
Family Caregiver Support:
*Policies, Perceptions and Practices in 10 States Since Passage
of the National Family Caregiver Support Program*

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OVERVIEW

Maine is a relatively small, rural New England state with a substantial lower-income population and few minorities. Over the past decade, the state has accomplished incremental long-term care reform by centralizing uniform assessment and care coordination, providing a broad array of home and community-based services, focusing on the consumer (i.e., care recipient) and offering flexible options in service delivery to meet consumers' needs. By 1997, more people were receiving care at home than in nursing homes.

The concept that family caregivers need support services themselves is relatively new for Maine; the state's long-term care system is based on viewing of only the care recipient as the client. Prior to passage of the National Family Caregiver Support Program (NFCSP), caregiver support in Maine was limited to the state's Alzheimer's Respite Program. Maine's developing caregiver support services are characterized by efforts to:

- ❖ Build on Maine's existing home and community-based services to broaden service delivery beyond respite care and reach a population wider than dementia caregivers alone
- ❖ Identify and work with families earlier in the process of caregiving
- ❖ Centralize policymaking and administration at the state level, mandate uniform data collection and provide flexibility to meet individual needs of caregivers at the local level
- ❖ Maintain a stand-alone identity for the new NFCSP program, rather than to integrate caregiver support into Maine's long-term care system

Maine respondents noted that the major service needs of family caregivers are (1) the ability of family members to self-identify as caregivers, (2) education and training on caregiver issues, (3) information, support and care management and (4) trained and consistent direct care workers to provide respite care.

As Maine develops its caregiver support program and at the same time expands home and community care, key considerations will be (1) whether the state views family caregivers as legitimate consumers themselves and (2) coordination of caregiver support with Maine's single point of entry to the long-term care system.

INTRODUCTION

Passage of the NFCSP has allowed Maine to expand services to family caregivers who need help because of a range of illnesses or disabilities beyond Alzheimer's disease and related dementias. The project team conducted site visits between April 15 and 16, 2002, through in-person interviews with

government officials and key stakeholders. One additional interview was conducted in person in early April, and the final interview was conducted by telephone in early July 2002. State agencies and programs within those agencies interviewed include:

Maine Department of Human Services, Bureau of Elder and Adult Services

- ✧ Family Caregiver Support Program (NFCSP funded)
- ✧ Home Based Care Program (state funded)
- ✧ Alzheimer's Respite (state funded)
- ✧ Aged, Disabled and Consumer Directed Medicaid waivers
- ✧ Alzheimer's Disease Demonstration Grant to States (federally funded)

Maine Department of Human Services, Bureau of Medical Services (Muskie School of Public Service, subcontractor)

- ✧ Real Choice Systems Change grant

Stakeholders interviewed were:

- ✧ Maine Area Agency on Aging Caregiver Coordinators
- ✧ Alzheimer's Association of Maine

Four programs are featured:

1. Family Caregiver Support Program
2. Home Based Care Program for the elderly and other adults
3. Alzheimer's Respite Program
4. Aged and Disabled Medicaid waivers

BACKGROUND

Maine is a relatively small, rural New England state with a population of nearly 1.3 million residing in 16 counties. Maine ranks 40th in population nationally. Although it is a small state in size (about 320 miles long and 210 miles wide), it is almost as large as all of the other five New England states combined.¹ Most of the residents are native to the state, with Maine ranking first in the United States in home ownership rate.²

The state has substantial rural and lower-income populations and few minorities. Nearly 60% of Maine's population live in rural areas.³ In 2000, Maine ranked 37th in personal income per capita at \$25,623, compared to the national average of \$29,676.⁴ Although per capita income is less than the national average, Maine has proportionately fewer people living below the federal poverty level than the national average (10.7% vs. 13.3% U.S.).⁵ The racial makeup of the state's population differs significantly from that of the United States as a whole, with a nearly all-white population and few African Americans (0.5% vs. 12.3% U.S.) or Hispanics (0.7% vs. 12.5% U.S.) (table 1).

Maine ranks 20th nationally in percentage of households with Internet access.⁶ About 15% of Maine's population use the Internet to obtain information about or locate services for older people.⁷

An estimated 238,099 persons in Maine, or 18.7% of the state's population, were 60 years or older in 2000, higher than the national average (16.3% U.S.). Maine ranks fifth nationally in the percentage of older persons (60+) residing in the state.⁸ Similar to the state's population as a whole, Maine has a largely white older population (98.6% vs. 82.4% U.S.) and few older minorities.⁹

Maine ranks 11th nationally in the proportion of its population ages 85 and older. In 2000, 23,316 persons, or 1.8% of Maine's total population, were ages 85+.¹⁰

An estimated 123,712 family caregivers reside in Maine. These family caregivers provide about 115 million hours of caregiving per year at an estimated value in 1997 of \$942 million.¹¹ About 47% of Maine's citizens report routinely helping out an older family member, and 11% say they routinely take time off from work to provide care.¹²

Maine is a progressive state with a history of implementing innovative health and human services programs. Key informants noted that Maine has had almost a decade of incremental reform to achieve a coherent system of long-term care. The goal of this system is to provide equal access to home and community-based services wherever consumers live in the state. Maine has a wide range of state- and Medicaid-funded programs for the elderly and for persons with disabilities to help people who need assistance to remain in their homes.

