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# PUBLIC POLICY ISSUE BRIEF

# Medicaid Managed Long Term Care for People with Alzheimer's Disease and Other Dementias

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# Medicaid Managed Long Term Care for People with Alzheimer's Disease and Other Dementias

## Summary

A growing number of states are turning to managed long term care in their Medicaid programs for younger adults and elderly people with disabilities, including those with Alzheimer's disease and other forms of dementia. States are doing this for two reasons: to control growth in their Medicaid expenditures and to improve care by helping Medicaid beneficiaries receive appropriate, quality services.

Although a number of studies of Medicaid managed long term care programs and plans have been done, none has focused on the special needs of people with Alzheimer's disease and other dementias. More attention to this group of beneficiaries is warranted because they represent a large proportion of those using Medicaid long term care services and because their diseases create a unique and difficult constellation of care challenges which, if not managed appropriately, result in poor care and excessive cost.

This issue brief describes how two states, Massachusetts and Wisconsin, have addressed the special needs of beneficiaries with dementia in the design and implementation of their Medicaid managed long term care programs and makes policy recommendations for states that are considering implementing or modifying such programs. In summary, these recommendations would:

1. Ensure that people with dementia and their caregivers have the help they need to make good choices about enrollment in Medicaid managed long term care plans.

2. Require managed long term care plans to identify enrollees with dementia.

3. Ensure that managed long term care plans have assessors, care managers, and providers who are dementia capable. This means that they must have the requisite knowledge and skills to assist with and manage the symptoms and care needs of people with dementia throughout the course of their disease.

4. Require that providers and professionals carry out assessment, care management, and service delivery in close cooperation with family and other primary caregivers, who are often best able to communicate the needs of those with dementia.

5. Require quality assurance processes that have special provisions for dementia care including evidence-based practice guidelines with clear outcome measures, as well as collection and analysis of data specific to beneficiaries with dementia.

**Medicaid Managed Long Term Care for**
**People with Alzheimer's Disease and Other Dementias**

## Introduction

Medicaid managed long term care is an arrangement in which a state Medicaid program contracts with plans that manage long term care services in return for a set monthly payment called capitation, regardless of the amount of services an enrollee in that plan uses.[1] These plans may manage long term care services only or both health and long term care. According to a recent report,[2] states are turning to managed long term care programs to control growth in Medicaid expenditures for their younger adult and elderly populations with disabilities, including those with Alzheimer's disease and other forms of dementia. States also recognize that managed long term care plans have the potential to improve care by helping Medicaid beneficiaries navigate the service systems and receive appropriate, quality services.

Although there have been a number of studies of Medicaid managed long term care programs and plans, none has focused on the special needs of people with Alzheimer's disease and other dementias. Special attention to this group is warranted for a number of reasons:

- People with dementia represent a large proportion of those using Medicaid long term care services.

- Their diseases cause a unique constellation of symptoms that create special and extensive long term care needs. These include progressive memory loss, difficult behavioral symptoms, and loss of the ability to communicate and to take care of oneself.

- Their ability to remain in the community depends heavily on the availability of family and other informal caregivers who function not only as caregivers but as surrogate decision-makers, and who have their own needs for assistance and support.

- Most people with dementia have one or more chronic health conditions, which are confounded by their dementia. As a result, they have frequent and costly medical crises that not only add to health care costs but precipitate functional decline and additional long term care needs.

This issue brief describes the requirements that two states, Massachusetts and Wisconsin, have established for Medicaid managed long term care plans to identify people with dementia and to address their special needs. We use information from these states, together with advice and experience of experts in Alzheimer care and state Medicaid programs, to make policy recommendations for states that are considering implementation or modification of Medicaid managed long term care programs.

## Background

Elderly Medicaid beneficiaries represent one of the primary target populations for Medicaid managed long term care programs. Almost all of them are "dual eligibles" – that is, they receive services through Medicare as well as Medicaid. Analysis of data from 2000 indicates that 28% of these elderly dual eligibles had Alzheimer's disease or other dementias. This included 59% of those living in nursing homes, 15% of those living in the community, and 71% of those who spent some time in the community and some time in nursing homes during the year.[3] Thus, people with Alzheimer's disease and other dementias constitute a substantial proportion of all elderly dual eligibles, particularly of nursing home residents.

