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

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By

Lynn Friss Feinberg, MSW
Sandra L. Newman, MPH
Carol Van Steenberg, MSS

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WASHINGTON

OVERVIEW

Washington is a northwestern state with more than three-fourths of its residents living in urban areas. State leaders have been committed to expanding home and community-based services and downsizing institutional care for decades. Today, Washington State has a single point of entry for all long-term care services needed by individuals ages 18 and older and for their family caregivers.

The passage of the National Family Caregiver Support Program (NFCSP) gave Washington State the opportunity to expand existing state-funded policies and programs for family caregivers. Changes in caregiver support resulting from the NFCSP include greatly increased funding, the addition of counseling for family caregivers and the inclusion of services for grandparents raising grandchildren. The state's caregiver support services are characterized by:

- ✧ Service to family caregivers ages 18 and older, regardless of conditions
- ✧ The targeting of underserved populations (e.g., ethnic communities)
- ✧ Program flexibility
- ✧ An emphasis on training, including widespread adoption of the “Powerful Tools” training program for caregivers, developed in Oregon, and specialty training on topics such as dementia care and mental health issues

Washington State respondents noted that the major service needs of family caregivers are (1) respite care, (2) specialized caregiver information, training and consultation with specialists and (3) support groups.

The NFCSP in Washington State, although delivered locally with unique features in each community, is moving toward statewide identification of the program through a uniform name, The Family Caregiver Support Program (FCSP), definitions and a common contact form to document caregiver needs. As Washington continues to build its caregiver support system, a key consideration will be how the state achieves one of its goals: integration of caregiver assessment into the state's uniform assessment tool for all long-term care programs.

INTRODUCTION

Washington represents an “old” state in this study since caregiver support policies and programs were already in place through state funds in Washington prior to passage of the NFCSP. The project team conducted a site visit on April 15 and 16, 2002, interviewing government officials and key stakeholders in Olympia and Seattle.

All government staff interviewed worked in one agency:

- ✧ Department of Social and Health Services, Aging and Adult Services Administration

The stakeholders held positions at the following agencies or associations:

- ✧ Washington Association of Area Agencies on Aging
- ✧ Pierce and Lewis-Mason-Thurston Area Agencies on Aging
- ✧ Senior Services (Seattle)
- ✧ Alzheimer's Association, Western and Central Washington Chapter (Seattle)

Three programs are featured:

1. Respite Care Program (state funded)
2. Washington State Family Caregiver Support Program (state funded)
3. National Family Caregiver Support Program (federally funded)

BACKGROUND

Washington is a northwestern state with a population of 5.9 million people who reside in 39 counties. More than three-fourths of the state's residents live in urban areas (76.4% in 1990).¹ The Cascade Range divides the state, geographically and politically. East of the Cascades lies the politically conservative, largely rural area predominated by agricultural crops such as wheat and apples. To the west are Seattle, Tacoma and Olympia; successful businesses such as Microsoft and Starbucks; and a relatively liberal population with a strong union history.²

In 2000, personal income per capita among Washingtonians was \$31,528, higher than the national average of \$29,676.³ About 10.2% of Washington's population live below the federal poverty level (vs. 13.3% U.S.).⁴ Washington ranks seventh nationally in percentage of households with Internet access (49.7% in 2001).⁵ The racial makeup of the state's population differs somewhat from that of the United States as a whole, with Washington having a smaller proportion of both African American (3.2% vs. 12.3% U.S.) and Hispanic persons (7.5% vs. 12.5% U.S.) and a higher proportion of Asian persons (5.8% vs. 4.1% U.S.)⁶ (table 1). Washington also is home to 26 federally recognized Native American tribes.

An estimated 873,223 persons in Washington were 60 years or older in 2000 (14.8%), a lower proportion than in the nation as a whole (16.3% U.S.). Washington ranks 45th nationally in the number of older persons (ages 60+) residing in the state.⁷ Compared to the national average, Washington's older population (ages 60+) has a much smaller proportion of African American (1.7% vs. 8.4% U.S.) and Hispanic (1.9% vs. 5.4% U.S.) persons and a larger share of Asian persons (4.1% vs. 2.5% U.S.) Washington also has twice the national proportion of older Native Americans (0.8% vs. 0.4% U.S.)⁸.

Washington ranks 34th nationally in the proportion of its population ages 85 and older. In 2000, 84,085 persons, or 1.4% of Washington's population, were ages 85+.⁹

An estimated 540,272 family caregivers reside in Washington. These family caregivers provide about 503 million hours of caregiving per year at an estimated value in 1997 of \$4.1 billion.¹⁰

Washington's state tax revenue in 2001 was \$12.7 billion, or \$2,117 per capita, placing the state 16th in the nation. Washington does not have a state income tax but relies upon property, sales and business taxes for its general revenues. A ballot initiative in 1994, I-601, imposed a stringent cap on general fund spending, limiting increases to a three-year average of inflation and population growth. During the economically robust mid-1990s, state budget surpluses grew because of this spending cap, setting the stage for tax cut initiatives, such as one in 1999 that replaced the state's motor vehicle excise tax with a \$30 annual fee and reduced state revenues by hundreds of millions of dollars. As a share of personal income, total state taxes dropped from 7.2% in 2000 to 6.8% in 2001.¹¹