Table 1. Selected Characteristics of MAINE and the UNITED STATES, 2000 ^a

	Maine	United States
Total Population Characteristics		
Total Pop. ^b	1,274,923	281,421,906
% African American ^c	0.5%	12.3%
% Hispanic ^d	0.7%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	238,099	45,797,200
% 60+ ^f	18.7%	16.3%
National ranking 60+ ^g	5	NA
Pop. 65+ ^h	183,402	34,991,753
% 65+ ⁱ	14.4%	12.4%
National ranking 65+ ^j	7	NA
Pop. 85+ ^k	23,316	4,239,587
% 85+ ^l	1.8%	1.5%
National ranking 85+ ^m	11	NA
% increase 1990–2000 60+ pop. ⁿ	9.4%	9.4%
% White (60+) ^o	98.6%	82.4%
% African American (60+)	0.2%	8.4%
% Hispanic (60+)	0.3%	5.4%
% Asian (60+)	0.3%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.0%	0.1%
% Amer. Indian/Alaska Native (60+)	0.2%	0.4%
Informal Caregiver Characteristics^p		
# of caregivers (1997)	123,712	25,798,370
Caregiving hours (millions) (1997)	115.2	24,013.1
Value of caregiving (millions) (1997)	\$941.9	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$25,623	\$29,676
% of pop. below poverty (1997) ^r	10.7%	13.3%
Internet		
% of households w/Internet access (2001) ^s	42.6%	41.5%
Nat'l ranking of households w/Internet access	20	NA

a Unless otherwise noted, all data are from 2000.

b Mapstats-Maine, *www.fedstats.gov* (June 2002).

c Ibid.

d Ibid.

- e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- f Ibid.
- g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank*, www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.
- h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- i Ibid.
- j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- l Ibid.
- m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- n U.S. Administration on Aging, *Profile of General Demographic Characteristics for the U.S.: 2000 with 1990 Data*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- o All percentages for 60+ white, African American, Hispanic, Asian, Native Hawaiian/Pacific Islanders and American Indian/Alaska Native populations are from U.S. Administration on Aging, *Percent of Persons 60+ by Race and Hispanic Origin—by State—2000*, www.aoa.gov/stats/2000pop/percent60plusrace-HO.html.
- p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
- q U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), www.bea.doc.gov/bea/newsrelarchive/2001/spi0401.htm (2001).
- r Mapstats-Maine.
- s Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, www.governing.com/source.htm. Source for Internet access is the National Telecommunications and Information Administration, 2001.

STATE ADMINISTRATIVE STRUCTURE

Maine utilizes a highly centralized approach to accessing and managing its long-term care programs, including the home and community-based care system. Caregiver support services for the elderly and for adults with physical disabilities are centrally administered by one state agency, the Department of Human Services (DHS).^a That department serves as the single state agency responsible for administering the Medicaid program, now known as MaineCare, effective July 2002.¹³ The department has five Bureaus: Elder and Adult Services, Child and Family Services, Health, Medical Services and Family Independence.

The Bureau of Elder and Adult Services (BEAS) serves as the State Unit on Aging to administer the provisions of the federal Older Americans Act, including the new NFCSP. The BEAS also administers the Aged and Disabled Medicaid waivers, a federal Alzheimer's Disease Demonstration Grant to States and state-funded programs in home and community-based care for the elderly and for adults with disabilities, including home based care and Alzheimer's respite programs.

The infrastructure of Maine's aging network is a statewide system of five nonprofit Area Agencies on Aging (AAAs), ranging from a one-county service area in the northern part of the state to a six-county AAA in the central part of the state. The AAAs provide a range of services under the Older Americans Act and coordinate services under the state-funded Alzheimer's respite program.

a Effective July 2002, oversight for all of Maine's consumer-directed personal assistance programs (through state funds and MaineCare, including the Consumer Directed Medicaid waiver) were transferred from the Department of Human Services, Bureau of Elderly and Adult Services, to the Department of Labor, Bureau of Rehabilitation Services. Alpha One, the state's Center for Independent Living, serves as the designated agency to coordinate home care programs for adults with physical disabilities who are able to direct their own care.

Maine's long-term care system underwent significant reform in 1996. Both executive branch and legislative branch leaders supported the move to a more integrated system of care. Specifically, BEAS changed from using the five AAAs to assess consumer needs and provide home care coordination to using two agencies to carry out these functions under the state-funded home care program. One agency does the assessments; a separate agency provides care coordination. This resulted in significant reductions in administrative costs and led to a consistent, statewide approach to eligibility and service delivery. Through a request for proposal process, the single agency selected to do assessments was Goold Health Systems, and the single agency chosen to provide care coordination was one of the AAAs, Seniors-Plus, in the western part of the state. Elder Independence of Maine, a division of Seniors-Plus, was designated as the statewide home care coordination agency. Today, Elder Independence manages all home care services delivered through agencies.^b

Three 1915 (c) Medicaid waivers have, until recently, been administered by BEAS.^c The waiver for persons ages 60 and older was originally approved in 1985, and it served about 1,300 persons in 2001. A second consumer-directed model waiver for persons 18 and older was also approved in 1985. State respondents noted that about 26% of the 325 clients served in the consumer-directed waiver are 65 years of age or older. The third Medicaid waiver is for adults ages 18 to 59 with disabilities. This waiver was approved in 1994, and about 500 persons were served in 2001.