Medicaid beneficiaries with Alzheimer's disease and other dementias have special and extensive care needs that arise from their cognitive impairment and related symptoms. Because of their impaired memory, judgment, and communication abilities, they need round-the-clock care and supervision to perform basic activities of daily living, and to manage behavioral symptoms like wandering, delirium, and agitation that frequently accompany their disease. The presence of dementia also makes it more difficult to manage coexisting chronic health conditions that are common in this population. Patients with cognitive impairment are more likely to experience post-hospital functional decline or nursing home admission than hospitalized patients without cognitive impairment.[4]

Beneficiaries with Alzheimer's disease and other dementias place heavy demands on the health and long term care system. But, because of their cognitive impairment, they cannot negotiate that care system on their own. They must rely on family and other primary caregivers and on care managers to identify and obtain the right mix of services and supports to maintain their health and remaining functional abilities, and to continue to live in the community.

Managed long term care programs have shown they have the potential to provide the kind of help that beneficiaries with dementia need. The programs increase enrollees' access to home and community services,[5] which can help alleviate caregiver burden and avoid unnecessary or premature nursing home placement. They also reduce the use of hospital and emergency room care.[6] Evidence on the quality of services Medicaid beneficiaries receive under managed long term care programs appears to be neutral to favorable. Evidence on cost-effectiveness is not conclusive.[7]

A number of states have seen the value of managed long term care programs. Seven had implemented them through 2005 and others are planning to do so. [8] Existing state programs vary a great deal in terms of populations and range of services covered, as well as in program administration.[9] Some states limit their programs to long term care only. Others include all health and long term care services covered by Medicaid. Several states have developed managed long term care programs that integrate all Medicaid services with Medicare in a single plan.

- Arizona's Long Term Care System or ALTCS is mandatory for Medicaid beneficiaries of all ages who need any type of long term care.

- Florida's Frail Elder Options and Diversion programs are voluntary programs that serve limited parts of the state. The state is currently undergoing major Medicaid reforms, which will likely result in changes to these programs.

- Massachusetts began its Senior Care Options program in 2004; it encourages voluntary enrollment of elderly beneficiaries throughout the state and provides the full range of health and long term care services funded by Medicaid and Medicare.

- Minnesota's Senior Health Options began in 1997 by covering the full range of Medicare and Medicaid services for dually eligible Medicaid beneficiaries who voluntarily enrolled in seven urban counties. Minnesota has expanded its program to cover about 33,000 beneficiaries statewide.[10] In addition, Minnesota recently added long term care benefits to its statewide mandatory managed health care program, Minnesota Senior Care, starting with 20 counties, and will phase in the rest of the state in 2006. [11]

- New York has about 15 small managed long term care plans voluntarily enrolling Medicaid beneficiaries throughout the state.

- Texas STAR+PLUS is a mandatory program serving enrollees who need long term care in the Houston area; beneficiaries must disenroll after one month in a nursing facility.

- Wisconsin has two programs – Family Care and the Wisconsin Partnership Program. Enrollment in Family Care is generally voluntary, but in 5 counties beneficiaries must enroll in order to receive Medicaid waiver services in the community. Those who do enroll are entitled to long term care regardless of setting. The Partnership program integrates Medicaid and Medicare services, and is optional for dual eligibles. Wisconsin is awarding planning grants to expand managed long-term care, and in January 2006, the governor said that he wants Family Care-like programs expanded statewide in five years.[12]

Medicaid managed long term care continues to evolve. California, Hawaii, Maryland, and Washington are planning to implement programs, while Texas, Florida, Minnesota, and Wisconsin are expanding existing ones.[13]

As an advocate for people with Alzheimer's disease and related dementias, their families, and their care providers, the Alzheimer's Association seeks to work with the states to assure that their Medicaid managed long term care programs address the special needs of this large and particularly vulnerable population. We have examined existing programs and consulted with experts in Alzheimer care and state Medicaid programs to develop policy recommendations related to planning, organizing, and delivering services

for people with dementia, for states that are considering or implementing managed long term care programs.

