



Public Policy Issue Brief

Consumer-Directed, Home and Community Services for Adults with Dementia

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Consumer-Directed, Home and Community Services for Adults with Dementia

Executive Summary

Consumer-directed home and community services programs give participants and their representatives more choice regarding their services than do traditional programs. In consumer-directed programs, some part of the control over services shifts from the professional to the person with disabilities and his or her representative. Depending on the program, consumers may be able to choose their services and supports, who will deliver them, and when they will be delivered. Consumers may be able to hire and fire individual workers, or manage an individual budget for services and supports.

Those with dementia represent a large minority of users of Medicaid home and community care programs. Their families help them remain at home by willingly providing care, often in the face of many challenges, including behavioral symptoms and increased dependency as dementia progresses.

People with disabilities and their caregivers, including those with dementia, benefit from participation in consumer-directed programs. Elderly and non-elderly participants in consumer-directed programs and their family caregivers have better outcomes related to quality of life, independence, and satisfaction with care than those who rely on agency services. Quality of care is at least as good in consumer-directed programs. Importantly, studies have found no systematic evidence of abuse and neglect of participants in consumer-directed programs. This evidence is particularly compelling because the results are consistent across a number of different countries with varying cultural traditions and programs.

Despite the many benefits, consumer-directed programs also present special challenges for consumers with dementia and their family caregivers (i.e., dementia families). Along with potential benefits come increased management responsibilities for consumers. These responsibilities can be particularly difficult for dementia families to manage. People with dementia eventually experience loss of decision-making capacity and ability to communicate as well as behavioral symptoms that can be difficult to manage. Family caregivers of people with dementia experience more stress and poorer health outcomes than do other caregivers. Older adults with dementia or cognitive impairment are at higher risk of abuse and neglect, including self neglect, than their peers, problems which likely stem from the symptoms of dementia and caregiver burden.

This report draws on input from program officials in 11 states -- Arkansas, Colorado, Florida, Maine, Massachusetts, New Jersey, Oregon, South Carolina, Vermont, Washington, and Wisconsin who participated in telephone interviews about practices related to helping older adults with dementia direct their own services. The topics addressed during the telephone interviews include: determining whether a participant needs assistance with managing services, use of representatives, meeting family caregiver needs, special training, and quality assurance.

All states permit older adults with dementia to participate in at least one consumer-directed program. Oregon, Vermont, Washington, and Wisconsin have consumer-direction available as an option in all their home and community care programs serving older adults. So, consumer-direction in these states is not confined to a subset of programs. State practices regarding decision-making, caregiver needs, and quality assurance vary. Consumer-directed programs come in many different forms, ranging from programs that only offer services to those who can direct their own care, as is the case in some older state programs, to new Cash and Counseling programs that offer beneficiaries the option of managing a budget for services and supports to help them exercise this choice.

Based upon the study states' practices, the Cash and Counseling Vision Statement and a previous analysis, the Alzheimer's Association developed a set of policy recommendations, which is designed to ensure that the full range of consumer-directed programs meet the special needs of older adults with dementia. This set of recommendations was vetted by experts in dementia and consumer-direction, but they only represent the views of the Association, not necessarily those of the experts consulted.

1. Consumer-directed programs should be an option for adults with dementia who receive home and community services. However, no one should be required to direct services as a condition of receiving them.
2. It is critical for states to use the assessment of need process to determine if an individual has cognitive impairment. If so, the program should ensure that the individual has the help needed to manage services. This help often takes the form of a representative who handles whatever management tasks the consumer and the representative agree upon.
3. States need to evaluate a family caregiver's needs when that caregiver is making it possible for the adult with dementia to remain in the community and then connect the caregiver with available supportive services.
4. Assessors and consultants should have the skills and knowledge necessary to effectively help participants with dementia and their representatives use consumer-directed programs. Thus, states should require these professionals to have specialized training as some states do or to demonstrate that they have the requisite skills. Among the forms of training or expertise that assessors and consultants should have are methods of recognizing signs of abuse or neglect of consumers.
5. Quality assurance involves preventing problems and ensuring that quality of care and life is optimal for the consumer. Several steps could help ensure quality: the consultant should have frequent contact with the participant and his or her representative; quality assurance systems need to collect and analyze data on quality of care for adults with dementia; these systems could develop measures designed to alert consultants to the possibility that a consumer needs more monitoring; consultants could develop lists of consumers that they think need more oversight, with the presence of dementia being one of the considerations.

Consumer-Directed, Home and Community Services for Adults with Dementia

Consumer-directed, home and community services programs give participants and their representatives more choice regarding their services than do traditional programs. In consumer-directed programs, some part of the control over services shifts from the professional to the person with disabilities and his or her representative. Depending on the program, consumers may be able to choose which services and supports they receive, who will deliver them, and when they will be delivered. They may be able to hire and fire individual workers, or manage an individual budget for services and supports. People with disabilities and their caregivers, including those with dementia, benefit from participation in consumer-directed programs.

Despite the many benefits, consumer-directed programs also present special challenges for consumers with dementia and their family caregivers (i.e., dementia families). Along with potential benefits come increased management responsibilities for consumers. These responsibilities can be particularly difficult for dementia families. People with dementia eventually experience loss of decision-making capacity and ability to communicate as well as behavioral symptoms that can be difficult to manage. Family caregivers of people with dementia experience more stress and poorer health outcomes than do other caregivers. Older adults with dementia or cognitive impairment are at higher risk of abuse and neglect, including self neglect, than their peers, problems which likely stem from the symptoms of dementia, and caregiver burden.