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

	Washington	United States
Total Population Characteristics		
Total Pop. ^b	5,894,121	281,421,906
% African American ^c	3.2%	12.3%
% Hispanic ^d	7.5%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	873,223	45,797,200
% 60+ ^f	14.8%	16.3%
National ranking 60+ ^g	45	NA
Pop. 65+ ^h	662,148	34,991,753
% 65+ ⁱ	11.2%	12.4%
National ranking 65+ ^j	43	NA
Pop. 85+ ^k	84,085	4,239,587
% 85+ ^l	1.4%	1.5%
National ranking 85+ ^m	34	NA
% increase 1990–2000 60+ pop. ⁿ	14.2%	9.4%
% White (60+) ^o	90.2%	82.4%
% African American (60+)	1.7%	8.4%
% Hispanic (60+)	1.9%	5.4%
% Asian (60+)	4.1%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.1%	0.1%
% Amer. Indian/Alaska Native (60+)	0.8%	0.4%
Informal Caregiver Characteristics^p		
# of caregivers (1997)	540,272	25,798,370
Caregiving hours (millions) (1997)	502.9	24,013.1
Value of caregiving (millions) (1997)	\$4,113.6	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$31,528	\$29,676
% of pop. below poverty (1997) ^r	10.2%	13.3%
Internet		
% of households w/Internet access (2001) ^s	49.7%	41.5%
Nat'l ranking of households w/Internet access	7	NA

a Unless otherwise noted, all data are from 2000.

b Mapstats-Washington, *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-Washington.
- 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

Unlike in most other states, caregiver support services and long-term care for the elderly and adults with physical disabilities are administered in Washington through the Aging and Adult Services Administration (AASA), a part of the Department of Social and Health Services (DSHS). AASA is responsible for virtually all financing, regulation, quality assurance and policy for long-term care, whether these services are delivered in nursing homes, in private dwellings in the community or in nonmedical residential facilities. DSHS serves as the "single state agency" for Medicaid and has assigned to AASA the tasks for Medicaid long-term care services. In addition, AASA has responsibility for community-based services and nursing home care (state and federally funded), a small chore services program (state funded), and the state's respite care and family caregiver support programs (state funded). Last, AASA also serves as the State Unit on Aging, administering the provisions and programs of the federal Older Americans Act, including the NFCSP.

Washington's aging network includes a statewide system of 13 Area Agencies on Aging (AAAs). Most of the AAAs are part of city or county government, although two are Tribal governments and one is under a nonprofit agency. AAAs' planning and service areas range in size from one county or reservation to six. The state's AAAs administer home and community-based care and caregiver support at the local level.

Washington has a single point of entry for all state-funded long-term care services needed by anyone age 18 or older. Employees of the AASA, organized into six regions that cover the state, assess each applicant, create a care plan and authorize services. If the consumer will receive services in a nursing home or a nonmedical residential facility (adult family home, adult residential care or assisted living), an AASA staff member continues as the ongoing case manager. If the consumer remains in his or her own home, however, the local AAA takes over the ongoing case management role, including reauthorization of services and payment of agency providers. DSHS reimburses the AAA for these expenses. The state, rather than the AAA, pays independent providers directly.

Washington officials have been committed to expanding community resources and downsizing institutional care for decades. About 85% of the aging, developmentally disabled and mentally ill populations are served today in the community. Washington has a lower-than-average supply of nursing home beds, with 27,204 beds in 285 facilities in 1998 (41.7 beds per 1,000 persons ages 65 and older, compared to an average of 52.5 beds nationally).¹² The number of nursing home beds has actually fallen in recent years, partly because of an expansion of alternative services, including adult family homes, adult residential care facilities and assisted living facilities.

Washington's Aged/Disabled 1915(c) Medicaid waiver for the elderly and for adults with disabilities is called "Community Options Program Entry System," or COPES. Implemented in 1983, COPES offers a range of home and community-based services to persons who would otherwise require care in a skilled or intermediate nursing care facility. Within its state Medicaid plan, Washington has a personal care benefit and provides reimbursement for assisted living.

In FY 2002, the DSHS was awarded a \$1.4 million Real Choice Systems Change grant by the Centers for Medicare and Medicaid Services (CMS). The grant is administered by the Department's Health and Rehabilitation Services Administration. The purpose of the grant is to integrate systems that support transition from institutional settings and direct payment systems.

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT

Washington set the stage for caregiver support programs with its historic commitment to home and community-based services. Having long recognized the informal caregiver as a major provider of long-term care services, Washington State has built caregiver support services into existing infrastructures and state-funded programs. The state has been a leader in caregiver-specific policies and programs.

Washington's state officials identified one statute, Chapter 74.41 RCW, that recognizes family caregivers. Respite Care Services were enacted statewide in 1989. The Fred Mills Act, enacted in 2000, added to Chapter 74.41 RCW, broadening the array of services to create the state's Family Caregiver Support Program. In addition, Washington State's strategic plan for long-term care references family caregivers. A bill to take effect in January 2003, SSB 6426, requires the state to offer family and medical leave benefits beyond the federally prescribed minimum. Under that bill, employers must allow employees to use "sick leave or other paid leave to care for a spouse, parent, child, parent-in-law, or grandparent with a health condition requiring treatment or supervision or for emergency purposes."¹³ Washington, having no state income tax, does not have a caregiver tax credit. Through SHB 1397, passed in March 2002, a "kinship caregivers working group" was convened, within existing resources, to review the study conducted by the Washington State Institute for Public Policy and published in June 2002 and prepare a briefing for the legislature due November 1, 2002.

