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Dementia Capability Toolkit

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Dementia Capability Toolkit

States serve a substantial number of people with dementia and their family caregivers living in the community through their Aging Networks and long-term services and supports (LTSS) systems. Serving this community-based population effectively involves accommodating the needs of a population that, in addition to memory loss, experiences a variety of physical, cognitive, and behavioral symptoms resulting from dementia, along with other medical conditions. In model dementia-capable systems, programs are tailored to the unique needs of people with Alzheimer’s disease or other dementias, and their caregivers:

- Information and assistance services have a method to identify people with dementia. Individuals with possible dementia receive a recommendation for follow-up with a physician.
- Options counseling staff communicate effectively with persons with dementia and their family caregivers and know what services this population is likely to need.
- Eligibility criteria and resource allocation take into account the impact of dementia on the need for services.
- Publicly and privately financed services are capable of meeting the unique needs of persons with dementia and their caregivers.
- Self-directed services ensure that persons with dementia and their caregivers are supported in their decision-making and involve others who can represent the person’s best interest when necessary.
- Workers who interact with persons with dementia and their caregivers have appropriate training in identifying a possible dementia in persons that they serve, the symptoms of Alzheimer’s disease and other dementias, the likely illness trajectory, and services needed.
- Quality assurance systems measure how effectively individual providers, the Aging Network, and LTSS systems serve persons with dementia and their family caregivers.

This toolkit complements the issue brief titled *Making the Long-Term Services and Supports System Work for People With Dementia and Their Caregivers* by identifying resources that states and communities can use to design initiatives to ensure that programs are dementia-capable.

**Prevalence and Impact of Dementia**

A substantial number of people have a cognitive impairment related to dementia. A definitive diagnosis of Alzheimer’s disease and other dementias is difficult, so national estimates of the number of people with dementia vary, ranging from about 3 million people over the age of 65 in the period 1999 to 2001 to 5.4 million Americans of all ages having Alzheimer’s disease in 2011. When assessing the needs of persons with dementia and caregivers in the community, it is important to understand the number of persons affected and their unique needs for services and programs. This section includes resources that provide national and state-by-state information addressing the prevalence and impact of dementia.

1. Tools for understanding prevalence
   a. *Alzheimer’s Disease Facts and Figures*, Alzheimer’s Association (2011)—A statistical resource that is published annually for United States data related to
Alzheimer’s disease and other dementias.  

   i. Estimated Prevalence and Economic Value of Family Caregiving By State
      —A state-by-state analysis of family caregivers, hours of caregiving
      provided, and an estimated market value calculated by the Family Care
      Alliance and the National Family Caregivers Association.  
      http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1805
   ii. State Profiles—State profiles provide background characteristics related to
        caregiving, long-term services and supports spending, information on
        persons receiving care, state system of home and community-based
        services, state program information, and information on consumer-
        directed care options.  
      http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1789

2. Tools for learning about the impact of Alzheimer’s disease and its effects on the
   individual and the family
   a. Understanding Stages and Symptoms of Alzheimer’s Disease, National Institute
      on Aging. Addresses common changes in mild, moderate, and severe Alzheimer’s
      disease.  
      http://www.nia.nih.gov/NR/exeres/6739F4B3-C1A9-4564-8AC3-77DC1315974E.htm
   b. The Basics: Memory Loss, Dementia and Alzheimer’s Disease, Alzheimer’s
      Association. An online training that includes information on Alzheimer’s disease
      and related dementias, causes and risk factors, stages of the disease, and
      treatment.  
      http://elearning.alz.org/Default.aspx
   c. CDC Features: Alzheimer’s Disease, Centers for Disease Control and Prevention. A
      web page providing a brief overview of Alzheimer’s disease and its effects on
      the individual and the family.  
      http://www.cdc.gov/Features/Alzheimers/index.html
   d. HBO Documentary: The Alzheimer’s Project, Home Box Office. A four-part
      television documentary series with 15 short supplemental films, and a website that
      addresses personal and family experiences with the disease, issues for children,
      and care needs for those affected.  
      http://www.hbo.com/alzheimers/
   e. Caring for a Person with Alzheimer’s Disease, National Institute on Aging. An
      easy-to-understand guide for caregivers of persons with Alzheimer’s disease. The
      guide is divided into sections: understanding Alzheimer’s disease; caring for
      a person with Alzheimer’s disease; caring for yourself; when you need help; the
      medical side of Alzheimer’s disease; coping with the late stages of Alzheimer’s
      disease; and other information. The guide contains quotations from individuals
      who were part of Alzheimer’s disease support groups at Duke University.  
      http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/
f. *AlzBrain.org*, Dementia Education & Training Program, Alabama Department of Mental Health and Mental Retardation. Provides information for family caregivers, professionals, and persons concerned about memory loss. [www.AlzBrain.org](http://www.AlzBrain.org)