The benefits of consumer-directed programs for dementia families and program features designed to support them are particularly important to consider now. The positive results of a large experiment with consumer direction – Cash and Counseling – and funding from the Robert Wood Johnson Foundation has led many states to consider implementing similar programs. In addition, the federal Deficit Reduction Act of 2005 give states much more leeway to implement or expand consumer-direction options in their Medicaid programs. This act permits states to integrate consumer-direction into their home and community services programs without obtaining Medicaid waivers. Today, most states in the country have at least one consumer-directed program under Medicaid and are considering more moves in this direction.

This issue brief, which is one of a series on health and long term care issues, is designed to accomplish four things:

- Provide background information about dementia and its effects on dementia families and their need for support in consumer-directed programs
- Discuss the evidence about consumer-directed program outcomes for dementia families
- Describe key program provisions in 11 consumer-directed programs that serve older adults with dementia
- Provide policy recommendations for states considering expansion or implementation of consumer-directed programs that serve dementia families.

Background

Medicaid consumer-directed programs are likely to be serving many people with dementia and their family caregivers. These dementia families present a unique challenge to programs because of the complex symptoms and progressive decline in functioning that are the hallmarks of dementia and the special challenges that family caregivers face.

The population with dementia represents a large minority of users of Medicaid home and community programs, many of which are consumer-directed. Seventy percent of the population with dementia lives in the home and community, largely with the help of family caregivers.¹ When individuals with dementia become impoverished, they rely on Medicaid for help with their long term care needs. Twenty-four percent of people of all ages who receive Medicare or Medicaid-funded home health care have moderate to severe cognitive impairment; this figure does not include people with mild impairment.² In addition, available data indicate that a large minority of people receiving Medicaid- and state-funded home care services have cognitive impairment – about 37 percent of people in Connecticut, Florida, and Michigan programs.³

Caring for those with dementia is challenging because of the nature of the disease and co-existing health conditions. Those with dementia often have deficiencies in decision-making capacity and communication that limit their ability to direct services without help. For example, Alzheimer's disease, which is responsible for at least half of dementias,⁴ is a progressive disease that gradually destroys a person's memory and ability to learn, reason, make judgments, and communicate. At some point in the course of their disease, most people with dementia experience changes in personality and may become withdrawn and depressed, experience agitation, or wander away from their homes unsupervised. People with advanced dementia need help with bathing, dressing, using the bathroom, eating and other daily activities. In the final stages of the disease, people lose their ability to communicate, fail to recognize loved ones, and become bed bound.

This situation is complicated by the fact that most of those with dementia have other conditions. For example, 95 percent of Medicare beneficiaries with dementia have at least one other chronic condition such as heart disease, diabetes, or chronic obstructive pulmonary

¹ Alzheimer's Association, *Alzheimer's Disease Facts and Figures 2007*, Washington DC.

² U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, Unpublished data from Rollup Summary Reports, Case Mix Means and Episode Counts, National Values for the 12-month period from Mar 2003–Feb. 2004, Baltimore, MD.

³ Fortinsky RH, Fenster JR, and Judge JO. Medicare and Medicaid home health and Medicaid waiver services for dually eligible older adults: Risk factors for use and correlates of expenditures. *Gerontologist* 2004;44(6):739-749. The data come from assessments of 5,232 elderly people served by Connecticut's Medicaid home and community-based waiver program. Mitchell G, Salmon JR, Polivka L, and Soberon-Ferrer H. The Relative Benefits and Cost of Medicaid Home- and Community-Based Services in Florida. *Gerontologist*. 2006;46(4):483-494. The data come from assessments of 6,014 adults age 60+ served by 5 any of 5 Florida Medicaid home and community-based waiver programs. Hirdes JP, Fries BE, Morris JN, et al., Home Care Quality Indicators (HCQIs) Based on the MDS-HC. *Gerontologist*. 2004;44(5):665-679. The data come from assessments of 11,252 low income adults served by a Michigan home and community-based waiver program and a state-funded case management program.

⁴ Alzheimer's Association, *Alzheimer's Disease Facts and Figures 2007*, Washington DC.

disease.⁵ These conditions can be very difficult to manage. Diabetics, for instance, may require a special diet, medications, and careful monitoring of blood glucose levels.

Given the complicated nature of dementia symptoms and the presence of other health conditions, being a dementia caregiver presents special challenges and consequences. Challenges involve managing complicated medical conditions, coping with behavioral symptoms, and providing heavy care. For example, dementia caregivers are much more likely than other caregivers to help with loss of bladder or bowel control (32% v. 13%); and with bathing (35% v.25%).⁶ As a consequence, dementia caregivers experience disproportionately high levels of stress, and health problems, and miss work more often than their peers. For example, about one quarter of dementia caregivers report that their responsibilities are highly stressful, compared to 15 percent of other caregivers.

Finally, although families do a great deal for their loved ones with dementia, those with this condition are at a higher risk of abuse and neglect, including self neglect, than others. A study of clients referred to adult protective services in two counties in New Jersey found that the most prevalent newly diagnosed condition was dementia at 62 percent of clients.⁷ Dementia was positively correlated with caregiver neglect among women and cognitive impairment was associated with caregiver neglect for both genders. Another study conducted in Connecticut found that abuse and neglect at the hands of others was more likely in people with cognitive impairment than in those without.⁸ The risk of abuse or neglect worsened for those who acquired cognitive impairment during the course of the study, while risk did not get worse for those who acquired physical disabilities. The same was not true for those who acquired new impairments in activities of daily living. The researchers note that the effect of cognitive impairment is probably even greater because the data only include “self-reported” abuse.