Washington has three statewide programs explicitly designed to help family caregivers: (1) the state-funded Respite Care Program, (2) the state-funded Washington State Family Caregiver Support Program (FCSP) and (3) the new federally funded NFCSP. AASA's goal for its family caregiver support programs is "to develop a coordinated caregiver support program, linking existing infrastructure and network services with new programs/services."¹⁴ With all three of these programs run through the AAAs, as are the state's other community-based long-term care programs, this goal

seems reasonable. For example, caregivers whose family member receives services through the COPES Medicaid waiver or other state programs are to be made aware of the AAA's Information and Assistance (I&A) number so that they may access additional services for themselves. The I&A programs also cross-refer to COPES, Medicaid personal care and chore services during caregiver screening.

Stakeholders agreed that family and informal caregivers are recognized as a central part of Washington's long-term care system. Some saw this as a work in progress, however. "More so now," said one: "For a long time family caregivers were taken for granted." Another felt that NFCSP is "opening a lot of eyes." Like state officials, stakeholders cited the state's Family Caregiver Support bill and said it had raised the awareness of legislators about caregivers' situations. Still, the main perspective has to do with the economic value to the state of family caregivers' services, rather than with the needs of this group. Several stakeholders mentioned that caregivers do not see themselves as caregivers eligible for services, making outreach a challenge. "A caregiver usually self-identifies as a son or a daughter who is doing what they are supposed to do—taking care of a parent who needs help." Ethnic minority caregivers, in particular, were reported to believe that caring for a relative is normal and not to see this service as a huge burden for which they should receive help. One informant wondered, "Do we need to make people, who are doing what they think is the right thing to do, be 'dependent'?"

The annual caregiver conference convened by DSHS/AASA, AARP, the Alzheimer's Association and others provides training on emotional health and well-being, along with hands-on training for care provision. State officials view the conference as a place to coalesce groups of providers for work on joint projects, and as a support service for caregivers. Some tribal areas now offer caregiver training, too, and some workshops take place in Spanish. The local coalitions created to carry out the workshops and conferences throughout the state proved to be useful for developing more sophisticated caregiver support services after the NFCSP passed.

State officials believed that the priority for caregiver support services in Washington was "somewhat low" among long-term care programs offered by DSHS because Medicaid programs, with a \$1 billion budget, drive the priorities. In comparison, family caregiver services are small. One observer considered this low priority ironic, given all the talk in the state about natural support systems, and felt that growing these resources was an evolutionary process.

PROGRAM BACKGROUND/DEVELOPMENT

Washington has built its caregiver support capacity through state-funded demonstrations, federal demonstration grants and foundation funds. Between 1993 and 2000, Washington received two federal Alzheimer's Disease Demonstration Grants to States, administered by AASA and funded first by the Health Resources and Services Administration (HRSA) and then by the Administration on Aging (AoA). The demonstration projects targeted four ethnic communities, (Chinese, Hispanic, Korean and Native American), as well as rural communities. Through the demonstration, 4,822 caregivers and others were trained, 387 families received culturally appropriate respite services, 268 persons received in-home diagnosis through the University of Washington/Alzheimer's Disease Research Center and various educational tools were developed.

Since 1993, Washington has had an annual regional training conference for caregivers, with the first conference launched as a collaborative effort of AASA, AARP, AoA and numerous community organizations. In 1998, the state developed the 57-page *Caregivers' Handbook*,¹⁵ it has distributed 45,000 copies of this guide to family and other unpaid caregivers of adults with disabilities. In 1998, the Brookdale Foundation awarded the state a Relatives as Parents Program (RAPP) State Initiative grant, making possible the creation of a state RAPP coalition of 40 public and private organizations, a RAPP website (parenting.wsu.edu/relative/index.htm), a training video, a resource guide, a state conference on laws and resources, and a statewide kinship caregiver survey.

Initially the state's Respite Care Program was a demonstration project operated by three AAAs; during its first two years, it served 1,408 caregivers with an appropriation of \$545,000. Legislation in 1989 made the Respite Care Program statewide. The program is designed to provide relief to unpaid caregivers who offer continuous care and/or supervision to persons ages 18 or older who have a functional disability.

Washington State's FCSP was a natural extension of the state-funded Respite Care Program. In 1999, the AAAs' Respite Care Program managers, the Washington Association of Area Agencies on Aging, caregiver organizations and AASA created a framework to provide unpaid caregivers supportive services. At the same time, State Representative Carolyn Edmonds and six other Washington State legislators attended a national policy conference on caregiving for state legislators in October 1999, sponsored by the San Francisco-based Family Caregiver Alliance. As a result of both efforts, SHB 2454, the Family Caregiver Support bill, (also known as the Fred Mills bill), was authored by Representative Edmonds, was introduced and received unanimous support. It passed during the 2000 legislative session with a modest \$610,000 appropriation, in a year when passage of any new programs was deemed most unlikely. The new state funds allowed Washington to enhance service delivery to caregivers beyond respite care, emphasizing specialized information and assistance, caregiver training and consultation, support groups and supplemental services.

Following passage of SHB 2454, AASA requested plans from the AAAs in the fall of 2000 to identify local family caregiver needs, current caregiver activities (those of the AAA and of other public/private local agencies), culturally relevant services, outreach strategies that would include those who do not recognize themselves as caregivers, collaboration with other agencies and core services to be implemented.