In October 2001, the Maine Department of Human Services, Bureau of Medical Services, was awarded a Real Choice Systems Change grant by the Centers for Medicare and Medicaid Services (CMS). The grant's focus is largely interdepartmental, involving representatives from five departments (Human Services, Behavioral and Developmental Services, Education, Labor and Corrections). The purpose of the grant is to (1) improve existing community-based services in specific ways (e.g., offer greater consumer choice and control, consumer voice, interdepartmental collaboration and data integration) and (2) address gaps in service and supports (e.g., provide greater consumer access and availability of qualified personal-assistance workers, affordable housing, transportation and information). Key informants noted that the grant does not have any direct project activity related to family caregiver issues.

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT

Maine's long-term care system is characterized by uniformity in assessment and care coordination through a single point of entry, a broad array of home care and residential resources, a focus on the consumer (i.e., care recipient) and flexibility in service delivery to meet the consumer's needs. As a result of a budget crisis in 1993, Maine adopted a policy of long-term care reform to reduce reliance on institutional long-term care and to offer consumers a wider range of affordable choices in home and community-based care. In 1997, case study respondents noted that, for the first time, more

^b Alpha One, the state's Center for Independent Living, manages the consumer-directed programs with independent providers.

^c Effective July 2002, the Department of Labor, Bureau of Rehabilitation Services, administers the Consumer Directed Medicaid waiver. The Department of Behavioral and Developmental Services administers a waiver for individuals with mental retardation or developmental disabilities (MR/DD).

people in need of long-term care received help at home, rather than in nursing facilities. Reliance on nursing home care has continued to decline dramatically, reducing the costs of care overall. The total number of persons who received long-term care services increased from 19,803 in 1995 to 25,455 in 2001. At the same time, per person spending on long-term care in all settings (e.g., nursing homes, home care) was reduced from \$14,985 in 1995 to \$10,952 in 2001.¹⁴

Maine does not yet have a comprehensive system of support in place for family caregivers. Prior to the passage of the NFCSP under the Older Americans Act Amendments in 2000, caregiver support was neither a major policy issue nor a major interest of state leaders in Maine, although some support had been provided to caregivers of persons with Alzheimer's disease or other dementias through a state-funded Alzheimer's respite program and two federally funded Alzheimer's Disease Demonstration Grants to States. State leaders commented that recognizing family caregivers who need support services themselves—as part of the system of long-term care—is a new concept for Maine because their long-term care system is based on looking only at the care recipient as the client. Moreover, several respondents expressed confusion over the notion of the family caregiver as a “client” in long-term care. Respondents also noted that although family caregivers are not explicitly recognized in state statute, respite care for family caregivers has been part of the state-funded home based program since 1981. According to one stakeholder, however, the state's entire home and community-based care system was built upon the presumption that family and informal caregivers could provide day-to-day care to complement formal services. Another observer commented that the “entire system takes family caregivers for granted.”

Given that the state has successfully reduced reliance on nursing homes and has seen the use of home and community-based care double, it is interesting that none of the key informants discussed the potential impact of this shift on Maine's family caregivers and on their need for support services to sustain them in their caregiving role. One stakeholder noted that a major challenge has been to “get the formal home and community-based care system to recognize family caregivers as something other than reduced spending on home care services.” A state official commented that the needs of consumers and their families are changing and that “some of the assumptions that we made 20 years ago don't hold today; it is now a ‘new generation’ of older people, and their caregivers and families are more likely to seek out and use services.”

Maine has two programs that specifically address the needs of persons with Alzheimer's disease and their families, a state-funded Alzheimer's Respite Program and a federal Alzheimer's Demonstration grant. Maine has received two federal demonstration grants to states for Alzheimer's disease. The first, awarded in 1993, developed models of respite, and the state has now replicated one of the models through the state-funded Alzheimer's respite program. The second grant, funded at \$255,000, focuses on Alzheimer's coordination and information. The state was in the second year of the three-year grant at the time of the site visit. This federal demonstration is considered a stand-alone program, functioning apart from other Older Americans Act programs at the state and local levels in terms of funding, eligibility and assessment but coordinated at the service delivery level with other state programs through the AAAs, each with a respite coordinator on staff.

With the advent of the new NFCSP funds to support family caregivers, the state's goal is to reach a broader population than Alzheimer's disease and dementia caregivers and to provide support beyond respite care. One way to achieve this, according to some respondents, is to establish new referral sources, particularly with the medical and health communities. For example, Maine's Eastern Agency on Aging and the Center on Aging at the University of Maine are presently conducting a three-year project to forge partnerships among primary care practitioners, the university and the AAAs to develop referral relationships between physicians and other health care providers and the caregiver coordinators at Maine's AAAs.^d

State leaders noted that they want the emerging family caregiver support program, as a new program in the start-up phase, to maintain its own identity rather than to be integrated into Maine's home and community-based care system. That system has different eligibility requirements, provides services based on functional ability of the care recipient and requires a co-payment. Although the state has a well-coordinated and centrally administered long-term care system, the new caregiver support program is not integrated into Maine's other long-term care programs administered by the BEAS. Rather, the intent, according to state officials, is to coordinate with the existing long-term care system so that family caregivers are served earlier in the caregiving process and are aware of the range of long-term care services available in the state when they are needed.

PROGRAM BACKGROUND/DEVELOPMENT

The original impetus for Maine's family caregiver support program was the passage in 2000 of the Older Americans Act Amendments, which created the NFCSP and provided federal funding (based on a congressionally mandated formula) to the State Units on Aging to provide caregiver support services. State officials commented that "it was not a program that we would have been able to set up without the federal mandate and funding." Prior to the passage of the NFCSP, Maine supported family caregivers by providing respite care from a variety of funding sources administered by BEAS (i.e., Medicaid waivers, state-funded home based and Alzheimer's respite programs, federal Alzheimer's demonstration grants). Respondents noted that the modest federal funding through the NFCSP allows the state to broaden service delivery to family caregivers beyond respite care.