Despite the challenges dementia families face, they are capable of participating in consumer-directed programs. Although adults with cognitive impairment may have difficulty managing their services without assistance, unless they have very severe impairments, they retain the ability to indicate who should make decisions on their behalf and to make their preferences about services known. A study of 51 pairs of older adults with cognitive impairment and their caregivers living in the community found that individuals with mild to moderate cognitive impairment are able to respond to questions about preferences for care and their involvement in making decisions consistently over time.⁹ Almost all of people with mild to moderate cognitive impairment were able to identify someone they wished to have handle health and personal care decisions for them.¹⁰ Seventy-four percent of these

⁵ Ibid.

⁶ Alzheimer’s Association & National Alliance for Caregiving, *Families Care: Alzheimer’s Caregiving in the United States*, 2004.

⁷ Heath JM, et al, “The Prevalence of Undiagnosed Geriatric Health Conditions among Adult Protective Services Clients,” *The Gerontologist*, vol.45, no.6, pgs.820 -823.

⁸ Lachs, et al., “Risk factors for reported elder abuse,” *Gerontologist*, vol. 37, no.4, pgs.469-474 1997.

⁹ Friss Feinberg L, and Whitlatch CJ, “Are Persons with Cognitive Impairment Able to State Consistent Choices?” *The Gerontologist*, vol.41, no.3 pages 374-382.

¹⁰ Friss Feinberg L, and Whitlatch CJ, “Decision-making for Persons with Cognitive Impairment and their Family Caregivers,” *American Journal of Alzheimer’s Disease and Other Dementias*, vol.17, no.4, pgs. 237 – 244, July/August 2002

individuals named their primary family caregiver as the person who should be making these decisions and most individuals preferred help from family and friends, compared to having to rely on a paid worker. The study results are similar to those of earlier case studies and studies of nursing home residents with dementia who were able to state preferences about health care decisions.

Family caregivers know their loved ones with dementia and provide the types of assistance their relatives need so they can remain in familiar, comfortable surroundings in their own homes.¹¹ Families cobble together whatever assistance they cannot provide themselves. In traditional programs, family caregivers may have to adjust to rules such as those some agencies have, which can include prohibitions against performing certain tasks or only allowing workers to come from 9:00 AM to 5:00 PM. In contrast, consumer-directed programs permit dementia families to find help that fits their needs.

To summarize, those with dementia represent a large minority of users of Medicaid home and community care programs. Their families help them remain at home by willingly providing care in the face of many challenges including behavioral symptoms and increasing dependency as dementia progresses. Family caregivers provide heavy care for years and face increasing costs in terms of their own health and stress levels. Although most families cope with this stress, a person with dementia can be at increased risk of abuse or neglect.

Consumer-Directed Program Outcomes for Participants and their Caregivers

Consumer-directed home and community services offer those with dementia and their families the ability to tailor services and supports to their needs and reap benefits in terms of quality of care, quality of life, and reduced caregiver stress. The following example shows the potential benefits for dementia families and available research indicates that older people with cognitive impairment and their caregivers have better outcomes in consumer-directed programs than they experience in traditional programs.

Mrs. Bennett's Experience

The example of Mrs. Bennett, a 98-year-old widow who lives with her granddaughter, illustrates how one form of consumer-direction -- Cash and Counseling -- can be helpful to dementia families.¹² Mrs. Bennett has mild dementia, high blood pressure, and needs help with three daily activities and walking. Mary, her granddaughter, is Mrs. Bennett's representative. Before enrolling in consumer-directed care, Mrs. Bennett received care from Mary and a home care agency. The agency's hours were such that workers came at 8:00 AM, even though Mrs. Bennett does not get out of bed until 10:00 AM and workers often changed daily and sometimes did not show up for work. With consumer direction, Mary hired one worker -- Sylvia—who receives higher hourly pay and a more convenient schedule than she had while working in an agency. Since Sylvia is reliable and her schedule is convenient, Mary has been able to resume her in-home accounting business. The relationship

¹¹ Doty P, *Consumer-Directed Home Care: Effects on Family Caregivers*, Family Caregiver Alliance National Center on Caregiving, October 2004.

¹² This case history was adapted from San Antonio P et al., "Case Histories of Six Consumers and Their Families in Cash and Counseling," *Health Services Research*, vol.42, no.1, pgs.533-549. February 2007.

between Mrs. Bennett and Sylvia is a good one and Mrs. Bennett's family appreciates Sylvia's good work.

Evidence from US and International Research

The example of Mrs. Bennett illustrates why in U.S. and international studies, consumer-directed programs perform well in comparison with home and community services programs that rely on professionals and home care agencies to manage and deliver services.¹³ Elderly and non-elderly participants in consumer-directed programs and their family caregivers have better outcomes related to quality of life, independence, and satisfaction with care than those who rely on agency services. Quality of care is at least as good in consumer-directed programs. Importantly, studies have found no systematic evidence of abuse and neglect of participants in consumer-directed programs. This evidence is particularly compelling because the results are consistent across a number of different countries with varying cultural traditions and programs.

U.S. Studies

In the U.S., studies of consumer-directed programs were largely carried out on means-tested programs, where participants have to be impoverished to participate. Two major studies have been conducted that have demonstrated positive results.