**Methods**

To develop the information base for the policy recommendations, we began by reviewing legal frameworks, regulatory structures, and contractual requirements governing managed long term care plans that serve older persons in six states – Arizona, Massachusetts, Minnesota, New York, Texas, and Wisconsin. Florida was not included in this review because the state is undergoing major structural change in its Medicaid program. For each state, we reviewed relevant laws, regulations, and contract language available on the internet for mention of dementia, Alzheimer's disease, or cognitive impairment. After summarizing these provisions, we contacted state officials to verify the accuracy of our interpretation of requirements and to make sure we had not missed any major provisions. In addition, we reviewed managed care principles that were developed through a consensus process by Alzheimer's Association chapters in California to help guide that state's development of a Medicaid managed care program.[14]

Using this state information and other sources, we developed policy recommendations for states considering Medicaid managed long term care programs. These recommendations were submitted to a Technical Advisory Group (TAG) composed of dementia, Medicaid, and long term care experts. After receiving this group's comments, we finalized the recommendations which are presented in this policy brief. The recommendations are those of the Alzheimer's Association and do not necessarily represent the views of individual TAG members or their affiliated organizations or states.

**Results**

We identified three states -- Massachusetts, New York, and Wisconsin (the Family Care Program) that had plan requirements specific to beneficiaries with dementia or cognitive impairment The remaining state programs generally require managed long term care plans to meet the needs of enrollees, but do not have provisions that specifically address dementia or cognitive impairment.

New York only requires that its managed long term care plans ensure that their marketing materials address the needs of people with cognitive impairment. Massachusetts and Wisconsin --the newest programs -- each had extensive, though differing requirements for managed long term care plans related to enrollees with dementia or cognitive impairment.

- Massachusetts administers its program through contracts with managed long term care plans called Senior Care Organizations (SCOs.) All proposals must demonstrate specifically how they will approach dementia care. SCOs must identify enrollees with cognitive impairment or dementia. These enrollees and their families or caregivers must receive education about dementia and special

assistance from a primary care team that includes a geriatric support services coordinator. SCOs must gather and submit to the state quality data that is specific to dementia.

- Wisconsin Family Care contracts with Care Management Organizations (CMOs) that manage long term care services for enrollees. The state does not specifically require identification of people with cognitive impairment, but it does require comprehensive assessments that should identify enrollees with dementia. CMOs must educate enrollees with cognitive impairment and families about choice and use of services, and how to manage them. During care planning, unique emphasis is placed on the role of acceptable risk in community-based care.

The Massachusetts and Wisconsin program requirements are described in more detail in the Appendix.

## RECOMMENDATIONS

Our policy recommendations for Medicaid managed long term care programs build on the Massachusetts and Wisconsin requirements and the managed care principles developed in California. Four key principles underlie the Alzheimer's Association recommendations:

1. Plans must identify and diagnose their enrollees with dementia in order to serve their needs appropriately.

2. The best dementia care is person-centered; that is, care tailored to the abilities and changing needs of each enrollee.

3. Plans, their case managers, and the providers with which they contract must be "dementia capable." This means they must have the requisite knowledge and skills to assist with and manage the symptoms and care needs of people with dementia throughout the course of their disease.

4. Quality assurance systems must have special provisions for dementia care including evidence-based practice guidelines and dementia-specific data collection and analysis.

Our specific recommendations begin with the state's planning process and address many aspects of enrollment, service arrangement and delivery, and quality assurance, presented in that order.

### State Planning and Oversight

Because beneficiaries with dementia represent such a significant portion of potential enrollees, because their care needs are so extensive and complex, and because managed long term care -- if done right – holds real potential for improving the quality

and outcomes of their care and managing the costs of that care, states must give special attention to the needs of this population in designing their managed long term care programs. As part of its planning process, M**assachusetts** examined existing service utilization data and found heavier use of community services by persons with dementia – leading the state to incorporate specific program requirements to assure effective management of services for this population.

States should involve the full range of stakeholders – consumers, providers, advocates, and public officials – in the planning, development, implementation and oversight of its Medicaid managed long term care program. This must include experts in Alzheimer care and representatives of people with dementia and their caregivers. **Massachusetts** developed its program with real involvement of an effective advisory group of consumer advocates, including the Massachusetts chapter of the Alzheimer's Association, and the state's program reflects that involvement.

**Application and Enrollment Processes**

People with dementia and their families and caregivers will need help navigating the enrollment processes. This is even more the case for beneficiaries who have no family or caregivers. Employees who deal with people with dementia during the enrollment process must have special training in assisting persons who have cognitive impairments.