By the time the NFCSP was enacted at the end of 2000, the state of Washington had some experience in providing caregiver support services. Thus, both the AASA and the state's AAAs were primed to respond to the new federal caregiver support initiative and to further expand family caregiver support. Seeing its role as shaping local processes rather than as prescribing the exact way in which AAAs should provide services, AASA developed a framework for and facilitated discussions with the AAAs, distributed materials to them and made it clear that a multifaceted system was to be developed, rather than a system with a single-service focus. In addition, AASA required the AAAs to develop plans showing how NFCSP funding would result in something new and address each of the five core service categories. In March 2001, AASA asked the AAAs to present their NFCSP plans, addressing its requirements in addition to the requirements of the state FCSP, including counseling, targeting caregivers in the greatest social and economic needs and serving both older grandparents raising children and older caregivers of persons with a developmental disability.

Most rewarding: Respondents felt that the availability of a variety of services offered by the 13 AAAs was particularly rewarding in the development and implementation of Washington’s family caregiver support services. “The beauty of it is that it’s turned out so different in each place, that we see there was enough flexibility to allow it to sort of blend with whatever the community already had or didn’t have,” one said. “There’s definitely flexibility. We like to say flexibility with accountability.” Another rewarding aspect is that “people really like supplemental services, be they...technology or...giving a caregiver transportation if they don’t have their own.” Also noted were the energy and innovation seen across the state among the aging network and service providers.

Biggest Challenge: “A big challenge that we faced—in both the state-funded FCSP and the NFCSP—was discouraging the AAAs from simply focusing on respite services,” reported one state official. “Respite is a wonderful service and caregivers really need it. It’s hard when you recognize how important respite is to people,” she explained, “to take that extra step and say now we’ve got to go move onto these other more important support services.” The state initially limited the share of funds that could go to respite programs under the state FCSP to 25%, then increased it to 35% when the federal dollars came. “We had an expectation that all core services would be offered.” Initially the AAAs felt that with such a small amount (around \$30,000 for most during the first year of the state FCSP), the funding should simply be incorporated into their current budgets. “We were saying, ‘We really want you [the AAAs] to develop an in-depth plan, and tell us what will be done to meet the identified roles.’ There was no guarantee that the federal dollars would come, but we were very hopeful,” the state official said. “The AAAs really had to go on faith.”

As a result of some of the state’s policies, the AAAs developed programs that created “a lot more sophisticated presentation of specific information,” especially about dementia and Alzheimer’s disease. “Whereas respite focuses on relief, which is really important, these other activities focused on some real specific tools these caregivers could use,” the official continued. “I’ve had a number of caregivers call me and say that they had been [respite] participants for a long time... and they really appreciated it. They thought it was wonderful, but the other...caregiver support activities sort of took them to a new level in terms of things that they could use to make their caregiving experience more successful.”

Respondents indicated that reporting has been a “nightmare” with such flexibility and with the three different programs (i.e., the state-funded Respite Care Program and FCSP and the federally funded NFCSP). “Even the funding cycles are different,” said one state official. A related challenge is the differing eligibility criteria for the state and federal programs: Whereas the federal program is only interested in caregivers of people age 60 and older, the state helps caregivers of any age who care for adults (age 18+). “So it’s a lot” for the front line worker “to figure out where this person is going to be served.”

FUNDING

In FY 2001—the first year of federal funding under the NFCSP—Washington State received \$2.1 million in federal funds. In FY 2002, the federal appropriation increased, so that Washington’s share was nearly \$2.3 million. This past year, Washington had a budget of \$2.8 million for the Respite Care Program, \$610,000 for the state FCSP and \$2.3 million for the NFSCP. The sum of these funds represents just a bit over half of 1% of the agency’s total budget of \$1 billion (including Medicaid expenditures) for FY 2001–02.

In the first two years of the state's FCSP, the AAAs have received an annual allocation ranging from a low of \$7,966 (for a tribal AAA) to a high of \$172,111; most AAAs received between \$30,000 and \$40,000. In the first year under the NFCSP, the AAAs received funds from a low of \$25,853 to a high of \$558,656, with most receiving allocations between \$100,000 and \$130,000.

The downturn in the economy has not yet had an impact on funding for family caregiver support services, but respondents were uncertain what would happen in the coming year. The state budget situation was described as "dismal," "very sour," "a crisis," "bleak" and "horrible." State officials and stakeholders all agreed that the recession had hit Washington very hard.

Adding to the woes of two major segments of the state's economy, technology and aerospace, are populist ballot initiatives that changed the way the state pays (or does not pay) for services. Initiative 601 capped expenditures based on a combination of inflation and demographics, but the "market basket" used for its calculation does not reflect the needs of the long-term care population. The demographic measure is a global one, not taking into account the mix (i.e., that the 85+ population is growing at twice the rate of the general population, while the overall numbers decline as younger people exit the state in a "down" economy.) This impacts the state by having fewer persons available to support children and older persons financially and through caregiving. Another recent initiative increased teachers' wages without a revenue source, putting stress on other programs because the budget cannot grow overall. With no income tax, the state must rely upon sales and property taxes, including an automobile excise tax. Initiative 695 cut the latter from an average of \$400 to \$30 per vehicle. Although I-695 was challenged and found by the courts to be unconstitutional, the legislature accepted its limits during the budget process anyway and enacted the cuts. The state has been betting on "Pro Share" (increased federal reimbursement for rural hospitals) to make the budget work.