- A random sample of participants in California's In-Home and Supportive Services Program (IHSS) found that those who directed their own services reported more satisfaction with their services, higher quality of care, and better well-being than those who relied on agency services.¹⁴ Participants with paid family caregivers reported more of a sense of security and satisfaction with services than those who hired non-family members. Paid family caregivers reported more stress and better relationships with participants than non-family workers. Paid family caregivers of consumer-direction participants reported that they supervised themselves more often than being supervised by the participants with disabilities.
- The Cash and Counseling Demonstration used a randomized-controlled trial to test the outcomes of consumer-directed programs in three states. The study found that elderly and non-elderly participants who managed their own services had fewer unmet needs for care, and reported more satisfaction with their care and quality of life than

¹³ Foster L, et al, *Effects of Consumer Direction on Adults' Personal Care and Well-Being in Arkansas, New Jersey, and Florida*, USDHHS, ASPE, Washington DC May 2005.; Foster L, et al., *How Cash and Counseling Affects Informal Caregivers: Findings from Arkansas, Florida, and New Jersey*, USDHHS Washington DC July 2005. Tilly J, *Consumer-Directed Long-Term Care: Participants' Experiences in Five Countries*, AARP Washington DC April 1999; Tilly J, Wiener JM, & Evans Cuellar A, *Consumer-Directed Home and Community Services Programs in Five Countries: Policy Issues for Older People and Government*, The Urban Institute, Washington DC, October 2000. Lundsgaard J, *Consumer Direction and Choice in Long-Term Care for Older Persons, Including Payments for Informal Care: How Can It Help Improve Care Outcomes, Employment and Fiscal Sustainability?* OECD Paris May 2005.

¹⁴ Benjamin AE, et al., *Comparing Client-Directed and Agency Models for Providing Supportive Services at Home: Final Report*. Los Angeles University of California 1998.

participants who relied on agency services.¹⁵ This group also reported the same or significantly fewer adverse health outcomes. A comparison of older Arkansas participants with and without mental health diagnoses found that Cash and Counseling worked well for both groups in comparison to the control groups.¹⁶ The family caregivers of consumer-directed participants reported less physical and financial strain and less worry about the care participants were receiving.¹⁷ In Arkansas, consumer-direction participants had significantly less use of nursing homes over a three-year time period than those who relied on agency services.¹⁸ In the three demonstration states, there was no widespread abuse of participants or improper use of public program funds¹⁹ and counselors reported few incidents of abuse, self neglect, or financial exploitation.²⁰ Counselors also reported their view that representatives generally acted in the participants' best interest.²¹

These two studies have some limitations related to interpreting results for older persons with cognitive impairment because of the methodological issues inherent in studying this population. People with severe cognitive impairment cannot speak for themselves with any reliability in telephone surveys. So, if they are to be included in a study, a proxy must respond to questions for them.

The California, and Cash and Counseling studies took different approaches to dealing with this issue. The California participant survey excluded those with severe cognitive impairments, although those with mild and moderate impairment were surveyed. The Cash and Counseling results have not been analyzed separately for those with cognitive impairment, although this population was included in the demonstration project. Available data show that about 28.8 percent of consumers aged 65 and over in Arkansas were likely to have cognitive impairment.²² The figure was 45.7 percent of those aged 60 and over in Florida. No data were available from New Jersey.

It is possible to infer that older adults with cognitive impairment or dementia did benefit from consumer direction in California's IHSS program and in Cash & Counseling because results for the older participants were largely positive and a large minority of study enrollees likely had these conditions. Older persons in the consumer-directed treatment groups in New Jersey and Arkansas were more likely to receive paid care, were more satisfied

¹⁵ Foster L, et al, *Effects of Consumer Direction on Adults' Personal Care and Well-Being in Arkansas, New Jersey, and Florida*, USDHHS, ASPE, Washington DC May 2005,

¹⁶ Ce Shen, et al., *Does Mental Illness Affect Consumer Direction of Community-Based Care? Lessons from the Arkansas Cash and Counseling Program*, cited with permission from author March, 2007.

¹⁷ Foster L, et al., *How Cash and Counseling Affects Informal Caregivers: Findings from Arkansas, Florida, and New Jersey*, USDHHS Washington DC July 2005.

¹⁸ Dale SB, Brown R, "Reducing Nursing Home Use Through Consumer-Directed Personal Care Services," *Medical Care*, vol.44, no.8, August 2006.

¹⁹ Choosing Independence An Overview of the Cash & Counseling Model of Self-Directed Personal Assistance Services, Robert Wood Johnson Foundation. Princeton, New Jersey, Fall 2006.

²⁰ Schore J, Foster L, Phillips B, "Consumer Enrollment and Experiences in the Cash and Counseling Program," *Health Services Research*, vol.42, no.1, pgs.446-466, February 2007.

²¹ Ibid.

²² Brown RS & Dale SB, "The Research Design and Methodological Issues in the Cash and Counseling Evaluation," *Health Services Research Special Issue*, vol.42, no.1 February 2007, Part II.

with their care, and had fewer unmet needs for care.²³ However, in Florida the older treatment group did not have more positive outcomes than those in the control group because so few consumer-directed treatment group members received services.

International Studies

International studies largely were conducted on programs that are not means-tested; that is, participants do not have to be impoverished to participate. These studies' results are consistent with those in the U.S.

- Sixty-five percent of Austrians who received a cash allowance reported that it gave them more independence, choice and control in their lives and that they had greater freedom to select their caregivers.²⁴
- In Germany, 43 percent of beneficiaries reported that the quality of their care had improved as a result of their cash allowance; another 55 percent said that quality remained the same.²⁵
- The Netherlands conducted a randomized-controlled trial of consumer-direction and found that 85% of participants who received cash had the ability to choose and control their services, while only 46% of those relying on agencies could do so. Those receiving cash reported more satisfaction with quality of care.²⁶

Adults with cognitive impairment and dementia participated in all the studies, including the randomized, controlled trials in the Netherlands and the U.S. The careful design of these studies and their positive results for adults of all ages with disabilities and their caregivers indicate that that older adults with dementia or cognitive impairment could benefit from participation in consumer-directed programs.