A state may require that all beneficiaries enroll in its Medicaid managed long term care plan, or enrollment may be voluntary. If enrollment is voluntary, then the state must have in place a process to help beneficiaries with dementia and their family and caregivers determine whether managed long term care is appropriate. Whether enrollment is voluntary or not, if the state offers a choice of managed long term care plans, it must provide assistance to applicants with dementia to help them choose the plan that best meets their needs. States must provide clear information about each plan's capacity to serve people with dementia, including the range of programs and services available and the capability of specific providers to meet their special needs.

States must prohibit managed long term care plans from discriminating among applicants based on type of disability. **Massachusetts** does this by requiring that plans accept enrollees in the order they apply and by prohibiting any restrictions in enrollment based on an applicant's mental condition or mental disability.

**Marketing and Orientation Materials**

Plans should be required to have a marketing strategy that is flexible, person-centered, and responsive to the needs of those with dementia. Marketing and orientation materials must include information about how plans and their providers will meet the need of enrollees with dementia. In addition, plans must use communication vehicles that accommodate cognitive deficits of potential enrollees and their reliance on surrogate decision-makers. For example, simply mailing materials to the beneficiaries with

dementia will not suffice. The beneficiary may be unable to read or comprehend the materials and family and caregivers who could help the beneficiary may not see them. States should require that plans use alternative approaches, such as telephone calls, home visits or video screenings (as required in **Massachusetts**) for beneficiaries for whom written materials are not appropriate. Such mechanisms are a better way to explain managed long term care and can also be used to determine the need for and to identify a surrogate decision-maker. For applicants with cognitive impairment, all communications might have to be directly with family and caregivers. Surrogate decision-makers must receive all written materials that the beneficiary receives.

**Identification and Diagnosis of Dementia**

Managed long term care plans will not be able to care appropriately for enrollees with dementia unless and until they identify them. Plans should be required to identify enrollees with possible dementia within 30 days of enrollment. **Massachusetts** requires that plans identify enrollees with complex care needs, including persons with dementia. **Wisconsin** does not specifically require that plans identify enrollees with dementia, but the state does require an assessment that should identify signs and symptoms of possible dementia. For enrollees who display signs or symptoms of dementia in this initial assessment, managed long term care plans should have in place a protocol for obtaining an accurate diagnosis.

When a formal diagnosis of Alzheimer's disease or another dementia is made, it must be included in the enrollee's record and in all care planning documents. All providers serving the beneficiary must have access to that information.

Identification of enrollees with dementia is not only essential to assuring appropriate quality care and good outcomes for the beneficiary. It is also needed so that plans can collect data about enrollees with dementia for quality assurance purposes.

**Assessment, for Care Planning, and Family and Caregiver Involvement**

States must require that plans develop and periodically review and update a care plan for each enrollee with dementia. That plan should be based on a comprehensive assessment of the enrollee's remaining cognitive and functional capabilities and how to support them, as well as his or her ongoing care needs and preferences. The plan must also conduct an assessment of the family or other informal caregivers' capacity to care for the person with dementia in the community and their own need for assistance, support and education.. Family and other informal caregivers play an essential role in caring for a person with dementia who lives in the community and, as the disease progresses, become surrogate decision-makers. Plans must involve the family and caregivers in the assessments unless the enrollee objects.

Because Alzheimer's disease and other dementias are progressive conditions, assessment must be conducted on a periodic basis, to evaluate functional decline, changes

in coexisting chronic health conditions, and changing needs of both the beneficiary and the caregiver.

In **Massachusetts,** for every enrollee identified with a complex care need, a primary care team, which includes a geriatric support services coordinator, is responsible for conducting a needs assessment and developing a care plan. The enrollee and any surrogate decision-maker are members of the care team. In **Wisconsin**, Aging and Disability Resource Centers (single point of entry systems) work with family members and informal caregivers to ensure that the personal needs and preferences of enrollees with dementia are addressed.

**Care Management**

Enrollees with dementia have complex needs that require services from a variety of health and long term care providers. Care managers play a critical role not just in assessing needs and ordering services but in assuring that services are coordinated across providers. Effective care management for enrollees with dementia requires care managers who are knowledgeable about the disease and capable of identifying needs and managing services for this population. Care managers must have the training and dementia-specific skills to carry out the following essential tasks:

- A comprehensive assessment of the person with dementia and the family or other informal caregiver.
- Development and management of a comprehensive plan of care, with the involvement of the enrollee and family or other caregiver.
- Ongoing communication with the person with dementia, which becomes increasingly challenging as the condition progresses.
- Linkages with health and long term care service providers that are capable of providing good dementia care to ensure that the enrollee receives the services that he or she needs.
- Consultation with families and providers on dementia care issues and management of behavioral symptoms.