Washington received about \$132 million in tobacco settlement funds during FY 2000 and another \$142 million in FY 2001. This year the tobacco settlement was used to balance the state budget, helping with the Basic Health Plan (BHP), the low-income insurance plan sponsored by the state. Washington State is pursuing tobacco securitization.

PROGRAM ADMINISTRATION

Respite Care Program: The 13 AAAs manage the Respite Care Program. AASA distributes funding to the AAAs using the Older Americans Act Title III allocation formula. A sliding fee scale is used, based on the income of the care recipient. "Banking" of respite is discouraged in this program and the family caregiver support programs, because past experience shows that caregivers may not use the banked services, resulting in the AAA having to return unspent respite funds to the state.

Washington State FCSP: AASA is charged with administration of the program, which is implemented at the local level by the AAAs. Funding is distributed to the AAAs based upon the state's funding formula. The state-funded FCSP is now used as the state match for the federally funded NFCSP. In implementing the FCSP, the state developed common core service definitions, reporting requirements and screening processes for use by the AAAs. State officials reported that the flexibility allowed by AASA has led to unique local programs. Since a strong state-funded respite program already existed,

AASA capped respite care expenditures at 25% during the first year of the state program, then increased it to 35% in the second year of program operation. The state does not impose an individual cap on the amount of respite, and the caps imposed by the AAAs are not uniform across the state.

NFCSP: AASA administers the NFCSP at the state level, and the AAAs implement the program at the local level. Again, funding is distributed to the AAAs by an allocation formula. AASA's role at the state level is to set policy for caregiver services and to establish requirements for developing services, reporting and setting up contracts. The state also coordinates sharing of information among the AAAs and provides training, administrative coordination and promotion of the program. AASA has imposed a 35% cap on respite care. A sliding fee scale is used for respite care and is optional for other services. One AAA is experimenting with cost-sharing for supplemental services. The state does not impose individual respite caps, but AAAs may set such for their locality. The NFCSP has been publicized in Washington through conferences, websites, AAAs' local outreach, caregiver kits, the Community of Faith program (and kit) and pharmacy bags. The NFCSP in Washington, although delivered locally and with unique features in each locality, is moving toward statewide identification. The state-funded FCSP is also moving toward statewide identification through a uniform name, The Family Caregiver Support Program (FCSP), definitions and a common contact form.

The state has set aside 5%, or \$130,000, of the administrative support provided by the federal funds as seed money for special projects to target underserved populations. This initiative is called "Innovations in Family Caregiver Support." In June 2002, 10 projects (four rural, five ethnic and one ethnic-kinship) were selected through a Request for Proposal (RFP) process and received one-time-only funding (e.g., up to \$15,000 each for ethnic and rural projects and up to \$10,000 for ethnic-kinship projects).

Some stakeholders felt that Washington does not provide strong oversight to ensure consistency across the state. These stakeholders believed that an increased level of consistency in eligibility requirements, similar to that of the Medicaid program, would be helpful. Additionally, standardization would help facilitate caregivers' access to services—knowing where to go for a particular service and who is in charge of what. Despite some concerns about statewide consistency, stakeholders agreed that the flexibility allowed the AAAs is good, because it enables AAAs to respond to local needs and to innovate.

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

Respite Program: In this program, the caregiver may be of any age, but the care recipient must be age 18 years or older. The caregiver must be unpaid and provide continuous care and/or supervision. Respite eligibility is driven by daily time in caring (on average, at least 12 hours), rather than by the caregiver's perception of need, which are considered during the service priority process. The care recipient must need substantially continuous care or supervision and must be assessed as requiring placement in a long-term care facility in the absence of an unpaid caregiver.

Stakeholders pointed out that the 12-hour daily caregiving requirement means that working caregivers, including self-employed persons who work at home and give care while they work, are ineligible for services. The rules for eligibility are interpreted inconsistently across the state, stakeholders said. In one AAA, for example, respite is provided on a first-come, first-served basis, making it impossible for a caregiver to count on a standing respite period. Each month, the caregiver has to call to request respite, hoping that the limit has not been reached. This approach makes consistency of respite workers difficult, which is a problem for a person with dementia.

Washington State FCSP: As with the Respite Care Program, caregivers must be unpaid and can be of any age, but kinship caregivers are not eligible. The care recipient can be of any age 18 or older and must have a functional disability.

NFCSP: The entry point for the caregiver is usually through the AAA's I&A staff, although two-thirds of the AAAs have identified "family caregiver specialists." AAAs use the federal eligibility criteria under the Older Americans Act: informal caregivers of any age who provide care to persons age 60 or older, as well as caregivers age 60+ who are caring for grandchildren age 18 or younger, and older caregivers (age 60+) who are caring for children who are mentally retarded or have developmental disabilities. For respite and supplemental services, the care recipient must have two or more ADL limitations or cognitive impairment.

Washington has developed a uniform Family Caregiver Contact Form for use by AAA staff and service providers to document caregiver needs, primary health conditions of the care recipient, ethnicity and language; the form also includes referrals for caregiver support and long-term care services. Even more significant, caregiver assessment is being integrated into the state's Comprehensive Assessment (the uniform assessment tool for all long-term care programs). Currently, the Comprehensive Assessment tool focuses on the care recipient, taking the informal caregiver into account only when determining unmet needs of the care recipient. One respondent pointed out that the tool does not currently capture the need for emotional support. In the future, AASA plans to incorporate caregiver needs into the uniform assessment tool.