Many of these U.S. and international studies relied on proxy respondents to answer questions on behalf of participants. The Cash and Counseling Demonstration in the U.S. conducted a telephone survey of Medicaid beneficiaries in New Jersey that examined whether satisfaction with paid home care agency workers differed if the consumer or a proxy respondent responded to the survey.²⁷ There were no statistically significant differences in how these two groups responded to four questions related to satisfaction with workers; that is, the type of respondent did not predict satisfaction with workers. The authors speculate that the results may have been due, in part, to the fact that proxy respondents were asked to have the consumer present during telephone interviews and to respond as they believed the consumer would have responded. This study indicates that consumer-directed research results

²³ Carlson BL et al., "Effects of Cash and Counseling on Personal Care and Well-Being," *Health Services Research*, vol.42, no.1, pgs.467-487, February 2007.

²⁴ Tilly J, *Consumer-Directed Long-Term Care: Participants' Experiences in Five Countries*, AARP Washington DC April 1999

²⁵ Ibid.

²⁶ Tilly, op cit.

²⁷ Squillace MR, et al., "An Exploratory Study of Personal Assistance Service Choice and Decision-Making Among Persons with Disabilities and Representative Representatives," *The Journal of Mental Health and Aging*, vol.8, no.3, pgs 225-240, December 2001.

are applicable to those with cognitive impairment who had proxy respondents answer questions for them.

Consumer-Directed Program Provisions

Older adults with dementia can express preferences regarding their care and are participating in Medicaid consumer-directed programs. Given dementia families' vulnerabilities and the course of the disease, they are likely to need assistance with managing their services. The Alzheimer's Association decided to examine how states address the special needs of this population and to identify and report on related program practices.

Methodology

We reviewed a recent survey of consumer-directed programs serving older people²⁸ and consulted with experts in consumer direction to identify states for further study. From the publication we identified ten states that have existing individual budget programs serving elderly people. Consultation with experts identified an additional four state programs, which they thought might have special provisions related to helping older people with cognitive impairments manage their home and community services.

Program officials in each state were asked if they would participate in a telephone interview about practices related to helping older adults with cognitive impairment direct their own services. The topics addressed during the telephone interviews include: determining whether a participant needs assistance with managing services, use of representatives, meeting family caregiver needs, special training, and quality assurance.

Interviews were conducted with program officials in 11 states -- Arkansas, Colorado, Florida, Maine, Massachusetts, New Jersey, Oregon, South Carolina, Vermont, Washington, and Wisconsin. Detailed results by state are available in Appendix 1. Officials reviewed the descriptions of their programs for accuracy.

Findings

All states permit older adults with cognitive impairment or dementia to participate in at least one consumer-directed program. Oregon, Vermont, Washington, and Wisconsin have consumer-direction available as an option in all their home and community care programs serving older adults. So, consumer-direction in these states is not confined to a subset of programs. State practices regarding decision-making, caregiver needs, and quality assurance vary.

1. Decision-Making Issues

For older adults with dementia, having the assistance of a representative who can act on their behalf is critical to the success of consumer-directed programs. Representatives and

²⁸ Spillman BC, Black KJ, Ormond BA, *Beyond Cash and Counseling: An Inventory of Individual Budget-Based Community Long Term Care Programs for the Elderly*, Kaiser Commission on Medicaid and the Uninsured, Washington DC April 2006.

participants with dementia together manage services, but the representative often retains primary responsibility for making and implementing decisions, including managing services; assuring the receipt and quality of services; handling the participant's budget for services; and, in some cases, paying workers.

A high percentage of older participants in consumer-directed programs use representatives in those states that provided data. In Massachusetts 62 percent of participants use representatives and 26 percent of program participants are aged 65 and older (14,200 participants in FY2006). Seventy-five percent of participants in Maine's program use a representative (73 total participants in January 2007). In 2006, about 65 percent of Vermont Choice for Care participants used the consumer-direction option and, of those, 50 percent have representatives.

States recognize the importance of representatives and use the assessment of need process to find out whether an older person with dementia needs a representative to help manage services. All states assess whether the participant has cognitive impairment and many of the states have special assessments of the participant's ability to manage services. Arkansas, New Jersey, and Vermont have the most informal approaches in that the consultant²⁹ or the participant initiates discussions about use of a representative. Arkansas has a self-assessment form available to help participants decide whether they need a representative.

A second group of states has a more formal approach to determining whether a participant with cognitive impairment will use a representative. Colorado requires that a physician fill out a form stating that the participant is capable of managing services. If the physician cannot attest to the participant's capacity, he or she must have a representative. If cognitive impairment is detected during the assessment of need, South Carolina requires a formal assessment of the participant's ability to direct services.

States have a variety of approaches to rules governing who can be a representative. In most Oregon programs, Washington and Wisconsin anyone can be a representative. In Arkansas, Florida, Massachusetts, New Jersey, Oregon's Independent Choices, South Carolina, and Vermont anyone can be a representative except a paid caregiver. Other states have more specific requirements governing representatives. In Maine, the representative must be a family member or significant other and cannot be a paid caregiver. In Colorado, representatives must know the participant for at least two years and must have no criminal convictions.

Representatives' responsibilities fall into three categories. In Oregon Project Independence, the representative must take on all management responsibilities for the program participant, including payroll functions. In the remaining Oregon programs, Washington, and Wisconsin, the representative takes on whatever tasks the participant asks them to manage. In the other states, representatives manage services but the state requires them to rely on financial management services agencies to handle payroll functions for workers.

²⁹ Consultant is a term some consumer-directed programs prefer to use in place of case manager or service coordinator. These latter terms are thought to indicate that control rests with the program official rather than the consumer.