**Identification and Awareness of a Possible Dementia**

Although there is no cure, it is important that a person be diagnosed as early in the disease process as possible. An early diagnosis allows the individual and the family to plan for the future, to participate in care planning, and to take advantage of available treatments. The process of getting a diagnosis involves education and awareness, screening and assessment, and a comprehensive examination. This section provides warning signs that can be used as an education tool and various assessment instruments for cognitive impairment that include brief mental status tests and instruments for informant interviews. A definitive diagnosis of Alzheimer’s disease or a related dementia requires a comprehensive examination by a trained medical professional that includes a medical and psychiatric history, a physical and neurological exam which may include brain imaging, laboratory tests (blood and urine), an evaluation of the person’s functional ability, a mental status exam, and a family or caregiver interview.

1. Tools for identifying a possible dementia:
   a. **Know the 10 Signs**, Alzheimer’s Association. Webpage provides a variety of resources including the 10 Warning Signs of Alzheimer’s, a doctor’s appointment checklist, a free online course, and information on the importance of early detection. Tools are designed for consumers and results can be shared with the doctor. [http://www.alz.org/alzheimers_disease_know_the_10_signs.asp](http://www.alz.org/alzheimers_disease_know_the_10_signs.asp)


2. Informant interview tools
   A family member or close friend or neighbor of the person is often more likely to be able to recognize the decline in cognitive function that is a component of dementia. It is important to involve them in the assessment process as an informant. These are tools specifically designed for key informants such as family members or close friends.

   a. *AD-8*, James Galvin. An eight-item informant interview instrument that can be given to the respondent for self-administration or can be read aloud. If an informant is not available, the AD-8 can be used with the person with possible dementia. Scoring guidelines are available and administration of the instrument does not require prior staff training. Galvin JE; Roe CM; Powlishta KK; et al., “The AD8: A brief informant interview to detect dementia.” *Neurology* 2005;65:559-564. [http://www.neurology.org/content/65/4/559](http://www.neurology.org/content/65/4/559)


3. Modified assessment procedures
   Some states, including Missouri and Minnesota, have modified existing assessment procedures to identify dementia.

   a. Missouri’s Project Learn MORE uses the AD-8 developed by Dr. James Galvin as part of a statewide formalized identification and referral process that is being delivered through the Area Agencies on Aging (AAAs) and four Alzheimer’s Association chapters.


4. Government-funded assessment clinics
   a. *Alzheimer’s Disease Centers*, National Institute on Aging. At major medical institutions across the country, Centers offer diagnosis and medical management;
information about the disease, available services, and resources; and opportunities for volunteers to participate in drug trials and other clinical research projects.  

b. California Alzheimer’s Disease Centers, California Department of Public Health.  
A network of 10 dementia care Centers of Excellence at California medical schools established to improve Alzheimer’s disease health care delivery, provide specialized training and education to health care professionals and others, and advance the diagnosis and treatment of Alzheimer’s disease.  
http://cadc.ucsf.edu/cadc/

Measuring Functional Ability for Care Planning and Resource Allocation  
The need for assistance to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs) can be determined with general assessment instruments developed by Katz, Lawton and Brody, and numerous others. Some researchers and clinicians have developed assessment instruments intended specifically for people with cognitive impairment and dementia. Some of these instruments measure IADLs and ADLs, and specifically identify the kinds of difficulties people with cognitive impairment often experience in performing daily activities. These measures are important in determining whether people with cognitive impairment meet functional impairment eligibility standards for government and private programs and for deciding how many resources to allocate to these individuals.

1. Dependence Scale, Yaakov Stern. Rating is based on informant responses to 13 questions about functional activities. The scale is sensitive to medication effects, psychosis, and other symptoms. It has been used as a predictor of nursing home placement. The Dependence Scale is designed to be administered by a trained professional interviewer. Stern Y; Albert SM; Sano M; et al., “Assessing patient dependence in Alzheimer’s disease.” *Journal of Gerontology: Medical Sciences* 1994;49(5):M216-M222.  
http://geronj.oxfordjournals.org/content/49/5/M216.abstract.

