

# Consumer-Directed Care

HOME AND COMMUNITY-BASED SERVICES  
FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS



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THE AGING NETWORK

  
INTERNATIONAL

# HOME AND COMMUNITY-BASED SERVICES FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS



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# About This Toolkit: Consumer-Directed Care

## Home and Community-Based Services for People with Dementia and Their Caregivers

Consumer-directed care programs encourage consumers to manage their own care. This less traditional type of Home and Community-Based Service (HCBS) program enables families to do such things as choose the type and timing of their services, hire and manage their workers, purchase supplies, make home modifications, and pay for personal care such as bathing, transporting, dressing, and other tasks. These services are especially helpful to families coping with dementia. As Alzheimer's disease progresses, so do the needs for dementia capable services for both individuals and caregivers. Consumer-directed care services provide the flexibility that caregivers need to manage their busy lifestyles and the opportunity to make informed choices about their families' long-term care needs. **This toolkit outlines actions that states can take to integrate dementia capability into consumer-directed care programs.**

### The Consumer-Directed Care Toolkit:

- Explains how consumer-directed care programs play a critical role in increasing Home and Community Based Services while decreasing institutional care.
- Describes how state officials can incorporate dementia capability into consumer-directed care programs to better serve the unique needs of persons and families coping with Alzheimer's disease and other dementias.
- Offers an array of resources that are model programs or unique examples for state officials to use when developing programs. Many of these programs are funded by the Administration on Aging through the Alzheimer's Disease Demonstration Grants to the States (ADDGS) program.
- Includes a step-by-step guide to enhance your consumer-directed care program that will best serve families and persons with dementia. Information is provided on how to:
  - Identify participants with dementia.
  - Determine whether these participants need representatives to manage their care and who will represent these individuals.
  - Identify risks to consumers' health and safety and specify how consumers and their representatives are going to manage those risks.
  - Take into account caregivers' needs when determining care plans.
  - Ensure that participants with dementia receive high-quality care.
  - Make certain that staff and professionals have dementia training or expertise.
  - Ensure that funds are spent properly.

This toolkit provides information on promising practices, with hyperlinks to material available on the Internet.

# Promising Practices: Consumer-Directed Care

## Home and Community-Based Services for People with Dementia and Their Caregivers

### Why Make Consumer-Directed Programs Dementia Capable?

- Alzheimer's disease is a devastating degenerative disease that causes memory loss, challenging behavior problems, and severe functional limitations. According to the Alzheimer's Association's *2008 Alzheimer's Disease Facts and Figures*, an estimated 5.2 million Americans have Alzheimer's disease. By 2050, the Alzheimer population may grow to at least 16 million. While 24 percent of all home health care clients have moderate or severe cognitive impairment, at least half of those using adult day programs have dementia.
- The progressive and unpredictable nature of Alzheimer's disease causes many challenges for caregivers. Dementia caregivers experience poorer health and more stress than other caregivers. One program in which consumers are given a budget to control and use to purchase services, the [Cash & Counseling demonstration](#), found that elderly participants in consumer-directed programs had fewer unmet needs for care and reported more satisfaction with their care and quality of life than those in traditional agency services. Family caregivers of consumer-directed participants reported less physical and financial strain and less worry about the care family members were receiving. In Arkansas, users of consumer-directed services had significantly less use of nursing homes than those who relied on agencies.

### What Are Dementia-Capable Services?

To be dementia capable, individuals who help consumers access home and community-based services (HCBS) must be

- skilled at identifying people with dementia, including Alzheimer's disease,
- knowledgeable about the kinds of services that help people with dementia and their caregivers, and
- capable of providing linkages to other organizations that can help.

