Funding

Caregiver support services are financed through a variety of public and private funding sources. In this study, we wanted to gain an understanding of the sources and amount of federal and state funding for caregiver support in the 50 states since the enactment of the NFCSP. We also wanted to identify general trends and issues in spending by the state-administered programs. We expected these trends would provide insight into broader spending patterns for caregiver support.

In all programs included in this study (i.e., NFCSP, Medicaid waivers, state-funded), states have enormous flexibility in determining what services are provided to best meet locally identified needs, how they are delivered, and how services and expenditures are reported. However, this flexibility at the state level poses challenges: without comparable data, cross-state comparisons cannot be made and we cannot obtain a clear picture of spending, across all the states, for caregiver support services.

During the study period, the NFCSP, in particular, was in a developmental stage: states have been identifying needs, building programs and services, and creating reporting systems to meet the new client mandate under the OAA. Data are available on the federal allocations to the states, but variance in fiscal years among the states and in treatment of carryover funds results in inconsistent reporting of actual state program expenditures. Beginning in FY 2005, states will use a new version of the National Aging Program Information System (NAPIS). As part of NAPIS, SUAs will complete utilization and expenditure profiles for the NFCSP to provide more consistent programmatic and expenditure data across the states.

State program administrators use a range of definitions and data collection methods to track expenditures and caregiver service delivery, resulting in much variability across the states.

Due to data limitations, we could not obtain consistent and accurate information on expenditures (and persons served) for programs providing caregiver support services. Indeed, many states have no uniform system in use across their own state's HCBS programs. Thus it was not possible to consistently identify total funding (or the total number of families served) for programs in this study. On the other hand, study respondents give us insights into the sources of funding, how these vary across states and how the sources and funding levels are changing over time, especially with the advent of the NFCSP. In addition, data reported for the Medicaid waiver programs allow us to see expenditure trends for one service of significant help to caregivers, respite.

Most states rely on multiple sources of funding to provide caregiver support services.

We asked state program administrators to identify the major sources of public funding that their program receives for fiscal year 2003. Most state programs report multiple sources of funding, with the majority of funding

Figure 4. Major Sources of Program Funding, FY 2003	# of programs receiving funding from this source*	% of programs receiving funding from this source
State General Fund	86	57%
NFCSP	55	37%
Medicaid HCBS Waiver	49	33%
Client Contribution	36	24%
Tobacco Settlement Fund	11	7%
Local/County Fund	10	7%
AD** Grants to States	7	5%
Social Services Block Grant (Title XX)	5	3%
Lottery Fund	3	2%
Private Foundation	2	1%
Other Sources	20	13%

Note. Many programs identified more than one source of funding. *N = 150.
**AD = Alzheimer's disease.

coming from four main sources: State general funds; NFCSP; Aged/Disabled Medicaid HCBS waivers; and client contributions. Figure 4 shows the range of funding sources.

State general revenues are a source of funding for the majority (57%) of programs in this study. State general funds allow states to develop programs that are generally not constrained by federal rules and regulations. States also use their general revenues to match federal funds (NFCSP or Medicaid waiver programs). Some "over-match" by supplying more state money than required for federal funding.

- In California, Florida, New Jersey and Pennsylvania state coffers have significantly funded caregiver support programs.

In this study, some state-funded programs provided expenditure data for fiscal years 2001-2003. In all, 22 of the 50 state-funded programs in 14 states[12] (44% of programs of this type in these states) provided expenditure data, with the most complete data for fiscal years 2002 and 2003. These identified expenditures represent less than half of the state-funded programs in this study. Based on previous research (Feinberg & Pilisuk, 1999; Feinberg et al., 2002), as well as data limitations and reporting variances, these expenditures clearly under-report the amount of state funding for caregiver support across all states. (See State Profiles for expenditure data).