2. Direct Assessment of Functional Status (DAFS), David Lowenstein. Includes observation and rating on tasks in seven functional domains, including time orientation, transportation use, financial skills, shopping skills, and eating skills. The assessment is designed to be administered by a trained professional interviewer. Lowenstein DA; Amigo E; Duara R; et al. “A new scale for the assessment of functional status in Alzheimer’s Disease and related disorders.” *Journal of Gerontology* 1989;44(4):p114-p121.  

3. Self-Care Performance Tool, Joan Thralow. Includes observation and rating on four self-care activities. This tool requires administration by a trained professional interviewer. Thralow JU; and Rueter MJS. “Activities of daily living and cognitive levels of function in dementia.” *The American Journal of Alzheimer’s Care and Related Disorders & Research* 1993;8(5):14-19.  
http://aja.sagepub.com/content/8/5/14.abstract.
Information, Assistance, and Options Counseling
Some people with dementia and their families can arrange for community services and the support they need if they are given a list of local agencies and providers. Others need more assistance to define their service needs, select a provider that can accommodate dementia-related care needs, and initiate the service. People with dementia need assistance with these tasks because of their cognitive impairments and families may need assistance because caregiving activities are overwhelming to them.

Below is a brief description of available community resources. It is often difficult to know what type of care is best for a person with dementia. A person’s care needs depend on how independently he or she can do everyday things. It is important to understand a person’s functional ability when making any kind of care transition.

- Early Stage Socialization Programs—In the beginning stage of Alzheimer’s disease or a related disorder, individuals have special needs that may be overlooked. Support groups and socialization programs aimed at persons with early-stage Alzheimer’s help identify some of these needs and provide suggestions to assist early-stage individuals and their caregivers.
- Adult Day Care—An adult day center provides care outside the home, and in this setting, people can socialize, participate in activities, and get health care.
- Home and community-based services, such as those funded through the Older Americans Act and Medicaid, help persons with dementia maintain their independence and dignity in their homes and communities. Programs include transportation; case management; personal care, chore and homemaker assistance services; legal services; mental health services; and adult day care.
- Independent Living communities are usually in a small, easy-to-maintain private apartment or house within a community of seniors. No personal care or medical care is provided, but other services may be available such as transportation or recreation activities.
- Assisted Living residences generally provide personal and supportive services, recreational activities, meals, housekeeping, laundry, and transportation. Definitions and specific regulations differ from state to state.
- Nursing Homes may provide a full range of care needs, including skilled care and long-term services and supports.

Information, Referral, and Assistance
People with dementia and their caregivers need information about the services and supports available in their local communities so they can make informed choices about selecting services that will best meet their needs.

1. **ElderCare Locator**, 1-800-677-1116, Administration on Aging, U.S. Department of Health and Human Services. Connects older Americans and their caregivers with information on senior services, including information on finding help within the local community, and also provides tools, links, and other resources.
   [http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx](http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx)
2. *Alzheimer’s Association Helpline*, 1-800-272-3900, Alzheimer’s Association, funded in part by the Administration on Aging. Serves people with Alzheimer’s disease and related dementias, caregivers, health care professionals, and the public, providing information and support, 24 hours a day, 7 days a week. Provides confidential care consultation, help in caller’s preferred language, and referrals to local community programs and services. [http://www.alz.org/we_can_help_24_7_helpline.asp](http://www.alz.org/we_can_help_24_7_helpline.asp)


4. *Family Caregiver Alliance*. Offers programs at national, state, and local levels to support and sustain caregivers including the Family Care Navigator to help caregivers locate support services in their communities. [http://www.caregiver.org/caregiver/jsp/home.jsp](http://www.caregiver.org/caregiver/jsp/home.jsp)


6. *Michigan Dementia Coalition*. Website offers a variety of resources for consumers and professionals including a respite care resource list, professional education and training materials, and research-based recommendations for effective caregiver interventions. [www.dementiacoalition.org](http://www.dementiacoalition.org)

7. *AlzBrain.org*, Dementia Education & Training Program, Alabama Department of Mental Health and Mental Retardation. Provides information for family caregivers, professionals, and persons concerned about memory loss. [www.AlzBrain.org](http://www.AlzBrain.org)