SERVICES

Caregivers' access to services varies by geographic area, according to several observers. In part, this is because of the lack of trained providers in some regions of the state. Generally, and increasingly, because of the infusion of federal funds through the NFCSP, services to caregivers are provided as part of a larger, multicomponent family caregiver support program.

Respite Program: In-home, out-of-home and institutional respite are covered, with all levels of care included (from supervision to nursing care), both on a planned and an emergency basis.

Washington State FCSP: Caregiver support services include information, assistance, promotion and implementation of support groups, caregiver training, respite care and supplemental services. Counseling services are *not* included. Despite the latitude granted to the AAAs, there is commonality across the state, including family caregiver conferences (offered in different languages depending upon the locality), family caregiver training ("Fundamentals in Caregiving," "Powerful Tools for Caregiving" and individualized training) and caregiver resource centers, with books, videos and CDs,

caregiver web pages and caregiver kits. The most common condition among care recipients is Alzheimer's disease or related dementias, and the most commonly used service (based on the number of calls) is the provision of specialized caregiver information.

During the first year of the FCSP (October 2000 through September 2001), the AAAs received 3,165 calls for specialized caregiver information, provided 135 group training sessions or presentations reaching 2,236 persons, gave one-on-one training by professionals to 193 caregivers, assisted 1,454 family caregivers in gaining access to long-term care services and provided 189 caregivers with 9,307 hours of respite. During the second year, three times as many calls were received in the first six months as in the entire first year: 4,114 between October and December 2001 and 6,002 between January and March 2002.

Examples of promising efforts of specific AAAs include:

1. A focus on "hidden" caregivers through work with the Community of Faith outreach services, with presentations and printed materials ("Community of Faith Caregiving" curriculum)
2. Targeted outreach and service delivery focusing on male caregivers
3. A peer mentoring program, in which former caregivers provide support to current caregivers
4. Caregiver resource libraries
5. Pharmacy bags and posters in physician offices
6. Caregiver kits, many being translated

NFCSP: All NFCSP core services are available in almost every AAA region. Following the standard assessment, the intent is to give caregivers a menu of services from which they may choose to help meet their needs: information; assistance; individual counseling, support groups, training; respite care; and supplemental services.

The COPES Aged/Disabled Medicaid waiver covers an array of home and community-based services for Medicaid-qualified care recipients who are eligible for nursing home care. Many COPES services also support the client's family caregivers. Key examples are help with personal care and household tasks in the home, adult day care, environmental modifications, home-delivered meals, home health aide services, personal response systems and training and transportation to meet a therapeutic goal.

Major service needed by caregivers: The major services needed by family caregivers, state agency respondents noted, were respite, specialized caregiver information, training and consultation with specialists (lawyers, rehabilitation therapists, registered nurses). One respondent believed that caregivers need a sense of community to minimize their isolation. One stakeholder identified a range of services, including home help, education, care consultation and ongoing support groups for emotional support and to relieve isolation.

Stakeholders agreed that respite is crucial to sustaining family caregivers. They also mentioned information and assessment by an expert with empathy who can help caregivers self-identify. Another key informant stressed the value of "listening, being there at the time when they need to make a difficult step" to provide counseling and help with negotiation of family roles. "This is not a cookie

cutter situation,” one key informant said. “Caregivers have unique needs. Some want to do the caring themselves, so what they need most is someone to do chores. Others are totally burned out and what they need is residential placement for their loved one.” Key informants also indicated that education and planning (e.g., learning the Medicaid eligibility rules) and both group and individual training are valuable, especially to people who already self-identify as caregivers.

Stakeholders identified several caregiver support services that would enhance the program. Some said that they would like to see more direct payments go to caregivers—“grants to remove the barriers to services.” A caregiver with a grant might try adult day health care and then decide it was well worth using, for example. Another need is for early-stage Alzheimer’s classes to educate the caregiver before the crisis occurs.

Table 2. Family Caregiver Support Services in Washington

Program	Respite Care Program	State Family Caregiver Support Program	National Family Caregiver Support Program
State Administrative Responsibility	Aging and Adult Services Administration, Department of Social and Health Services	Aging and Adult Services Administration, Department of Social and Health Services	Aging and Adult Services Administration, Department of Social and Health Services
Local Service Delivery	AAAs ^a —information, assistance, assessment & case management; AAAs are not direct service providers but contract for respite care services.	Most of the AAAs provide FCSP information and assistance in-house. Some contract out these services. AAAs also contract most of the training and support groups and all of respite and supplemental services.	Same as the FCSP. Under the NFCSP, the AAAs also contract out most of the counseling services.
Funding Source	State general funds	State general funds	Older Americans Act, III-E
Expenditures FY 2001–02	\$2.8 million	\$610,000	\$2.3 million
Client Population	Family & informal caregivers	Family & informal caregivers	Family & informal caregivers
Eligibility:			
Age	18+ care recipient	18+ care recipient	60+ care recipient
Income	Family and other unpaid caregivers of any age	Family and other unpaid caregivers of any age	Family and other unpaid adult caregivers of person 60+ ^b
Functional Ability	None	None	None
	Care recipient who needs substantially continuous care or supervision (at least 12 hours/day) and has been assessed as requiring placement in LTC facility in the absence of an unpaid caregiver	Caregiver who has primary responsibility for the care of an adult with a functional disability and does not receive financial compensation for the care	For respite and supplemental services, care recipient with at least 2 ADLs or cognitive impairment
Uniform, Statewide Caregiver Assessment	Yes	Yes	Yes
Services Provided to Family Caregivers	In-home respite Out-of-home respite Institutional respite	Information Assistance & consultation Support groups Training Respite care Supplemental services (e.g., consumable supplies)	Information Assistance Counseling, support groups, training Respite care Supplemental services
Respite Cap	Individual caps on amount of respite vary by AAA	35% cap on respite expenditures per AAA Individual caps on amount of respite vary by AAA	35% cap on respite expenditures per AAA Individual caps on amount of respite vary by AAA
Consumer Direction	No	No	No
Family Caregivers Paid as Respite Providers	No	No	No