Maine's BEAS began planning for the establishment of the new program prior to the passage of the NFCSP in June 2000. The BEAS convened a roundtable of key stakeholders across the state, including family caregivers, to identify both caregiver needs and ways in which the proposed NFCSP could enhance Maine's existing caregiver support efforts beyond respite care. Once the Older Americans Act was reauthorized, including the creation of the NFCSP, BEAS convened a meeting with Maine's five AAAs to brainstorm and identify what this new program "would look like" in the state. The BEAS was interested not only in how much federal funding would come to Maine for family caregiver support and how the AAAs would use the funds, but also in how the new funds would complement what the state was already doing in long-term care.

BEAS established several core requirements for the AAAs:

1. Use the NFCSP funds to *expand* efforts to newly identified caregivers, not to supplant services to family caregivers already receiving services from other publicly funded programs.

^d This project is funded under a three-year NFCSP demonstration grant.

2. Submit a plan with AAA draft contract for state FY 2002 and identify the caregiver program as a separate item in the budget to the BEAS.
3. Set aside a portion of the base allocation to each AAA for joint activities with statewide impact: (a) development of an informational packet and promotional items (e.g., jar openers) that can be distributed to doctors' offices, hairdressers, pharmacies and so on; (b) website development; (c) statewide collaboration with specific disease associations and AARP and (d) data collection and evaluation. Each AAA pooled \$5,000 of its funds (\$25,000 total) for joint activities.
4. Set aside a portion of funds for grants/contracts to local community agencies or businesses, rather than just take the federal funds and use them for services provided only by the AAAs.
5. Add staff at each AAA to (a) organize and run support groups; (b) work with employers to identify caregivers working outside of the home and their needs, including offering on-site caregiver education; (c) make home visits to evaluate and support individual needs and requests of caregivers; (d) provide in-person counseling, information, assistance and referrals; and (e) demonstrate effective initiatives to reach caregivers earlier in their caregiving experience.
6. Collect data as required for monitoring and evaluation.

Beyond these requirements, the state gave the AAAs considerable flexibility in designing their caregiver support programs, particularly with respect to respite care and supplemental services. Maine's AAAs prioritize services to family caregivers of older persons who are not currently receiving caregiver support services under the Alzheimer's respite or home based care programs. If the care recipient is eligible for state or Medicaid waiver respite services, the caregiver is referred first to these services. A family caregiver can receive NFCSP respite if the care recipient is on a waiting list for respite through other state or Medicaid waiver respite services. The state encouraged the AAAs to work closely with Maine's federal Alzheimer's Disease Demonstration Grant to States so that the new caregiver support program could build on the federal demonstration but not duplicate services. The BEAS encouraged the AAAs to be creative and innovative in program development and to make the maximum use of limited federal funds.

The BEAS elected not to hire a statewide caregiver coordinator, in part because of the state's lack of administrative funds under the federal funding formula to run the program. Because of the small number of AAAs in the state, the respondents did not view this as a major challenge to statewide program implementation. The manager of BEAS's community programs unit was assigned the role of managing the family caregiver support program.

When developing policies and standards for the program, the state utilized the U.S. Administration on Aging (AoA) website and listserv. Respondents commented that the AoA-sponsored conference in September 2001 also was extremely helpful in designing the program. The state released the federal funds to the AAAs in July 2001, the start of Maine's fiscal year.

Most rewarding: The flexibility of the program's design was considered the most rewarding aspect of program development. Respondents commented that family caregiver issues are gaining increasing levels of support in Maine.

Biggest challenge: State officials raised two major challenges of the program's development in the first year of start-up. First, the aging network had to "change their mind-set to thinking about the family caregiver, not just the older person, as consumer," said several respondents. Concerns were expressed that "this is how our systems are set up in Maine; this is how we have always done it—to look at the older person as consumer, and now we must look at the caregiver, too." Respondents acknowledged that although they have some experience with the concept of family support and a family systems orientation from their state-funded Alzheimer's Respite Program and the federal Alzheimer's Disease Demonstration Grant to States, these programs are small in scope.

Second, respondents said that reporting issues were the biggest challenge, particularly in trying to figure out what information they needed to collect, because the client population of family caregivers was a new focus of the state's data collection. Respondents were concerned that AAAs and service providers would face requests to collect more or different caregiver data in a few years. They said that it is always easier to build data collection systems from the start, rather than to build in more data collection over time.

FUNDING

In FY 2001, the first year of federal funding under the NFCSP, Maine received \$564,300 in federal funds. In FY 2002, the federal share of NFCSP was increased to \$641,505, or only about 2% of the BEAS \$35 million budget (excluding Medicaid waivers).

In contrast, Maine's expenditures in FY 2001 for the state-funded Home Based Care Program (including consumer-directed home care) was \$15.5 million; for state-funded Alzheimer's Respite Care, \$754,600; and for the Aged and Disabled Medicaid waivers, about \$19 million.¹⁵ Respondents did not provide data on the proportion of state or waiver funds for respite care specifically.