**Options Counseling and Assistance**

Options counselors can help individuals with Alzheimer’s disease and their caregivers make the appropriate choices on insurance and financial planning, legal matters, care transitions, long-term services and supports, and end-of-life care.


b. *Massachusetts Alzheimer’s Disease Supportive Service Project*. Massachusetts Executive Office of Elder Affairs, the Alzheimer’s Association, and the Aging and
Disability Resource Centers (ADRCs). ADSSP program to strengthen the referral network, enhance capacity of ADRCs to identify persons with dementia, and to increase the expertise of options counselors in recommending services. http://www.adrc-tae.org/tiki-index.php?page=ADSSP-April11


f. Caring Connections, National Hospice and Palliative Care Organization. Website that provides information on planning for end-of-life care and links to state-specific advance directive forms. http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1

Understanding Decision-making Capacity for Care Planning and Resource Allocation

As memory, language, and judgment abilities change, a person with Alzheimer’s disease or a related dementia will lose the capacity for decision making and managing financial affairs. The following resources will assist in addressing a person with dementia’s declining capacity to participate in decisions.


2. Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists, American Bar Association Commission on Law and Aging and American Psychological Association. Reviews psychological assessment of six civil capacities of particular importance to older adults including medical consent capacity, sexual consent capacity, financial capacity, testamentary capacity, capacity to drive, and capacity to live independently. In addition, this handbook addresses undue influence and emerging areas such as capacity to mediate, capacity to participate in research, and capacity to vote. Mediation is a form of alternative dispute resolution that provides a way for resolving
disputes between two or more parties.


4. *Elder Investment Fraud and Financial Exploitation Clinician Pocket Guide and Patient Brochure*, Investor Protection Trust. Resources developed through the Elder Investment Fraud and Financial Exploitation Prevention Program that seeks to educate medical professionals about how to spot older Americans who may be particularly vulnerable to financial abuse, particularly those with mild cognitive impairment, and then to refer suspected investment fraud involving these at-risk patients to state securities regulators or to local Adult Protective Services professionals.
- Clinician Pocket Guide
- Patient Brochure

Services Capable of Meeting the Unique Needs of Persons With Dementia and Caregivers
Assistance to help persons with dementia and their caregivers identify, choose, and obtain services and supports is provided by various agencies, organizations, and other entities, including ADRCs and AAAs. Many of these entities partner with other organizations and agencies.

Support Resources for Persons With Early Stage Alzheimer’s Disease or a Related Disorder

1. *Early Alzheimer’s disease: clinical practice guideline, number 19, consumer version*, Agency for Health Care Research and Quality. Presents information for persons with dementia, family members, and other caregivers including signs and symptoms, the need to consult a doctor, the steps involved in a comprehensive evaluation, treatable causes, getting the right care, and additional support resources.
http://www.ahcpr.gov/clinic/alzcons.htm

2. *Taking Action: A personal and practical guide for persons with mild cognitive impairment and early Alzheimer’s disease*, Alzheimer’s Association, Colorado; Minnesota Board on Aging and Alzheimer’s Association, Minnesota/North Dakota. A workbook for persons with mild cognitive impairment or early Alzheimer’s disease that addresses common concerns, educational information, and perspectives of people living with memory loss. This workbook can be used alone or with family and friends.
Development was supported in part by an Administration on Aging grant.  

3. **Living Well Workbook**, Alzheimer’s Association Minnesota-North Dakota Chapter, HealthPartners Center for Dementia and Alzheimer’s Care and the Center for Spirituality and Healing at the University of Minnesota. Workbook presents brain wellness strategies and offers an opportunity to explore lifestyle changes that could lower the impact of disease symptoms and improve day-to-day living. Topics include Exercise, Nutrition, Brain Exercise, and Stress Reduction.  