a AAAs = Area Agencies on Aging.

b Also a caregiver age 60+ providing care to a person with a developmental disability or a grandparent caregiver raising a child.

CONSUMER DIRECTION

Washington has not yet adopted consumer direction in its caregiver services. Within the COPEs Aged/Disabled Medicaid waiver, consumer direction is strong: anyone requiring 112 or more hours of service per month *must* use an independent provider (rather than an agency) for services. The state pays the independent provider directly, but the client (i.e., the care recipient) is considered the employer. Since the state, rather than the AAA, pays these independent providers, the AAA cannot build consumer direction into the caregiver support program based on local experience. Family members who are hired as providers for COPEs or the Medicaid Personal Care program must have criminal history background checks and must complete required training. If the provider has not lived in the state of Washington for at least three years, an FBI check is done. As one respondent observed, however, many workers are immigrants from another country, so the FBI check is of little use. Parents can be paid as providers, but spouses cannot be. The impetus for consumer-directed care in these programs is the shortage of workers and the preference of many clients to have a family member provide the care. Washington has no restriction related to whether or not the provider lives with the care recipient. State officials commented that about half of the paid providers are family members.

Paid caregivers are required to have 22 hours of caregiver training (soon to be increased to 28 hours) and 10 hours of continuing education each year. The training is provided through contract with the AAAs. Some AAAs provide the training directly and some contract it out. State officials noted there is funding for a substitute caregiver while the independent provider is in training. Training is also available for COPEs clients, on a one-to-one basis, to help them learn how to be more involved with their own care.

State officials said that Washington is not yet looking at fiscal intermediaries for the family caregiver support program, and they did not think it made sense to handle consumer direction for respite through the state system, rather than at the AAA level, because the scale is so limited (i.e., handling a bill for 8 hours of respite vs. 184 hours of personal care). Providing caregivers with vouchers, along with a list of preferred providers, is the more likely option. AAAs have not yet developed this option but are considering it. One of the Innovation in Caregiver Support grants was awarded to the Olympia AAA. They are developing a pilot project to allow caregivers to employ independent providers for respite care. A service system will be developed, implemented and evaluated, resulting in a program that gives caregivers greater flexibility and control in how, when and to whom respite will be provided as well as serving as a model for others to replicate statewide.

A recent development reported by one state official was a voters' initiative to establish a Home Care Quality Authority, a statewide public authority that would cover any long-term care eligible person, including private pay and children. The official was not sure what impact this development might have on respite or family caregiver programs. With money in the budget, the governor was appointing nine members to the public authority, and funding was going to the Public Employees Negotiating Board to work with the union to implement this program. "We need to get better at consumer direction," commented one respondent. "We need to enable consumers to be equal partners with case managers in the design of services, as well as the hiring and firing of workers, etc."

QUALITY ASSURANCE AND EVALUATION

The AAAs collect data for care recipients through the Comprehensive Assessment instrument and for caregivers primarily through the Family Caregiver Support Program Contact Form. The Comprehensive Assessment instrument is currently undergoing revision and will include caregiver questions in the future; in the meantime, only the following “yes/no” items are included:

1. Primary caregiver who is unpaid
2. Primary caregiver paid privately (not DSHS paid)
3. Caregiver able and willing to continue care

The Family Caregiver Support Program Contact Form collects the following information:

1. Contact information (date, staff, nature of contact, how person heard about the program, caller’s relationship to care recipient, age of care recipient)
2. Caregiver information (name, address, telephone number, whether person is primary caregiver, gender, ethnicity, language used, under/over age 60, relationship to care recipient)
3. Care recipient information (name, address, telephone number, gender, ethnicity, primary health conditions, whether care recipient receives case management services and from whom, narrative)
4. Disposition (type of information provided—12 topics and “other”; assistance in gaining access to services—type/s of referral/s provided; type of support provided; other action; unmet needs or requests)
5. Progress notes
6. ADL screening for supplemental services (needs assistance with two or more ADLs, requires supervision due to cognitive impairment)

AASA requires the AAAs to submit quarterly reports for the caregiver support programs. Each AAA must report on:

1. Specialized caregiver information services (number of calls for state and national FCSP, callers’ relationship to care recipient, age of care recipient)
2. Assistance in gaining access to long-term care family caregiver services (number of caregivers assisted through the state and national FCSP; age, ethnicity and language of caregiver; health conditions of care recipients)
3. Group presentations (number of events and attendees, separated by state and national FCSP)
4. Counseling (individuals and hours—NFCSP only)
5. Training/consultation (number of events and attendees, separated by state and national FCSP)
6. Support groups (number of new and existing groups, facilitators and caregivers involved, separated by state and national FCSP)
7. Respite (number served and hours provided, separated by state and national FCSP)
8. Supplemental services (number of durable goods/assistive devices, one-on-one consultations with specialists, specialized transportation trips, interpreter services, other)

These reports have been in a paper based format, but the state is working on computerizing the report. According to state officials, the current data collection system gives Washington a better picture of caregiver needs than what AoA requires in their annual report. Two limitations respondents noted are that the database is not yet computerized and that some of the definitions provided by AoA are unclear or not useful. No data are being collected on caregiver outcomes.