2. Caregiver Issues

Since older adults with dementia are likely to be living in the community with the help of stressed family caregivers, state officials were asked what they do to assess or meet the needs of these caregivers. In five of the states, the focus of the program is on the participant with disabilities, not family caregivers. In Arkansas, Maine, Oregon, Vermont, Washington, and Wisconsin, there is some attention to caregivers' needs during the assessment process and referral to caregiver support programs when the caregiver needs help. Some states offer respite services to caregivers. Washington has a caregiver burden screening as part of its assessment tool and, if the caregiver's burden exceeds a certain score, the caregiver is referred to support programs.

3. Quality Assurance

Quality assurance for those with cognitive impairments involves dementia training for those who interact with this population, recognition of risks to the participant and planning how to mitigate these risks, as well as monitoring the quality of care the participant receives.

a. Training

Determining the experiences of an older person with dementia can be difficult due to the deterioration in the person's 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 this set of diseases. Therefore, state officials were asked what kind of preparation assessors, consultants, and providers must have for dealing with the special needs of this population. In Arkansas, Colorado, Massachusetts, and New Jersey, assessors and consultants either are hired with knowledge and skills or acquire them on the job. In Florida, Oregon, South Carolina, and Washington, training on dementia issues is available to these professionals. Vermont makes a dementia specialist available to assist consultants. Three states have mandatory dementia training. In Maine, assessors and consultants receive dementia training as part of their orientation to their jobs and family service providers are required to have training. Washington and Wisconsin require consultants to have training. Washington developed a comprehensive training program for care providers, which covers the basics of dementia, communication, behaviors, and providing assistance with daily activities, among other topics.

b. Risks

A guide to quality home and community services, which was prepared for the Centers for Medicare & Medicaid Services, states that identifying risks and ensuring that they are well managed is part of providing quality home and community services.³⁰ Most study states address health, behavioral, and safety risks to the participant informally during the service planning process. However, four states have programs that require participants and their

³⁰ Galantowicz S et al., *Risk Management and Quality in HCBS: Individual Risk Planning and Prevention, System-Wide Quality Improvement*, published as part of CMS' National Contract for Quality in Home and Community Based Waiver Services February, 2005.

representatives to acknowledge and sign forms addressing any risks associated with the service plan. New Jersey developed a form that lists and scores risks and suggests methods of addressing the risks. Oregon Independent Choices requires formal risk agreements between the program and the participant and his or her representative. Vermont supports an individual's right to self-determination and to receive services under conditions of acceptable risk. The consultant will develop a formal risk agreement with the consumer, if he or she believes it is necessary. Wisconsin has a risk assessment form and process for documenting risks and how to mitigate them. Arkansas and Washington share a unique approach: their assessment forms have items that can trigger risks that a service plan must address. Examples of the triggers include medication management and a need for caregiver training.

c. Monitoring

The states monitor quality through their consultants. The frequency and type of consultant contact with program participants varies greatly among the states. For example:

- Arkansas' consultants contact participants monthly by telephone during the first six months after they begin receiving services. Afterward, contact occurs quarterly unless there is a reason to maintain monthly contact. In-home visits occur twice a year. More frequent monitoring visits are triggered by a change in caregiver or participant status.
- Vermont has frequent and intense contact with participants. Consultants visit participants at least once a month in their homes. Contact can be more frequent as the participants' need for services varies over time.
- New Jersey's consultants make quarterly home visits. In addition, monthly telephone contacts are required during the first 6 months after entering the program.
- South Carolina's consultants visit the consumer quarterly and have monthly telephone calls with the representative.

All states' programs refer suspected cases of abuse to Adult Protective Services. No state has special quality assurance procedures for older adults with cognitive impairment.

Although most states have separate quality assurance systems for their consumer-directed programs, no aspects of these systems are tailored to the special conditions of people with cognitive impairment, dementia, or their families. However, Arkansas is developing quality measures specific to the population with dementia.

Program Policies to Ensure that Consumer-Directed Programs Provide Supports to Dementia Families

Consumer-directed programs come in many different forms, ranging from programs that only offer services to those who can direct their own care as is the case in some older state programs to new Cash and Counseling programs that offer beneficiaries the option of managing a budget for services and supports to help them exercise this choice.

Based upon the study states' practices, the Cash and Counseling Vision Statement³¹ and a previous analysis,³² the Alzheimer's Association developed a set of policy

³¹ This statement represents expert consensus around the essential elements of state Cash & Counseling programs and can be obtained from www.cashandcounseling.org.

recommendations, which is designed to ensure that the full range of consumer-directed programs meet the special needs of adults with dementia. This set of recommendations was vetted by experts in dementia and consumer-direction, but they only represent the views of the Association, not necessarily those of the experts consulted.

1. Consumer-directed programs should be an option for adults with dementia who receive home and community services. However, no one should be required to direct services as a condition of receiving them.
2. It is critical for states to use the assessment of need process to determine if an individual has cognitive impairment. If so, the program should ensure that the individual has the help needed to manage services or has the option of choosing a representative. If the person with cognitive impairment has a condition like Alzheimer's disease, where functioning declines over time, periodic reassessments are critical.
3. A representative's responsibilities should be whatever the consumer and the representative agree upon. Representatives also should agree to have a consistent presence in the life of the person with dementia.
4. Adults with dementia and their representatives should have access to supports that can help them develop a purchasing plan for their benefits, manage services and employees, carry out payroll functions, and ensure quality of services. For example, most states make financial management services available to participants and representatives; this service provider handles payroll functions such as withholding taxes and issuing checks to workers.
5. The consultant, representative, and the consumer need a common understanding of the consumer's preferences regarding services. Representatives need to understand that they are expected to accommodate the consumer's preferences regarding services to the extent feasible. Representatives may want advice or training on how to elicit the preferences of the person with dementia, particularly as the disease progresses and behaviors become the primary form of communication.
6. States need to evaluate a family caregiver's needs when that caregiver is making it possible for the person with dementia to remain in the community. If the caregiver needs help, then the program should connect the caregiver with supportive services that may be available in long term care programs or in the community. The strain of being a dementia caregiver can be overwhelming³³ and family caregivers need relief to

³² Tilly J, Riggs J, Maslow K, Brown K, Medicaid Managed Long Term Care for People with Alzheimer's Disease and Other Dementias, Alzheimer's Association, May 2006.