4. **What Happens Next? A booklet about being diagnosed with Alzheimer’s disease or a related disorder**, Alzheimer’s Disease Education and Referral Center, National Institute on Aging. Developed by the early-stage support group at the Northwestern University Alzheimer’s Disease Center. Early-stage individuals share their firsthand views about diagnosis, what to expect, how to talk with others about the disease, ways to cope in order to help others who also are facing the beginning stages of dementia, and available resources.  
http://www.nia.nih.gov/Alzheimers/Publications/WhatHappensNext.htm#foreword

5. **Fact Sheet for early stage persons and their family members**, Family Caregiver Alliance. Includes information on managing transitions, coping, and helpful resources.  
http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=571

6. **Perspectives—a newsletter for individuals with Alzheimer’s or a related disorder**, University of California, San Diego Shiley-Marcos Alzheimer’s Disease Research Center. A quarterly publication that provides up-to-date information on relevant topics, research, and resources, and provides a forum for personal essays and reflections from persons with early-stage dementia around the world. Available free of charge by e-mail subscription. Contact Lisa Snyder, LCSW at lsnyder@ucsd.edu to request a subscription or call 858-622-5800.

7. **Early Stage Support Resources**, Alzheimer’s Association. Includes support groups and education programs through the local area chapter with information available at the chapter website under Find Us at http://www.alz.org/apps/findus.asp and the online support community at  
http://www.alz.org/living_with_alzheimers_message_boards_lwa.asp

**Caregiver Support Resources**

1. **Caregiver Guide**, National Institute on Aging. Provides caregiver tips on communication, personal care, home safety, driving, coping with holidays, visiting the doctor, and other topics.  
http://www.nia.nih.gov/Alzheimers/Publications/caregiverguide.htm
2. **Caregiver Tips**, ElderCare Locator. Provides tips, information, and a variety of suggestions shared by caregivers with caregivers.  
   [http://www.eldercare.gov/ELDERCARE.NET/Public/Resources/Caregiver_Tips/Index.aspx](http://www.eldercare.gov/ELDERCARE.NET/Public/Resources/Caregiver_Tips/Index.aspx)

3. **Caregiver’s Guide to Understanding Dementia Behaviors**, Family Caregiver Alliance. Provides communication tips and explanations of behavior by people with dementia including wandering, incontinence, agitation, and other behavioral symptoms.  


5. **Education and Care**, Alzheimer’s Foundation of America. Webpage addresses a variety of issues important to caregivers including strategies for success, communication of the diagnosis, ADLs, behavioral challenges, therapies, safety, and medical visits.  
   [http://www.alzfdn.org/EducationandCare/strategiesforsuccess.html](http://www.alzfdn.org/EducationandCare/strategiesforsuccess.html)

6. **Wait a Minute: When Anger Gets Too Much**, Project C.A.R.E., an Alzheimer’s Disease Demonstration Grants to States (the earlier name for the Alzheimer’s Disease Supportive Services Program), funded through the North Carolina Division of Aging and Adult Services. A pamphlet on anger management.  

### Resources for Diverse and Underserved Persons With Dementia and Caregivers

1. **Diversity Portals**, Alzheimer’s Association. Include resources on dementia-related topics for individuals with dementia, families, and professionals in several languages. Topics covered include an overview of Alzheimer’s disease and related disorders, signs and symptoms of Alzheimer’s disease, and caregiving tips.
   - Interactive Brain Tour explains how the brain works and how Alzheimer’s affects the brain. Available in English and 14 other languages. [http://www.alz.org/alzheimers_disease_4719.asp](http://www.alz.org/alzheimers_disease_4719.asp)

3. *Caregiving in Indian Country: Conversations with Family Caregivers*, Centers for Disease Control and Prevention in collaboration with the National Association of Chronic Disease Directors. Issue brief that addresses issues of caring for Native Americans with dementia.  
http://www.chronicdisease.org/nacdd-initiatives/healthy-aging/meeting-records/critical-issue-briefs

4. *Planning with Purpose: Legal Basics for LGBT Elders*, National Center for Lesbian Rights. Guide provides basic information about select areas of law that are important to lesbian, gay, bisexual, and transgender (LGBT) elders such as relationship recognition, finances, health care, and long-term services and supports.  

**Safety Resources**
Alzheimer’s and other dementias cause impairments, such as impairments in balance and mobility, judgment, sense of time and place, orientation and recognition of environmental cues, and changes in vision or hearing that can reduce an individual’s ability to remain safe at home.