To evaluate the success of the program, the state uses narrative and statistical reports on service utilization (both quarterly reports and case studies) and will be incorporating site visits in the near future, for which a tool was under development. Some, (but not all) AAAs do client satisfaction surveys, and satisfaction is assessed of caregivers who participate in the Powerful Tools training program.

SYSTEMS DEVELOPMENT

Both state officials and stakeholders said that the groundwork for implementing the NFCSP had been done through launching the state FCSP, so implementation of the federal program was relatively easy. State officials identified three main impacts of the first year of the NFCSP on future policy and program development:

1. Identification of problems in the referral process between the Medicaid programs and the family caregiver support programs
2. Recognition that the Comprehensive Assessment tool used for all community-based long-term care programs must assess caregiver needs
3. Growing use of the Powerful Tools training program for caregivers

Some stakeholders said that it was too soon to tell how the NFCSP would affect future policies and programs for family caregivers, especially with all the attention required to plug holes in the state budget. They underscored how important “nonsupplanting” language had been under such budgetary pressures. Others cited the launching of Caregiver Support Centers across the state and an increase in focus and visibility. One commented that this development stems from the cap on respite, which allowed funds to be channeled in other directions, encouraging the development of information and educational programs. These programs reach more caregivers than respite, but they may increase the demand for respite later. One respondent expressed concern as to whether implementation of the NFCSP distracts policymakers from the big money issue (i.e., Medicaid). That respondent hoped that there would be a big leap toward social insurance as family caregivers become involved and that the caregivers would galvanize support.

Washington does not have a body whose mission is coordination of family caregiver support services across state departments; AASA administers all long-term care services, including support for family caregivers. At the local level, AAAs are viewed as the coordinators for caregiver support.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD DECISION PLANNING*

The governor has designated DSHS as the lead agency for *Olmstead* planning. Washington has an *Olmstead* task force with a family representative on it. The family caregiver is the parent of a developmentally disabled child, however. “There is no one from ‘our system,’” observed one state official. Because the vast majority of people needing long-term care in Washington are already receiving it in the community, the *Olmstead* plan is seen in the state as an effort to further coordinate and accelerate ongoing processes and programs. The Washington State Disability Initiative Advisory Committee serves as the main conduit for stakeholder input.

OTHER POLICY ISSUES

State 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 varied in their estimation of the priority placed on caregiver support. One stakeholder indicated that the priority was “low-medium” while another said that it was “medium-high.” One state official believed the priority was “low.” Another state official and one stakeholder did not answer the question.

State officials commented that the legislature is interested in caregiver support, but budget problems have precluded action to expand services in the near future. One stakeholder believed that the priority had been “low” two years earlier but that it had climbed a little higher as recognition of and programs for caregivers in Washington State had increased.

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

Benefits and challenges: Key informants identified three aspects of their program that are most beneficial to family caregivers:

- ✧ Centralized access point for services for caregivers, with a consistent name for the program
- ✧ Training for caregivers
- ✧ Support groups

The following challenges were reported:

- ✧ Different funding sources for different populations; different funding cycles and reporting requirements
- ✧ Integration of respite for caregivers through the COPES Medicaid waiver and into the home and community-based long-term care system
- ✧ Difficulty reaching the underserved populations meaningfully
- ✧ Difficulty reaching caregivers earlier (many wait too long to use services)

Major lessons learned:

- ✧ The high level of innovation and interest at the AAA level
- ✧ Legislative support for family caregivers (“this was an easy sell,” one said)
- ✧ The need for better referrals between programs

Opportunities for expanding caregiver support: Respondents were not optimistic about the expansion of state-funded programs for family caregivers over the next three to five years. Two respondents noted the potential for Lifespan Respite, however, a concept that is gaining momentum in Washington State. One state official lamented that it is hard to get caregivers, who are tied down by caring for their loved ones, out to participate in educating policymakers and the public. One saw no increases for human services at all in the near future. Another thought that support for grandparents and relatives might be expanded, especially to reach younger grandparents who now are excluded. All key informants, however, emphasized a dismal budget picture over the next few years.

Recommendations for other states: State respondents offered several recommendations, based on their experience to date:

- ✧ Include caregivers of all ages, with no barriers tied to the care recipient’s condition.
- ✧ Create a comprehensive assessment that incorporates both the caregiver’s and the care recipient’s needs
- ✧ Build in flexibility, and focus on the caregiver in service delivery
- ✧ Give families a say in how money is spent on their behalf, whether through a cash-and-counseling approach or through a menu of services/providers from which they can choose
- ✧ Support thinking “out of the box”

As one key informant said, “Family caregiving is a critical public policy issue and we need to own it. We need to make clear that the caregiver, rather than the provider, should make the decisions. We need to invite them into the process. We all have a stake in the solution. Family caregivers are the ones to make that happen.”

NOTES

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