In **Massachusetts**, a geriatric services coordinator ensures that community services are coordinated and tailored to the needs of the individual. The coordinator may determine the need for and authorize additional hours of personal care, help family obtain counseling and education in such areas as home safety, and assist in finding surrogate decision-makers when family is not available. In **Wisconsin**, care management organizations must help enrollees exercise their choices about living arrangements, daily routines, and services. They must have written policies for determining acceptable risks for enrollees with cognitive impairment.

**Health and Long Term Care Service Provision**

Managed long term care plans and their subcontracting providers must have the capacity to provide good dementia care, beginning with educational and support programs for enrollees and their family and informal caregivers and extending to a wide range of long term care services. Requirements regarding capacity to serve enrollees will vary, depending upon whether the plans manage long term care services and only provide linkage to health care, or manage both health and long term care services.

Both types of managed plans should provide enrollees and their families with information about Alzheimer's disease, dementia, and options for treatment and care, as well as referrals to dementia support groups and counseling, as needed.

Plans must have contractual requirements with providers that have the proven capacity to deliver quality dementia care (as some states do for other conditions such as developmental disabilities and HIV/AIDS). This care includes personal care at home, specialized adult day programs and other services specifically designed for people with dementia, as well as respite services for family and other informal caregivers. Contractual requirements must ensure the availability of out-of-network care, when the plan's network is not sufficient.

In addition, managed long term care plans should make available a self-direction option to enrollees with dementia and their families who would prefer to manage their own long term care services. In **Massachusetts**, enrollees with dementia and their surrogates may direct their own services, if the care team agrees this is appropriate; family members may be paid to provide personal care services. In **Wisconsin**, enrollees with cognitive impairments must be given the choice of self-directed services. The CMO must identify resources needed to help the enrollee manage services, including training for the surrogate to help determine the enrollee's preferences.

Plans that manage long term care only must have linkages to providers of appropriate medical treatment for their enrollees with dementia, for treatment and medical management of their dementia and any psychiatric and behavioral symptoms as well as of any coexisting medical conditions. These plans must have methods for coordinating with other payers – especially Medicare and the Medicare prescription drug plans. For some people with dementia, the time will come when a nursing home is the most appropriate setting of care – because their needs have progressed to a point they cannot be met at home, or because family can no longer provide the care that is needed. The managed long term care plan must have in place policies and procedures for determining when care in nursing homes or assisted living is appropriate and for assisting in transitions of care.

**Quality Assurance**

States must require that managed long term care plans and their subcontractors use evidence-based protocols with measurable outcomes to manage the care of enrollees

with dementia. **Massachusetts** requires that each plan create written protocols under the direction of medical directors or geriatric consultants to manage care of enrollees with dementia. Protocols must be evaluated to determine their effects on enrollee outcomes.

Plans with significant numbers of enrollees with dementia should analyze quality indicators for this population separately from other populations. This will help plans determine whether enrollees with dementia are experiencing special problems that need attention in quality improvement programs. States must make the results of quality monitoring available publicly, including posting them on-line.

Managed long term care plans should create and maintain advisory committees composed of provider and consumer representatives, including representatives of enrollees with dementia and their families. These committees can help identify need for improvement in the plan's management and service delivery to meet better the needs of those with dementia. Plans may also use focus groups and surveys of enrollees with dementia and their families to obtain valuable input.

**Grievances and Appeals Processes**

Plans must establish procedures for appeals and grievances that include assistance for people with dementia and their surrogate decision-makers to help them navigate the processes. Information and notices about these procedures should go to the enrollee with dementia and his or her representative, with staff available to provide advice on how to proceed with filing appeals or grievances. Representatives and providers should be able to initiate appeals of denial of service on behalf of the enrollee and follow through on procedural requirements as necessary.

Plans should be required to include practitioners with dementia care expertise in their review processes so that people with dementia who appeal care decisions have access to someone who knows their special circumstances and needs.