**Challenging Behaviors and Wandering**

1. *Understanding How AD Changes People—Challenges and Coping Strategies*, Alzheimer’s Disease Education & Referral Center, U.S. National Institutes of Health. Webpage describes changes in communication skills, personality, and behavior and addresses specific issues such as wandering and safety.  
http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/caregiving/understanding.htm


**Driving**

1. *Dementia and Driving Resource Center*, Alzheimer’s Association. Created with support from a grant from the Department of Transportation National Highway Traffic Safety Administration. The website includes four videos depicting families having conversation about driving by a person with dementia, links to alternative driving resources, tips on recognizing when driving is no longer safe, how to obtain a driving evaluation, and other resources.  
http://www.alz.org/safetycenter/we_can_help_safety_driving.asp

2. *Dementia and Driving*, The Hartford Insurance. A comprehensive website that includes strategies for families for discussing driving by persons with dementia and different methods of determining when to cease driving.  

Falls


Home Safety

1. *Home Safety for People with Alzheimer’s Disease*, National Institute on Aging, U.S. National Institutes on Health. Provides information on general safety concerns, home safety throughout the home, responding to unsafe behaviors, driving, and evaluating when a person with dementia can be left home alone. A Spanish version of the publication is available. [http://www.nia.nih.gov/Alzheimers/Publications/homesafety](http://www.nia.nih.gov/Alzheimers/Publications/homesafety)


Medication Management

1. *HomeMeds*, U.S. Administration on Aging Evidence-Based Healthy Aging Program. Program to reduce falls, dizziness, confusion, and other medication-related problems for elders living at home. Care managers use software and a pharmacist consultant to screen their clients’ medications for potentially harmful problems and bring these problems to the attention of their physicians. [http://www.homemeds.org/](http://www.homemeds.org/)

2. *Get Connected! Linking Older Adults with Medication, Alcohol and Mental Health Resources*, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. A toolkit for aging services providers to increase awareness of alcohol and medication misuse and mental health issues in older adults that includes information on memory loss and dementia. [http://www.samhsa.gov/Aging/docs/GetConnectedToolkit.pdf](http://www.samhsa.gov/Aging/docs/GetConnectedToolkit.pdf)
Hoarding

1. *Working with Individuals with Dementia Who Rummage and Hoard*, Cornell University. A webpage that provides a list of 15 tips to consider when working with individuals with dementia who rummage or hoard. [http://www.environmentalgeriatrics.com/home_safety/working_with.html](http://www.environmentalgeriatrics.com/home_safety/working_with.html).

2. *Compulsive Hoarding*, National Center on Elder Abuse, Administration on Aging. A webpage that provides an overview and additional resources on hoarding. [http://www.ncea.aoa.gov/Main_Site/Library/CANE/CANE_Series/CANE_hoarding.aspx](http://www.ncea.aoa.gov/Main_Site/Library/CANE/CANE_Series/CANE_hoarding.aspx).


Travel


Disaster Planning


3. *Resources for Emergency Housing*, Federal Emergency Management Agency, U.S. Department of Homeland Security. Includes information on *Disaster Recovery Centers (DRC)* that are facilities or mobile offices where people may go for information about FEMA or other disaster assistance programs, including housing assistance and rental resource information. This webpage [http://www.fema.gov/assistance/opendrcs.shtm](http://www.fema.gov/assistance/opendrcs.shtm) contains a DRC Locator:
4. **Tips for First Responders**, Division of Disability and Health Policy, University of New Mexico. Offers tip sheets with information about many types of disabilities including cognitive impairment that first responders can use during emergencies and routine encounters. [http://cdd.unm.edu/dhpd/tipsEng](http://cdd.unm.edu/dhpd/tipsEng)

**Self-Directed Services**

Many Medicaid, Older Americans Act, and state-funded programs now offer self-directed home care. Under self-directed care, the individual consumer (or the person’s representative) is responsible for hiring, training, scheduling, supervising, paying, and firing the home care worker rather than an agency.

a. **Understanding Medicaid Home and Community Services: A Primer, 2010 Edition**, U.S. Department of Health and Human Services. Addresses how best to use the Medicaid program to expand the provision of home and community services to persons with disabilities of all ages. Primer emphasizes that states need to consider each individual and his or her unique needs, resources, and social, political, and economic environments. [http://aspe.hhs.gov/daltcp/reports/2010/primer10.htm#intro](http://aspe.hhs.gov/daltcp/reports/2010/primer10.htm#intro)


c. **Dementia-Capable Consumer-Directed Options**, Maine Department of Health and Human Services. An ADSSP grant-funded project in Maine that seeks to improve awareness, access, and utilization of consumer-directed options for individuals with dementia and their caregivers. The project has also developed a facilitated referral protocol to connect families not eligible for state support to other services through the Aging Network. [http://www.adrc-tae.org/tiki-download_file.php?fileId=30768](http://www.adrc-tae.org/tiki-download_file.php?fileId=30768)