Maine received \$63 million in tobacco settlement funds during FY 2000. In FY 2001, Maine used \$11.7 million of these revenues for prescription drug coverage for the elderly and \$3.7 million to expand Medicaid services. The bulk of revenues (\$25 million) has been used to fund the Healthy Maine Program established to serve as a reserve for future health care activities. No funds have been appropriated specifically for caregiver support services.

Key informants noted that while Maine has a budget shortfall, compared to other states, there have been no major cuts to date in health or social services programs. The economic downturn has not affected the new caregiver support program. The state-funded Alzheimer's respite funds, administered through the AAAs, are being used to meet 80% of the required match requirement for the NFCSP, as long as there is not a waiting list. AAAs are required to provide 20% of the match with local funds.

PROGRAM ADMINISTRATION

The BEAS considers its role in developing and implementing the state's first caregiver support program to be oversight, policy development, funding, data collection and technical assistance. State officials commented that policy development to date has been broad in scope, emphasizing uniform data collection and flexibility in service delivery. Policies for the program are developed at the state level. Because Maine has limited experience serving family caregivers, state officials continue to encourage AAAs to be flexible and creative in meeting caregiver needs with the limited federal dollars coming to Maine.

Housed in one agency, BEAS staff administer all home and community-based care programs and support for family caregivers. State staff coordinate regularly with the AAAs' family caregiver coordinators and the Alzheimer's coordinators through an on-line listserv and regular meetings. The manager of community services also administers the new family caregiver program; a project director housed in the BEAS manages the state Alzheimer's project; and the program manager for long-term care administers care coordination for MaineCare and the state-funded Home Based Care Program.

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

Eligibility for Maine's family caregiver support program is consistent with federal requirements under the Older Americans Act; the program is for family or informal caregivers of any age who provide care to persons 60 years and older, as well as caregivers ages 60 and older who are caring for children ages 18 or younger.^e For respite and supplemental services, the older person (age 60 or older) must need help with at least two activities of daily living (ADLs) or have cognitive or other mental impairment.

Consistent with federal policy, the family caregiver is considered the client in the program. Respondents acknowledged that this has been confusing at times to both state officials and local service providers, however, because Maine has always focused on the older adult or person with disabilities as the "consumer."

Unlike for Maine's state-funded Home Based Care Program and Medicaid and waiver services, currently there are no uniform assessment standards for the family caregiver support program. Because of the limited federal funds for caregiver support, BEAS is not yet requiring that family caregivers go through a uniform assessment process. At intake, however, when a caregiver first contacts an agency for help, the BEAS requires all AAAs to utilize a common intake form. The form was adapted from the Alzheimer's respite intake, developed by the AoA and utilized by Maine's AAAs. It focuses on both the caregiver and the care recipient. Some intakes are conducted on the telephone and some in a caregiver's home. The form includes 24 questions about the caregiver, focusing on basic demographic information (age, race, income level, employment status), length of time caregiving, number of caregiving hours per week and so on. Ten additional questions are asked about the care recipient, including how much help the care recipient needs with ADLs. None of the questions on the intake form directly ask the caregiver about his or her needs and ability to provide care. The intake data are collected by AAAs at the local level. Data are not yet aggregated at the state level, although state officials expect to do this.

^e This includes caregivers ages 60+ who are caring for children ages 18 or younger who are affected with mental retardation or who have developmental disabilities.

The care recipient is the identified client in all of Maine's state-funded home and community-based care programs, as well as in MaineCare waiver programs. Eligibility for Maine's state-funded Home Based Care Program for older persons and adults with disabilities is based on the care recipient's functional ability (i.e., help needed with one ADL plus two other ADLs, instrumental activities of daily living (IADL) or nursing). For the state-funded Alzheimer's Respite Program, a dementia diagnosis is required. Cost-sharing is mandated for all state-funded programs, based on the care recipient's income, except for the Alzheimer's Respite Program, which has no income requirements but for which the consumer must co-pay 20% of cost-of-services.

Eligibility for the Aged and Disabled Medicaid (MaineCare) waivers is based on age (60+ for the elderly waiver; 18 to 59 for the people with physical disabilities waiver), income (225% of poverty level), assets and functional criteria (Medicaid nursing home level of care). For the Consumer Directed waiver, the care recipient must also demonstrate the ability to self-direct.

In 1995, the Maine legislature adopted a policy of universal preadmission assessment for all long-term care services, including nursing facility care, specialized adult family care homes, Medicaid waivers and state-funded home and community-based care services. Key informants pointed out that the use of a standardized assessment instrument with uniform definitions and a single point of entry into Maine's long-term care system provides consumers with a comprehensive system for determining services needs and leads to more consistent assessments statewide. Maine utilizes a centralized approach to assessment and care coordination through a two-agency system: One agency conducts assessments, and another coordinates care.

The BEAS contracts with one agency, Goold Health Systems, to conduct assessments under Maine's home and community-based care system. Under state regulations, this agency may not be a provider of in-home services. Trained nurses, meeting with the consumer (i.e., client), conduct the assessment using an automated, uniform assessment tool, 'establish functional eligibility' and authorize a service plan. The in-person assessments take two and one half to three hours on average to complete. Assessment data are kept in a central data warehouse so that information can be easily accessed for policy and programmatic analyses. Bureau of Family Independence (BFI) staff determine financial eligibility for the Aged and Disabled Medicaid waivers.