**Conclusion**

These recommendations were developed in response to the expansion of managed long term care plans in the states and the implications this expansion has for Medicare and Medicaid beneficiaries with Alzheimer's disease and other dementias. This population, along with others who have cognitive impairments, need special consideration, given the unique nature of their disabilities. These unique needs are not confined to people who need long term care. Managed health care plans in Medicare Advantage, especially those serving "special needs populations" could benefit from examining the recommendations above.

# Appendix

## Summaries of Massachusetts and Wisconsin's Managed Long Term Care Plan Requirements Related to Dementia Care

### Massachusetts

Massachusetts' Senior Care Options program recognizes that cognitive impairment and dementia require special consideration because of results from data analysis the state conducted before program start-up. Contractors analyzed Medicare and Medicaid data from the late 1990s and found that people in the community with dementia and other forms of cognitive impairment used more home and community services than other community dwelling elderly beneficiaries.[15] The state wants to ensure that the services these beneficiaries use are carefully managed.

Massachusetts attended to dementia-related issues from the beginning of program implementation. The program has an advisory body composed of a wide range of advocacy groups, including the Alzheimer's Association Massachusetts Chapter, which provided substantial input through the planning and implementation process. The original Request for Responses, which solicited proposals from prospective managed long term care plans, required that bidders tell how they would identify people with "complex care needs," which include those with cognitive impairment.[16] Bidders also had to describe the composition of the Primary Care Team that would manage care for this group and respond to three hypothetical scenarios, including one focusing on a person with dementia. Bidders' proposals were judged, in part, based on their capacity to care for people with dementia.

Senior Care Organizations (i.e., managed long term care plans) must meet a number of contractual requirements related to enrollment and identification of people with complex care needs. Senior Care Organizations (SCOs) must accept enrollees in the order that they apply and cannot restrict enrollment based on an applicant's mental condition or mental disability. Anyone who enrolls in a SCO must receive an orientation and written materials within 30 calendar days of enrollment, and these materials must be made available to family or designated representatives. SCOs must use telephone calls, home visits, video screenings or group presentations with enrollees for whom written materials are not appropriate.

After enrollment, SCOs must use certain procedures for identifying enrollees with complex care needs. A person has a complex care need if he or she cannot perform 2 or more activities of daily living without human assistance or cueing, or needs continuous behavioral health or social services to maintain minimum daily independent functioning. This definition, with its inclusion of cueing and continuous service needs, incorporates people with dementia. A person with a complex care need receives the assistance of a primary care team, which includes a geriatric support services coordinator (GSSC). The team is responsible for assessing needs and developing a care plan for the enrollee and

the coordinator ensures that the community care services are coordinated and tailored to the needs of the individual. The GSSC may determine the need for and authorize additional hours of personal care service, help family members to obtain counseling and education in such areas as home safety procedures to support an enrollee's ability to remain at home, or assist in finding and engaging a surrogate decision-maker when family members are not available.

Educational activities that SCOs must implement are directed at subcontracting service providers as well as enrollees and their families. SCOs must train their subcontracting providers on identification and management of Alzheimer's disease. Each SCO must provide educational activities for enrollees, family members, and other significant informal caregivers. The topics must deal with health information relevant to the specific health status needs of seniors, including ways to cope with Alzheimer's disease.

Regarding quality assurance, SCOs must create written protocols, under direction of medical directors or geriatric consultants, to manage the care of enrollees diagnosed with dementia. These protocols must be accompanied by an evaluation of their effects on enrollee outcomes.

Managed long term care plans must implement quality improvement initiatives to address the needs of enrollees with dementia. To help identify opportunities for improvement and initiate quality management activities, SCOs must prepare reports on the following clinical indicators:

1. Number of enrollees diagnosed with dementia
2. Percentage of enrollees diagnosed with dementia who are receiving support services
3. Percentage of enrollees diagnosed with dementia with severe behavioral symptoms
4. Percentage of enrollees diagnosed with dementia residing in nursing facilities
5. Percentage of enrollees diagnosed with dementia receiving community long term care services.

The state has not yet had time to analyze these data because the first full year of operation (CY 2005) has just concluded, but envisions producing some type of consumer report card and using the data in its enrollment and disenrollment studies.

Enrollees with dementia and their surrogate decision-makers are members of their primary care teams, and as such, develop and sign-off on their own individualized plans of care. They may direct their own SCO services, if the team agrees that this is appropriate. Enrollees' family members can also serve as personal care workers. The SCO coverage model is designed to be very flexible so that virtually any benefit or form of service delivery is possible.