### Consumer-Directed Care

States can engage in several key activities to provide consumer-directed services to people with dementia and their caregivers:

1. Identify participants with dementia
2. Determine whether participants need representatives to manage their care and represent them
3. Identify risks to consumers' health and safety and specify how consumers and their representatives can manage those risks
4. Take into account caregivers' needs when determining care plans
5. Ensure that participants with dementia receive high-quality care
6. Make certain that staff and professionals have dementia training or expertise
7. Ensure that funds are spent properly

## Promising Practices for Each Key Activity

### 1. Identify participants with dementia

First, in order to help people with dementia, state consumer-directed staff must identify them. HCBS programs generally assess a person's ability to carry out daily activities such as eating, bathing, and dressing to determine the type and level of care that consumers need. This is known as the "assessment of need process." Identifying persons with dementia can be done during this process. To best serve persons with dementia, an assessment tool can be designed to identify those with dementia or cognitive impairment.

State HCBS assessments can measure types of support that people with dementia need for daily activities. The measurement of a person's need for supervision is critical to protect people with dementia from harm that might result from impaired judgment or behaviors such as unsupervised wandering. A Public Policy Issue Brief, [\*Medicaid Eligibility Criteria for Long Term Care Services: Access for People with Alzheimer's Disease and Other Dementias\*](#), provides guidance on how states can use their assessment tools to identify those with dementia. Key recommendations include assessing whether people need verbal reminders to complete tasks and determining how much supervision is needed to keep people safe. The issue brief includes examples of state assessment processes. **Oregon** has a computerized assessment tool that measures the need for assistance that results from a physical or a cognitive impairment. The tool also measures mental status, behaviors that pose a danger to self or others, and the need for verbal assistance.

### 2. Determine whether participants need representatives to manage their care and represent them

Once individuals with dementia are identified, state consumer-directed programs must determine whether people need representatives to manage their services and who will undertake these responsibilities. States with consumer-directed programs have taken a variety of approaches to determine if representatives are needed:

#### A. Determine whether participants need representatives to manage their care

- **Massachusetts** requires an assessment for all new consumers to determine their need for representatives. The consumer assessment determines whether consumers understand their disabilities and the care they need, as well as how to employ personal attendants. Under certain conditions, such as a change in health or functional status, the capabilities of the consumers are reviewed.
- **Arkansas** provides consumers with a *Participant Self-Assessment* form used to determine the consumers' need for support with management responsibilities. The form asks consumers to think about what type of services they need, how they will arrange for services, and how they will train, supervise, and discipline workers. After considering these questions, consumers then decide whether they need representatives and who will perform those duties.
- Another option for states is to determine the need for representatives informally through the assessment process. In **New Jersey**, during home visits, service consultants observe participants and offer them the option of designating representatives if it appears that participants require that type of support.

## B. Identify who will serve as representatives

If consumers choose to have representatives, then representatives take responsibility for a portion of service management. In most states, almost anyone, except paid caregivers, can be a designated representative.

- In **Arkansas**, if representatives are needed, then designated representatives are screened to establish whether they can manage the care. The *Representative Screening Questionnaire* asks potential representatives about their relationships with the consumers, whether they receive money from the consumers, and if they are willing to carry out management responsibilities.
- **Florida** formalizes a *Representative Agreement* by specifying responsibilities of representatives. These responsibilities include:
  - Controlling and managing consumers' budgets
  - Using the budget to purchase needed services and support
  - Keeping a log that details the use of funds
  - Performing background screenings on all employees
  - Ensuring consumers' health and safety
  - Keeping consumers' information confidential
  - Conforming to program rules

Representatives also agree to pay employees if the consumers' budgets are overspent. Many states, including Florida, contract with a financial management service organization to oversee the payroll functions for workers.

## 3. Identify risks to consumers' health and safety and specify how consumers and their representatives can manage those risks

Consumer-directed programs have ways to identify and reduce risks to consumers' health and safety. Generally, this occurs during the assessment and care coordination process. Service consultants will discuss with the consumer methods that can help prevent them from being harmed; however, some states have a more formal process for identifying and reducing risks. **New Jersey** and **Wisconsin** have forms designed to identify risks and to specify actions taken to prevent harm.

