is a service that provides education and support to the caregiver and suggestions modifications to the home environment to mitigate the disabilities of the disease.

³³ J. Quirk, Director of Home and Community-Based Programs, Massachusetts Executive Office of Elder Affairs, personal communication, August 11, 2011

³⁴ J. Miller, Programs Chief, Alabama Department of Senior Services, personal communication, July 8, 2011.

³⁵ J. Hoyle, Policy Analyst, Virginia Department on Aging, personal communication, May 31, 2011.

³⁶ Friss Feinberg, L., & Whitlatch, C. J. (2001). Are people with cognitive impairment able to state consistent choices? *The Gerontologist*, 41(3), 374–382.

³⁷ Friss Feinberg, L., & Whitlatch, C. J. (2002). Decision-making for people with cognitive impairment and their family carers. *American Journal of Alzheimer’s Disease and Other Dementias*, 17(4), 237–244.

³⁸ Tilly, 2007.

³⁹ O’Keeffe, J., Saucier, P., Jackson, B., Cooper, R., McKenney, E., Crisp, S., & Moseley, C. (2010). *Understanding home and community-based services: A primer*. Research Triangle Park, NC: RTI International. Available at <http://aspe.hhs.gov/daltcp/reports/2010/primer10.pdf>.

⁴⁰ Potter GG, Plassman BL, Burke JR, Kabeto MU, Langa KM, Llewellyn DJ, et al. Cognitive performance and informant reports in the diagnosis of cognitive impairment and dementia in African Americans and whites. *Alzheimers & Dementia* 2009;5(6):445–53.

⁴¹ Gurland BJ, Wilder DE, Lantigua R, Stern Y, Chen J, Killeffer EH, et al. Rates of dementia in three ethnorracial groups. *International Journal of Geriatric Psychiatry* 1999;14(6):481–93.

⁴² Sink, K. M., Covinsky, K. E., Newcomer, R., & Yaffe, K. (2004). Ethnic differences in the prevalence and pattern of dementia-related behaviors. *Journal of the American Geriatric Society*, 52(8), 1277–1283

⁴³ Alzheimer’s Association (2006). *Lighting the path for people with Alzheimer’s: A guide for African American clergy*. Chicago, IL. Retrieved June 24, 2013 from http://www.alz.org/national/documents/aa_brochure_clergy.pdf. Napoles, A. M., Chadiha, L., Eversley, R., & Moreno-John, G. (2010). Developing culturally sensitive dementia caregiver interventions: Are we there yet? *American Journal of Alzheimer’s Disease and Other Dementias*, 25(5), 389–406.

⁴⁴ Eiser, A. R., & Ellis, G. (2010). Cultural competence and the African American experience with health care: The case for specific content in cross-cultural education. *Academic Medicine*, 82(2), 176–183.

National Alliance for Hispanic Health. (2006). *Alzheimer’s disease: Outreach to the Hispanic community*. Washington, DC. Retrieved July 15, 2013 from <http://www.hispanichealth.org/assets/pdf/ALZReport.pdf>.

⁴⁵ Gray, H. L., Jimenez, D. E., Cucciare, M. A., Tong, H. Q., & Gallagher-Thompson, D. (2009). Ethnic differences in beliefs regarding Alzheimer disease among dementia family caregivers. *American Journal of Geriatric Psychiatry*, 17(11), 925-933

⁴⁶Ethnic Elders Care Network. (2013). *Chinese Americans and dementia*. Retrieved July 11, 2013 from <http://ethnicelderscare.net/dementia/chinese-america-and-dementia/>.

⁴⁷ National Resource Center on LGBT Aging. (2013). *Inclusive questions for older adults*. New York. Retrieved July 30, 2013 from

http://www.lgbtagingcenter.org/resources/pdfs/InclusiveQuestionsOlder%20Adults_Guidebook.pdf

⁴⁸ My Thinker's Not Working . (2012). Retrieved July 29, 2014, from http://aadmd.org/sites/default/files/NTG_Thinker_Report.pdf.

⁴⁹ Institute of Medicine. (2008). *Retooling for an aging America: Building the health care workforce*. Washington, DC: National Academy of Sciences.

⁵⁰ J. Quirk, Director of Home and Community-Based programs, Massachusetts Executive Office of Elder Affairs, personal communication, August 11, 2011

⁵¹ J. Miller, Programs Chief, Alabama Department of Senior Services, personal communication, July 8, 2011)

⁵²Konrad, T. R., Morgan, J. C., & Ribas, V. (2007). *Active and inactive workers on the North Carolina Nurse Aide I Registry: A wage and employment profile*. Chapel Hill, NC: North Carolina Institute on Aging, University of North Carolina at Chapel Hill; and Konrad, T. R., Morgan, J. C., & Green-Royster, T. (2011). *North Carolina Long-Term Care Workforce Turnover Survey: Descriptive results, 2010*. Chapel Hill, NC: North Carolina Institute on Aging, University of North Carolina at Chapel Hill.