³³ Friss Feinberg L, Wolkwitz K, Goldstein C, *Ahead of the Curve; Emerging Trends and Practices in Family Caregiver Support*, AARP, Washington DC March 2006.

- help them avoid deterioration in their own health or well-being and to delay institutionalization of their loved ones.
7. Assessors and consultants should have the skills and knowledge necessary to effectively help adults with dementia and their representatives use consumer-directed programs. Thus, states should require these professionals to have specialized training as some states do or to demonstrate that they have the requisite skills.
 8. In consumer-directed programs, responsibility for training workers rests with the consumer. However, the family caregiver, who may be a representative or a paid caregiver, may need training on how to care for an adult with dementia most effectively. For example, knowing about strategies for dealing with unsafe wandering could be very helpful to caregivers. Therefore, consultants need to know where to refer caregivers for sources of specialized training.
 9. Representatives, caregivers, and consumers may also need training in handling management tasks, such as how to hire, fire, supervise workers, handle responsibilities for oversight, payment, etc.
 10. Among the forms of training or expertise that assessors and consultants should have are methods of recognizing signs of abuse or neglect of consumers. If state law does not already require this, these professionals should be required to report abuse or neglect to adult protective services departments.
 11. Quality assurance involves preventing problems and ensuring that quality of care and life is optimal for the consumer. Several steps could help ensure quality.
 - a. Quality of care problems will be very hard to detect unless the consultant has frequent contact with the participant and his or her representative. Most states use a combination of telephone contact and in-home visits. Smaller programs like Vermont visit consumers at home once a month. Larger programs have monthly telephone calls and quarterly in-home visits. For participants with a progressive dementia, the frequency of visits should not decline over time because a situation that works for the participant and caregiver now may be untenable several months later.
 - b. Quality assurance systems need to collect and analyze data on quality of care for adults with dementia because this population is more vulnerable to problems than adults without this condition.
 - c. States should develop measures designed to alert consultants to the possibility that a consumer needs more monitoring. Such measures might include a change in cognitive status, or representative, hospitalization, an accumulation of unspent funds in a consumer's account, or consistent overspending. Consultants should develop lists of consumers that they think need more
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oversight, with the presence of dementia being one of the considerations.

- d. Consultants should work with dementia families to encourage them to set goals for improving quality of care and of life and plan how to achieve these goals, and then discuss progress toward those goals at periodic assessments or contacts.

Selected Characteristics of Consumer Directed Programs Serving Participants with Dementia

State/Program	Determination of Need for Assistance	Who can be a Representative?	Representative's Responsibilities	Caregiver Needs	Dementia training	Quality Assurance
AR/Independent Choices	Cognitive impairment or diminished capacity will trigger a discussion about whether the participant needs a representative. When indicated, assessor suggests the participant use a self assessment form.	Anyone except a paid caregiver.	Can be anything except payroll functions. State uses financial services management agencies to manage payroll, pay for goods and services and budget funds management. Representative has to be in weekly contact with consumer, and handles submission of time sheets, changes to cash expenditure plan, and coordination with paid and unpaid caregivers.	The assessment has caregiver burden questions and, if there are issues, caregiver will be referred to other programs or community resources.	No mandatory training requirement, but the program tries to hire nurses with geriatric certification and most nurse assessors get that certification after being hired. This certification addresses dementia issues.	In the first 6 months, consultants contact participants monthly by telephone. Afterward, contact occurs quarterly unless there is a reason to maintain monthly contact. In home visits occur twice a year. More frequent monitoring visits are triggered by a change in caregiver or participant status. Assessor call Adult Protective Services (APS) when they see potential abuse.
CO/Consumer-Directed Care for the Elderly	Physicians sign a "statement of consumer capability" to direct services. If physician cannot, then the family designates a representative, who completes a form accepting this role.	Representatives have to have known clients for 2 years, have no criminal convictions for harm against a person, among other standards.	Can be anything except payroll functions. State uses a financial management services agency to manage payroll.	Not the focus of the program.	Representatives receive training on the vulnerability of clients.	Consultants do in-home visits 2 times a year, telephone contact 2 times a month first 3 months and 3 times a year thereafter. Consultants report potential abuse to APS.
Florida/Consumer-Directed Care+	Staff can require a representative for a participant who is having difficulty managing employees or carrying out the purchasing plan. Representatives sign a representative agreement that lays out their responsibilities.	Anyone but a paid caregiver.	Representatives hire and manage workers, ensure participants receive services, and file paperwork for payment. The State uses a financial management services agency to manage the payroll, payment of approved goods and services, and budget funds management.	Not the focus of the program.	Training is available through dementia centers and Alzheimer's Association chapters.	Consultants contact participants monthly to discuss account statements and purchasing plans. Annual assessments occur to review eligibility, the care plan, and the purchasing plan. Consultants call in APS when they suspect abuse.
ME/Family Service Provider Option in all programs	The assessment collates responses to certain questions that determine ability to manage services.	A family member by blood or marriage or a significant other in a committed partnership, but representative cannot be a paid caregiver.	Representatives hire, fire, train workers, and maintain records for payroll. A financial management services agency manages payroll functions.	Assessment process asks caregivers what they do now for the participant, what they need help with, and what they can continue providing. Respite services are available.	Assessors and consultants receive dementia training as part of their orientations to their jobs. Family service providers receive mandatory dementia training.	Consultants make home visits 3 times a year and have telephone contact once a month. Consumers can request less frequent contact. All professionals and health care personnel have a mandatory reporting requirement when they suspect abuse.
MA/Personal Care Attendant Program	All participants are assessed for their capacity to manage services using a special form.	Anyone but a paid caregiver.	Representatives must live in close proximity to consumer and be ready to help with administrative tasks. A financial management services agency manages payroll functions.	Not the focus of the program.	Assessors and consultants must have 1 or 2 years of experience with disability populations.	During the first year, consultant has quarterly telephone or face to face contact with the participant. After one year, annual contact. Consultants are trained to report abuse when they see it.
New Jersey/Medicaid Personal Care Assistant/ Personal Preference Program	During home visits, assessors observe the participant and determine whether a representative may be needed. If so, the representative fills out a "nomination of representative" form to ensure that they know their responsibilities.	Anyone but a paid caregiver.	Representatives must send in time sheets to the financial management services agency, make sure cash management form is up to date, and report any problems that occur.	Not the focus of the program.	Consultants acquire requisite skills through their work.	Consultants make quarterly home visits, and, during the first 6 months, monthly telephone contacts. Consultants must report suspected abuse. A risk assessment form is something client or representative sign, which lists and scores risks and mitigating factors and suggests solutions to problems.