- **New Jersey's** *Personal Preference Program Risk Assessment Profile* addresses risks associated with living arrangements, eating, medications, toileting, mental status, communication, mobility, use of the telephone, and environmental factors. The form then identifies "risk reduction factors," such as having a live-in caregiver and having procedures for emergencies. A risk score is derived from this form.
- **Wisconsin's** *Risk Reduction Worksheet* simply requires a description of each risk, what the consumer would like to do about it, and how the risk will be minimized.

#### 4. Take into account caregivers' needs when determining care plans

Another way to ensure the health and safety of individuals with dementia is to assess the needs and capacity of their primary caregivers. People with moderate to severe dementia may have difficulty remaining in the community without the help of caregivers.

- The Family Caregiver Alliance (FCA), along with 54 nationally recognized experts, developed *Fundamental Principles for Caregiver Assessment*, which includes seven fundamental principles, such as caregiver assessment that are essential to development of a good care plan and embracing a family-centered perspective. Assessments should be multidimensional in approach and culturally competent. FCA has also produced a caregiver assessment online toolkit called [Caregivers Count Too!: A Toolkit to Help Practitioners Assess the Needs of Family Caregivers](#). This toolkit provides background information on caregivers and caregiving situations, caregivers' perceptions of consumers' health and functional status, caregivers' preferences regarding services, health and well-being of caregivers, and services needed.

After a comprehensive assessment, caregivers may need referrals to those services or community organizations that can best meet their needs. For example, many Alzheimer's Disease Demonstration Grants to the States (ADDGS) projects provide respite services that give caregivers a break from their responsibilities:

- **North Carolina's** [Project C.A.R.E](#) provides comprehensive support to dementia caregivers. *Project C.A.R.E.* developed two dementia-specific family caregiver assessment tools that are used together. The first tool, *Client Intake Form*, covers: (1) consumers' living arrangements, needs for assistance, demographic information, and behavioral symptoms of dementia; and (2) caregiver demographics, services provided to consumers, employment status, service use, and health and emotional status. The second form, *Project C.A.R.E. Supplemental Information Form* addresses symptoms of dementia and the need for respite services. This form also collects information about any other government-funded services the dementia family may be receiving. Dementia families who qualify receive respite care at home, in adult day care, or in a facility. Respite is available up to \$1,500 per fiscal year.
- **Colorado's** Virginia Behr Respite Care Program offers respite grants of up to \$1,000 a year. Funds are spent at the family's discretion for in-home care, adult day care, or short stays in a nursing home.
- **Nebraska** provides vouchers of up to \$300 a month for caregivers to use to purchase services. Caregivers also have access to mentors who provides information and counseling, as well as access to training opportunities.

#### 5. Ensure that participants with dementia receive high-quality care

Service consultation is essential to assure that high-quality services are delivered to people with dementia. Typically, service consultation involves the services of professional staff to help people navigate the difficult decisions that people with dementia and their families face at every stage of the disease. Service consultants are also knowledgeable about home and community-based services. This is particularly important because people with dementia can have difficulty managing their services and speaking for themselves. The need for contact with service consultants is likely to increase as dementia progresses, and consumers acquire more disability and have less ability to communicate over time.

The frequency and type of service consultation provided to consumers varies greatly among the states. For example:

- **Vermont** state staff have frequent and intense contact with participants in consumer-directed programs. Service consultants visit participants at least once a month in their homes. Contact can be more frequent as participants needs for services vary over time.
- **Arkansas**' service consultants contact participants monthly by telephone during the first 6 months after they begin receiving services. Afterward, contacts occur quarterly unless there are reasons to maintain monthly contacts. In-home visits occur twice a year. More frequent monitoring visits are triggered by a change in caregiver or participant status.
- **New Jersey's** service consultants make quarterly home visits. In addition, monthly telephone contacts are required during the first 6 months after entering the program.
- **South Carolina's** service consultants visit consumers quarterly and make monthly telephone calls with representatives.