Although respondents acknowledged that there is no formal assessment of the caregiver, the assessment tool does include questions on social supports available to the consumer (i.e., care recipient), including:

- ◇ Extent of help (in hours) provided to the consumer from family, friends and neighbors
- ◇ Names of two informal helpers most relied on for help with ADLs or IADLs
- ◇ Caregiver status, (e.g., primary caregiver receives help from other family/friends in caring for the consumer; caregiver is unable to continue in caring activities because of a decline in health status
- ◇ Caregiver's extent of knowledge about care

Respondents noted that the focus of the assessment in all of Maine's long-term care programs is the care recipient. The extent of informal care (i.e., whether or not the consumer has a family caregiver) is taken into account in the authorization of paid services for the consumer to supplement but not to duplicate caregiver support.

In the BEAS-administered programs, after the completion of the assessment, the nurse assessors inform the consumer of which programs he or she may qualify for. Elder Independence of Maine then arranges, pays for and manages home and community-based services statewide. Elder Independence oversees services delivered through agencies.^f Key Informants pointed out that consolidating the administration of care management for home and community-based services has saved the state about \$800,000 annually since 1996.

SERVICES

Maine offers a wide range of home and community-based services and options through its state-funded home based care and MaineCare (Medicaid) waiver programs and through the Alzheimer's respite program. Services are delivered through a network of home health, adult day services, personal care agencies and independent nurse contractors. Consumers also have the choice of hiring their own direct care worker rather than using an agency. Services include, but are not limited to, meals and shopping; housekeeping; help with bathing, dressing and eating; transportation; nursing care; physical, speech and occupational therapy; respite care; adult day services; and other services to help maintain independence.

Two of the MaineCare waivers (Aged and Disabled) offer respite care; the Consumer Directed waiver does not. Key informants noted that Maine's Aged and Disabled waivers also cover other services that can help the family caregiver, such as home modifications and adult day services. A registered nurse can provide home health services such as counseling the consumer and family on addressing nursing and related needs at home, and a social worker may provide medical social services to support the family as well as the consumer when the needs are more complex than the home care coordination agency can provide.

Family caregiver support program: The state does not mandate that each AAA provide all caregiver support services given the very limited federal NFCSP funds in Maine. Maine's AAAs are emphasizing services that the state had not provided specifically to caregivers before the passage of the NFCSP: information, assistance, counseling and training. Most of the state's five AAAs opted to provide limited respite or supplemental services under the NFCSP to augment other state funding sources that cover these service options primarily for dementia caregivers. At the time of the site visit, Maine's AAAs were utilizing various approaches to provide support to family caregivers. All of the state's AAAs opted to provide information, assistance and counseling/support groups/training.

With limited NFCSP funds and other sources of respite care funding in the state, only three of the five AAAs are offering respite reimbursement up to a cap of \$500 per year, one time only. (Each AAA determined the amount of the cap; it was not state mandated.) Two of these AAAs have annual allocations for respite of \$3,000 and \$10,000, which fund respite for only six to 20 family caregivers. In contrast, the state-funded Alzheimer's respite program caps the amount of respite per family caregiver at \$3,800 per year for respite provided in the home, by adult day services or through short-term overnight placement options. Up to \$2,000 can be used for home modifications.

^f Alpha One manages the consumer-directed programs. That agency utilizes a different system, conducting both assessments and care coordination.

AAAs also varied in their policies and procedures for supplemental services. One AAA set aside \$2,000 for one-time funding assistance for caregivers to receive skills training in personal care such as proper lifting or bathing, to purchase assistive devices (e.g., grab bars), or to obtain nutrition counseling. Two other AAAs offered limited individualized services that include home modifications, other safety needs and handyman services. Two AAAs did not offer any supplemental services as part of their package of caregiver support.

State respondents noted that federal funds for caregiver support enabled the AAAs to hire designated caregiver coordinators and to expand service delivery to family caregivers beyond respite care. Program officials are interested to see what the demand for respite care will be beyond the state funds.

Major services needed by caregivers: The ability of family members to self-identify as caregivers “so they don’t suffer in silence” was viewed as a major need. Other major service needs identified by state officials included education and training on caregiver issues, emotional support for the caregiver and, to a lesser extent, respite care. Several observers pointed out that due to Maine’s labor shortage, home care agencies have problems finding staff, especially well-trained and consistent direct care workers. Stakeholders noted the major services needed by family caregivers were information, emotional support and care management. One respondent commented that “family caregivers need validation in a way that is meaningful to them.” Other stakeholders noted that families also have the difficult challenge of finding trained and consistent workers to offer them some relief.

Regarding service delivery, at the time of the site visit (April 2002), the following services had been provided:

- ❖ About 12,330 family caregivers had received information on caregiver support and services
- ❖ 150 caregivers had received assistance in gaining access to caregiver support services
- ❖ 128 caregivers had received counseling or participated in a support group or training session
- ❖ Only one family caregiver had received respite care under this program