Selected Characteristics of Consumer Directed Programs Serving Participants with Dementia

Oregon/Project Independence (OPI) & Independent Choices (IC)	Assessment tool is used to determine whether someone has cognitive impairment and impaired decision-making capacity. If so, the need for a representative is discussed.	In OPI, anyone can be a representative. In IC, representatives cannot be paid caregivers or use IC cash benefits to pay themselves for managing program responsibilities on participant's behalf.	In OPI representatives' responsibilities are determined through the service planning process. An IC surrogate handles all benefit and employer responsibilities including managing payroll and tax functions (participant in IC Program remains the employer of record). An individual's capacity to jointly manage their IC cash benefit and assist with directing their services is determined by their planning team.	If caregiver burnout occurs, then referrals are made to caregiver support programs. The AAAs administering the programs in about half the state do integrate family caregiver needs into the care plan explicitly. Waiver programs have respite available when caregiver burnout is a concern. People control their cash benefits in IC. Hence a person who shares a home with and receives care from a family member spouse may use their IC cash benefits to support the well-being of his/her family. (For example: purchasing personal care or housecleaning services in order to give their family member time off from care giving.)	Training is available to professionals and direct service providers.	Oregon uses a common set of health, safety, risk management, and service satisfaction standards to measure program performance. Each program and many regional offices also use methods that exceed state minimum requirements. For example, the state requires an initial service assessment and, no less than annual reassessments for people receiving services. Some local offices and the IC program call for a service reassessment every six months. All programs identify, assess and address risks throughout service planning process. In addition, Adult Protective Services offers intensive case management to those at risk.
SC/SC Choices	If any cognitive impairment is detected during assessment, a second assessment of ability to direct occurs.	Anyone but a paid caregiver.	Representatives are the employer of record for workers and a financial management services agency manages payroll functions.	Not the focus of the program.	Training is available to assessors and consultants.	Consultants do quarterly in-person visits with participant & monthly calls with representative. Consultants must report suspected abuse to APS.
VT/Choices for Care	Assessment includes measures of cognitive impairment. If a participant with cognitive impairment chooses consumer direction, the consultant uses a questionnaire to help the participant choose a representative. The consultant uses an employer/agent certification form to discuss the representative's responsibilities.	Anyone but a paid caregiver.	Hire, fire, train workers and ensure care is received as called for in service plan. A financial management services agency handles payroll functions.	Caregiver needs are not assessed but the consultant refers caregivers to caregiver support programs and Choices can provide up to 720 hours of respite a year.	No mandatory training requirement. However, consultants have access to a dementia specialist, if consultation is needed.	Consultant does minimum of monthly home visits with participant and must report suspected abuse to APS. While the program supports maximum consumer choice, the consultant can ask a participant to sign a risk agreement.
WA/COPEs	Assessment determines cognitive impairment, presence of behavioral symptoms, & diagnosis. It also asks if participant has someone helping them make decisions.	Anyone.	Responsibilities vary according to participant's capacity and what he or she wants the representative to do.	The assessment tool has a caregiver burden screen. If caregiver's burden exceeds a certain score, a referral is made to caregiver support programs.	WA has a mandatory training requirement for consultants that includes dementia issues. An on-line training program on dementia is available.	Consultants must report suspected abuse to APS. Assessment tool has 6 triggers for risks that the care plan must address, such as medication management, need for caregiver training.
WI - Milwaukee Co./Family Care	Assessment has a screen for cognitive impairment and a more detailed evaluation that determines what assistance is needed.	Anyone.	Representative represents participant's wishes regarding services and can be the employer or use a financial management services agency for payroll functions.	Program use the AMA caregiver self assessment form to determine whether caregivers need help and those that do are referred to caregiver support programs.	No mandatory training requirement.	Consultant meets quarterly with participant & representative. Consultants refer suspected abuse to APS. They have a risk assessment form and process for documenting risks and how to mitigate them.