d. **Consumer-Directed, Home and Community Services for Adults with Dementia**, Alzheimer’s Association. A 2007 review of home and community-based services programs in 11 states that found that older adults with cognitive impairment or dementia were permitted to participate in at least one self-directed program in each state. [http://www.alz.org/national/documents/Consumer_Direction_issue_brief_2007.pdf](http://www.alz.org/national/documents/Consumer_Direction_issue_brief_2007.pdf)

e. **Self-Directed Care Guidebook: Developing Your Program**, Division of Aging Services, Georgia Department of Human Resources. A guidebook designed to comprehensively describe the elements of a self-directed care model employed in multiple geographic locales in Georgia. The purpose is to inform prospective program developers about opportunities and potential pitfalls.
Workforce Training and Tools

Given the needs of people with dementia, special training of people working in information and referral, options counseling, and service provision is needed, but often not provided. Dementia-specific training is often lacking at the level of home care aides, personal assistants, and other direct care workers including training of workers in self-directed programs. This section provides some professional workforce training resources and tools.

1. **Quality Care through Quality Jobs**, PHI. Outlines the essential elements of high-quality care, services and support for people who receive long-term services and supports, and of a quality job for direct care workers in long-term services and supports.
   
   


3. **AlzPossible.org**, Virginia Alzheimer’s Disease and Related Disorders Commission. Website developed as a “Virtual Alzheimer’s Disease Center” that supports effective interventions to maintain or extend the independent functioning of people with Alzheimer’s disease. The website contains links to webinars, resources, and the annual report. [www.AlzPossible.org](http://www.AlzPossible.org)

4. **Alzheimer’s Disease and Dementia Resources**, Wisconsin Department of Health Services. Website offers a variety of tools for providers and professionals in long-term services and supports settings and dementia care at home. Many of these tools were developed through Alzheimer’s Disease Demonstration Grants to States (the earlier name for the Alzheimer’s Disease Supportive Services Program) including the Quality Home Visits Guide for Care Managers and Dementia Care at Home Planning Guide. [http://www.dhs.wisconsin.gov/aging/genage/alzfcgsp.htm](http://www.dhs.wisconsin.gov/aging/genage/alzfcgsp.htm)

5. **Dementia Care Training for Home Health Aides**, Alzheimer’s Association, New York City Chapter. A 50-hour training provided once per week for 7 weeks at the New York City Chapter office, free of charge. Training covers a variety of topics including understanding the disease process, communication, home safety, behavior challenges, family interactions, and cultural awareness. [http://www.alz.org/nyc/in_my_community_18370.asp](http://www.alz.org/nyc/in_my_community_18370.asp)
6. Try This® Series, Hartford Institute for Geriatric Nursing. Offers suggested tools for nurses and other hospital staff caring for older adults with dementia. “How to” videos are also available to demonstrate particular techniques. [http://consultgerirm.org/resources](http://consultgerirm.org/resources)

7. Dementia Friendly Hospital Initiative, Alzheimer’s Association, St. Louis; Retirement Research Foundation; John A. Hartford Foundation; and Atlantic Philanthropies. A dementia-specific training program designed for hospital personnel to increase detection and treatment of ADRD in acute care settings, prevent complications from infection and malnutrition, facilitate recovery, prevent functional decline, and reduce high-risk behaviors to improve patient and staff safety.

http://journals.lww.com/alzheimerjournal/Abstract/2010/10000/_Dementia_friendly_Hospitals__Care_not_Crisis__11.aspx

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Quality Assurance Systems

A quality assurance system that addresses services for people with dementia would have at least three components: measures of dementia capability at both the LTSS systems level and the individual provider level, systematic and regular measurement of the experience of people with dementia and their family caregivers to demonstrate user experience, and a process of continuous quality improvement to be used to improve services. So far, little attention has been given to developing these dementia-specific systems and implementing them on an ongoing basis.

1. Dementia Quality of Life Outcomes Care Planning Tool, WI Department of Health and Family Services. The tool provides a structured approach to planning for quality of life issues with people who have dementia. The guiding principles and specific information allow care providers, in collaboration with care managers and consumers, to personalize and focus planning and monitoring of care for persons with Alzheimer’s disease and related dementia.