Table 2. Family Caregiver Support Services in Maine

Program	Family Caregiver Support Program	Alzheimer's Respite	Home Based Care ^a	Aged & Disabled Medicaid Waivers
State Administrative Responsibility	Bureau of Elder & Adult Services, Department of Human Services (DHS)	Bureau of Elder & Adult Services, DHS	Bureau of Elder & Adult Services, DHS	Bureau of Elder & Adult Services, DHS
Local Service Delivery	AAAs ^b Service providers/ contractors	AAAs Service providers/ contractors/family/ neighbors/friends	Elder Independence of Maine—case manage- ment only Service providers/ contractors	Elder Independence of Maine—case coordina- tion only Service providers/ contractors
Funding Source	Older Americans Act, Title III-E	State general fund	State general fund	Medicaid 1915 (c) waiver
Expenditures FY 2001	\$564,300 (for all caregiver support services)	\$754,609	\$15.5 million ^c	\$19.1 million
Client Population	Family informal caregiver	Care recipient & family caregiver	Care recipient	Care recipient
Eligibility Criteria				
Age	60+ care recipient Family caregivers of any age of persons 60+ Family caregivers of children ages 18 and under if the caregiver is age 60+	18+ care recipient	18+ care recipient	60+—elderly care recipient 18–59—disabled care recipient
Income	None	No income limit Assets <\$50,000 for 1, <\$75,000 for 2	No income limit	222% of poverty levels (\$1,635/month) <Assets \$2,000
Functional Ability	For respite & supple- mental services only— at least 2 ADLs or cognitive impairment for care recipient	Dementia diagnosis	1 ADL + 2 other ADLs, IADLs or nursing	Nursing home level of care

a Maine also has a small, state-funded adult day services program, funded at \$304,000 in FY 2001, that serves 119 clients.

b AAAs = Area Agencies on Aging

c About \$3.1 million, or 20% of funds, were expended for consumer-directed home care.

Table 2. Family Caregiver Support Services in Maine (continued)

Program	Family Caregiver Support Program	Alzheimer's Respite	Home Based Care ^a	Aged & Disabled Medicaid Waivers
Uniform, Statewide Caregiver Assessment	No (Uniform intake only)	No (Uniform intake only)	No (Uniform care recipient assessment only)	No (Uniform care recipient assessment only)
Services Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies) ^d	Respite care Information Assistance Counseling Education Referrals Home modification	Respite care	Respite care
Respite Cap	Varies by AAA up to \$500/year	\$3,800 per year	No	No
Consumer Direction	Yes	Yes	Yes	Yes
Family Caregivers Paid as Respite Providers	Yes	Yes	Yes	Yes

Source: Key Informant interviews and *State of Maine – State and Medicaid Long-Term Care Expenditures*, www.state.me.us/dhs/beas/lc/ltc-exp-97-01.htm.

^d All services are provided in Maine. Not all AAAs offer all services, however. All AAAs provide information, assistance and counseling/support groups/training.

CONSUMER DIRECTION

Maine has a long tradition of offering consumer direction in both its state-funded and waiver programs, allowing consumers to choose and hire their own personal care attendant or respite worker, including family or friends. One key informant noted that 67% of in-home respite care under the state-funded Alzheimer's respite program is provided by family, friends or neighbors.

Family members can be paid to care for their elderly or disabled relatives at home in Maine's Aged and Disabled Medicaid waivers^a as well as in the state-funded home based and Alzheimer's respite program with the following restrictions: Spouses or parents of minor children cannot be paid under the Medicaid waivers in keeping with federal regulations.

In Maine, family caregivers do not have to live with the consumer to be paid to provide care. Maine has neither established qualifications for family members to be paid that differ from formal caregivers (i.e., personal care assistants) nor required criminal background checks for family caregivers when the consumer hires the family member directly.

Under the state's MaineCare Aged and Disabled waivers only, the state also allows home care agencies to hire the consumer's relatives or friends to provide care, under limited circumstances, such as when the family lives in a rural area. In this option, families are paid through the agency, which is their employer, and the family member is required to have the same training as a regular personal care assistant hired through an agency and to undergo a criminal background check.

Under the new NFCSP-funded family caregiver support program, the state permits direct payments to family caregivers. Family caregivers can be paid regardless of whether they live with the older person or not. Spouses are not permitted to be paid, however, to be consistent with other programs.

QUALITY ASSURANCE AND EVALUATION

To date, the state is utilizing only AoA's data collection requirements for the family caregiver support program: type of service to caregiver (e.g., information, counseling), number of caregivers served by type of service, units of service provided (e.g., information contact, respite hours) and expenditures per service type. While state officials would like AAAs to report on the time spent providing services to family caregivers in each service category, this reporting item is currently optional, except for respite and supplemental services, to be consistent with current federal reporting requirements. Key informants noted that Maine is minimizing what the AAAs now collect and expressed concerns about future data collection requirements, "switching gears" and the impact on their automated client tracking system.

^a Under the Consumer Directed waiver, family members can be paid only to provide personal care. Respite care for caregivers is not covered.

Performance measures are collected once a year by surveys. Maine's legislature requires that all state social service programs collect outcome data. Given the early stages of development of the caregiver support program and the lack of overall guidance nationally, state leaders acknowledged that they don't yet have a clear method for evaluating the program or examining caregiver outcomes. Bureau of Elder and Adult Services respondents commented that, as the program gets off the ground at the local level, they will, at a minimum, be examining level of demand for caregiver support services.

Under the Medicaid waivers, no data are collected on caregiver outcomes. One respondent commented that Maine is a small state and that consumers themselves often call the state or home care coordination agency to express their satisfaction or dissatisfaction with services. (See also the section on Program Eligibility/Assessment Process for specific caregiver information collected by the state-funded programs, Medicaid waivers and new family caregiver support program.)

SYSTEMS DEVELOPMENT

Although the state has a history of long-term care reform, family caregiver needs have not been part of this debate. State leaders and stakeholders view the family caregiver support program as a new initiative with a new constituency group. At the time of the site visits, Maine had not yet completed the first year of program implementation.