## 6. Ensure that staff and professionals have dementia training or expertise

Service consultants need special skills to determine the needs of people with dementia because those consumers lose their ability to communicate. In addition, understanding the behavioral symptoms of dementia, such as wandering and agitation, can be quite difficult for those who are not familiar with the disease. Many states make dementia-specific training available to service consultants and other staff. Essential topics to cover in dementia training include the disease process and its symptoms, communicating with people who have dementia, managing the symptoms of dementia, and dementia caregiver stress. The following are examples of dementia training programs:

- **South Carolina's** dementia training is available to caregivers through the University of South Carolina's Office for Aging Studies. [\*Dementia Dialogues\*](#) is a five-session training course designed to educate individuals who care for persons who have symptoms of dementia. Topics covered include: dementia basics, communication skills, environment, challenging behaviors, and creative problem solving.
- **Washington** requires service consultants and all providers of home and community services to have dementia training. The training program, *Dementia Care Specialty Training*, has eight modules, six for direct care providers and two for managers. The modules cover such topics as the basics of dementia, communication, helping with daily activities, behaviors, psychiatric symptoms, sexuality, medications, and working with dementia families. The modules include a workbook, a video, take-away information sheets, and other learning tools.
- **Florida** mandates that all home health, adult day care, hospice, assisted living facilities, and nursing home professionals be trained in dementia care. The Florida Department of Elder Affairs partners with the [University of South Florida](#) to implement this state requirement.
- **Missouri** establishes minimum dementia training requirements for workers who provide care to persons with dementia who live at home or in residential care settings or who receive services in adult day care programs. Training includes: learning generally about Alzheimer's disease and related dementias, communicating with persons with dementia, managing behavior, promoting independence in activities of daily living, and understanding and dealing with family issues.

## 7. Ensure that funds are spent properly

The Cash & Counseling program ensures that taxpayer dollars are being spent properly. All states require consumers and their representatives to develop purchasing plans to specify how program funds will be spent. State program officials must approve plans. Each state offers financial management services to help consumers and their representatives prepare workers' paychecks, tax returns, and other payroll forms. Each state also requires that worker timesheets and invoices for goods and services be compared to the purchasing plans, so that financial management services agencies only pay for those items consistent with the plan.

The three state Cash & Counseling programs—[Arkansas](#), [Florida](#), and [New Jersey](#)—take a number of steps to ensure that program funds are spent properly:

- **Arkansas** and **New Jersey** prohibit paid caregivers from serving as consumers' representatives because of the conflict of interest that might occur if representatives are also being paid.
- **Florida's** *Consumer Directed Care Plus Purchasing Plan* requires consumers and representatives to specify which services will be purchased and at what cost. Calculations are required to ensure that plans remain within their budgets.

## Resources: Consumer-Directed Care

### Home and Community-Based Services for People with Dementia and Their Caregivers

#### Additional Resources

- **Georgia** created a [Self-Directed Care Guide Book](#) that walks the reader step-by-step through developing a successful program. It provides potential pitfalls and examples of flourishing programs, with advice from experts and inclusion of additional resources on those subjects.
- The [CareFinder™](#), supported in part by the U.S. Administration on Aging and administered by the Alzheimer's Association, is an online interactive resource. It provides customized recommendations on home and community care, based on individual needs and preferences to ensure the best care match. CareFinder™ offers ways to recognize good care, communicate effectively with care providers, plan and pay for care, and find local resources. Resources are available to assist users in finding all the information they need on one Web site.

#### Additional Information

The U.S. Administration on Aging has developed eight toolkits in this series that focus on different aspects of providing home and community based services to people with dementia and their caregivers. These online toolkits are available at:

[http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/Alz\\_Grants/compendium.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Alz_Grants/compendium.aspx) .

Toolkit titles include:

1. Consumer-Directed Care
2. Disaster Preparedness
3. Resources for Individuals and Families
4. Serving African American Families
5. Serving Asian and Pacific Islander Families
6. Serving Hispanic Families
7. Single Point of Entry Systems
8. Supporting Family Caregivers