Massachusetts recognizes the special needs of enrollees with dementia who join a SCO. There is a higher payment rate cell for enrollees with dementia who live in the

community that takes into consideration the increased costs of this group related to use of personal care and other home or community services.

**Wisconsin**

Wisconsin Family Care, which began in 2000, has a number of managed long term care plan requirements related to the population with cognitive impairments, which includes those with dementia, but there are no standards in the state's older Partnership program. The state recognized the necessity of meeting the special needs of people with cognitive impairment or dementia and weaved in requirements to accomplish this goal.

Family Care requirements[17] address 1) Aging and Disability Resource Centers (ADRCs), which serve as the single point of entry for Family Care and conduct pre-admission screening for nursing homes, and 2) Care Management Organizations (CMOs), which are responsible for managing long term care services, once members choose to enroll in their plans. ADRCs must work with the family members, friends, and other informal caregivers of an enrollee with a cognitive impairment to ensure that the enrollee's personal needs and preferences are included in the provision of the Resource Center services.

CMOs must meet requirements designed to ensure that enrollees with cognitive disabilities are able to express and make choices as well as accept risk. Upon enrollment, CMOs must provide each enrollee with a member handbook, including a provider network directory. The member handbook must include information about assistance available to enrollees with cognitive impairments. During development of care plans, the CMOs must ensure that family members, friends, and other informal caregivers help convey the enrollee's preferences and that enrollees receive assistance as requested or needed to exercise their choices about living arrangements, daily routines, and services. The CMO must have written policies regarding safety and risk, which establish methods for determining acceptable risks for enrollees, including those with cognitive impairment. The policies must include the member's right to be free of unnecessary restraints. For example, an enrollee with cognitive impairment with a surrogate decision maker's agreement or consent may choose to live in her home, and the care plan will address the risks that may entail. All enrollees, including those with cognitive impairments, must have a choice of self-directed supports where the enrollee or a surrogate decision maker manages long term care services. The CMO must identify resources available to help the enrollee manage services and whether a guardian needs training to help determine the enrollee's preferences regarding services. Finally, CMOs cannot counsel people with increased need for supervision and other conditions to disenroll from their plans.

While Wisconsin does not require identification of people with cognitive impairment, it does require assessments that should identify this population and education of the enrollee with cognitive impairment and family. In addition, Wisconsin requires managed long term care plans to help enrollees with cognitive impairment make choices

about their services and how to manage them. The requirements that CMOs must meet are designed to inform and educate enrollees with cognitive impairment and their families about choice and use of services, with a unique emphasis on the role of acceptable risk in care planning.

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[14] Alzheimer's Association of Los Angeles, Riverside & San Bernardino Counties, "*Alzheimer's Disease in California: Twenty-five Years of Investment a Vision for the Road Ahead, Alzheimer's Association Roundtable Meeting* April 15, 2005. Los Angeles, California.
[15] Personal communication with Diane Flanders, State of Massachusetts, January 4, 2006.
[16] The Massachusetts information was drawn from: Division of Medical Assistance, Commonwealth of Massachusetts Executive Office of Health and Human Services & US DHHS Centers for Medicare & Medicaid Services, *Request for Responses MassHealth Senior Care Options Program*, January 1, 2002. General Laws of Massachusetts, Chapter 118E; Division of Medical Assistance, Section 9D Senior care options initiative; senior care enrollment choices; advisory committee report. www.mass.gov/legis/laws/mgl/118e-9d. MassHealth Managed Care Requirements Chapter 508, revised 7/01/05. MassHealth Senior Care Options Program Contract between Unites States Department of Health and Human Services Centers for Medicare & Medicaid Services in Partnership with Commonwealth of Massachusetts Executive Office of Health and Human Services Division of Medical Assistance and SCOs. MassHealth Transmittal Letter ALL-122, January 2004.
[17] Information drawn from Department of Health and Family Services, Chapter HFS 10 Family Care November 2004. Contract between Department of Health and Family Services Division of Disability and Elder Services and Aging and Disability Resource Center of County January1, 2005 – December 31, 2005. Health and Community Supports Contract between Department of Health and Family Services Division of Disability and Elder Services and COUNTY, January 1, 2005 – December 31, 2005.