One state agency, BEAS, administers Maine's long-term care system and family caregiver support program. The relatively small-scale Alzheimer's Respite Program and the even smaller new federally funded family caregiver support program are being operated separately from the long-term care system, however. For example, these programs are not required to utilize the state's standard in-home assessment, mandated for the other home and community-based programs, including Medicaid waivers. Respondents commented that they could in this way preserve local flexibility and eliminate often complicated issues such as incompatible service definitions, reporting requirements or client identification (i.e., the care recipient or family caregiver).

Some observers noted that family caregiver support services and services under the Alzheimer's Respite Program are integrated in a few of the AAAs; in others they are separate. Another respondent commented that the new family caregiver support program has not been consistently implemented at all of Maine's AAAs. When the family caregiver support program was initiated, respondents indicated that there was not so much concern about competition between the two programs, but rather there was an attempt to avoid confusion because the programs are tied so closely in terms of purpose and mission. State leaders acknowledged that their intent is to build on the Alzheimer's programs and not to overlap or duplicate efforts. To encourage systems development of caregiver support services at the local level, the state has strongly recommended that in each AAA, the family caregiver coordinator and the Alzheimer's coordinator work together. If a person has Alzheimer's disease, for example, staff are to direct the consumer and his or her family caregiver first to the state-funded Alzheimer's Respite Program and then to the more limited resources under the new federally funded family caregiver support program.

Maine does not have a body whose mission is coordination of family caregiver support services across state departments. All support to families of older persons is administered through the BEAS. At the local level, AAAs are viewed as the service coordinators for caregiver support.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

Maine's *Olmstead* initiative has been a collaborative process through the Plan Development Workgroup for Community-Based Living, involving representatives from five state departments (Human Services, Behavioral and Developmental Services, Education, Labor and Corrections) and a broad cross-section of consumer representatives, including some family caregivers. The goal is to develop a community integration plan that fills the gaps in the existing community services system. The workgroup has been meeting for two years, and a report is expected to be prepared in the fall of 2002. Maine's Real Choice Systems Change grant will attempt to implement the recommendations from this interdepartmental planning effort. Key informants were uncertain as to how much attention would be paid to family caregiver issues in the state plan.

OTHER POLICY ISSUES

Priority on caregiver support: State officials and stakeholders were asked, "Within all the long-term care programs in your state, what priority (high/medium/low) is placed on caregiver support?" As shown here, the key informants interviewed felt that overall, Maine tended to place a "low-medium" priority on caregiver support services. State officials agreed that there was a "low-medium" priority, while one stakeholder indicated a "low" priority and the other a "low-medium" priority. One stakeholder did not respond.

Number of Key Informants	Priority on Caregiver Support
1	No response
1	→ Low
3	→→→ Low - Medium
1	→→→→→ Medium

Benefits and challenges: Maine's key informants identified three aspects of their program that are most beneficial to family caregivers:

1. Having a funding source (i.e., NFCSP) with a broader range of services focused on the caregiver rather than just respite care (e.g., counseling, support groups)
2. Being able to publicize the issue of family caregiving so that families can recognize that they are caregivers
3. Having a contact person at the local level to whom the caregivers can talk about their needs

When asked to identify the three main challenges for implementing family caregiver support programs in the state, Maine key informants noted the following:

- ❖ Making the new federal program "fit in" with other state-funded programs (i.e., Alzheimer's respite and state-funded home based care)
- ❖ Helping family caregivers understand that they *are* caregivers and asking for help earlier in the disease process

- ✧ Identifying outcomes measures to see if the program is making a difference
- ✧ Identifying equitable ways to allocate support to family caregivers—that is, assessing the needs of caregivers while maintaining the interests and needs of the consumer (i.e., older person or adult with disabilities)
- ✧ Dealing with a labor shortage resulting in a lack of trained direct care providers

Major lesson learned: The view of Maine’s state leaders is that the “best interests” of the consumer do not always align with those of the family caregiver. As the state expands its program of caregiver support, the challenge, as expressed by one observer, will be to keep in mind “who is the customer.” In Maine, the state has traditionally sided with the older person or the adult with disabilities, and this perspective has “not always endeared us to the family or other agencies,” said one state leader.

Other lessons learned in the first year of program implementation identified by the respondents included the needs to try to maintain flexibility as the program grows and to recognize that family caregiver support cannot be provided using volunteers. One respondent from the Medicaid waiver program pointed to the need to put parameters on respite care, either by limiting the number of hours or by requiring that the caregiver live with the consumer to receive benefits.

Opportunity for expanding caregiver support: In general, Maine respondents did not view their state as expanding state-funded programs to support and strengthen family caregivers over the next three to five years. Maine, like most states, is experiencing another budget crisis. This makes program expansion with state revenues unlikely. One observer noted that another budget crisis began Maine’s process of long-term care reform a decade ago, however. With rising expectations, baby boomers will demand good-quality care for their parents and themselves. Respondents believed that caregiver issues will be addressed in the longer term.

Recommendations for other states: When asked what recommendations they would make to other states that are developing programs to support family caregivers, Maine’s respondents had many suggestions, including:

- ✧ Involve all stakeholders from the beginning to get their input and ideas.
- ✧ Ensure flexibility in service design and delivery at the local level, while maintaining consistency in assessment, eligibility and data collection across the state.
- ✧ Think through the parameters of the program before implementation.
- ✧ At the state level, identify a lead person to manage the program who has a history of good relationships with the AAAs; at the local level, hire caregiver coordinators with excitement and “fresh eyes.”
- ✧ Have a system in place to accommodate the demand for services (i.e., address workforce issues).

NOTES

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