- These 22 state-funded programs (a combination of explicit caregiver support programs and HCBS programs with a caregiver component) expended approximately $132.4 million in state general funds in fiscal year 2002 and $128.5 million in fiscal year 2003.

The NFCSP (Title III-E) is the funding source that state officials cite second most frequently (by 37% of study respondents). Through this relatively new funding source, explicit family caregiver support services now operate in all 50 states and the District of Columbia. Where caregiver support programs existed before the NFCSP, these funds expand the range and scope of services to families. In the other states, the NFCSP serves as the major funding source for a range of caregiver support services not available previously.

- Federal data on the NFCSP show the AoA provided the 50 states and the District of Columbia with about $110.9 million in fiscal year 2001, $126.6 million in 2002 and $138.7 million in 2003.
- In fiscal year 2003, federal funding varied from a high of $13.9 million in California and $11.1 in Florida to a low of $705,756 in 11 states[13] and the District of Columbia.

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[12] California, Connecticut, Florida, Maine, Michigan, Minnesota, Nevada, New Jersey, North Carolina, North Dakota, Pennsylvania, Texas, Washington, Wisconsin.

[13] Alaska, Delaware, District of Columbia, Hawaii, Idaho, Montana, New Hampshire, North Dakota, South Dakota, Rhode Island, Vermont, Wyoming.

- Between fiscal years 2001 and 2003, the NFCSP federal allocations to the states increased 25 percent. (See State Profiles for allocation data).

Aged/Disabled Medicaid HCBS waiver programs are a significant source of funds for services that help family caregivers of beneficiaries, typically for respite care.

- According to data reported to the Centers for Medicare and Medicaid Services (CMS), the Aged/Disabled 1915(c) waivers provided an estimated $84.5 million for respite care alone in FY 2001.[14]
- Respite care expenditures under these waivers grew to $101.4 million (a 20% increase) in fiscal year 2002, the most recent year for which these data are available. (See State Profiles for expenditure data).[15]

Client contributions are a funding source for about one-fourth (24%) of program respondents. These funds are more likely to contribute some support to state-funded programs (36%) or the NFCSPs (28%) rather than those offered through Medicaid waivers (8%).

Tobacco settlement funds, study respondents report, support 11 programs in seven states[16] including four Medicaid waivers, six state-funded programs and one state NFCSP. These monies have typically been used to expand services to more older people or adults with disabilities or to support specific services, such as respite care for family caregivers.

State officials report several other funding sources:

- Revenue from *state lotteries* supports two Pennsylvania programs (OPTIONS and NFCSP) and West Virginia's Aged/Disabled Medicaid waiver.
- *Casino revenue* contributes to New Jersey's state-funded Adult Day Services Program for Persons with Alzheimer's Disease or Related Dementias.
- *Escheat*[17] monies benefit Michigan's State/Escheat Respite program.
- Arizona and Wyoming use federal *OAA Title III-B* social services funds for state-funded programs (Non-Medical Home and Community Based Services Program in Arizona and Community Based In-Home Services Program in Wyoming).
- Alaska's Innovative Respite Program uses *Mental Health Trust Authority* authorized receipts.

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[14] Source: CMS Form 372 (Annual Report on HCBS Waivers), with data analysis performed by Kitchener, M., Ng., T. & Harrington, C., UCSF Department of Social and Behavioral Sciences, 2004.

[15] Source: CMS Form 372 (Annual Report on HCBS Waivers), with data analysis performed by CMS Center for Medicaid and State Operations, 2004.

[16] Medicaid waivers in Georgia, Iowa, Nevada and Pennsylvania; state-funded programs in Florida (RELIEF and Community Care for the Elderly), Nevada (Independent Living Grant), Michigan (Caregiver Respite Program), Nebraska (Respite Subsidy Across the Lifespan), Pennsylvania (BRIDGE program); and the Pennsylvania NFCSP.

[17] "Escheat" refers to unclaimed reimbursements or payments made by Blue Cross/Blue Shield for insurance in Michigan. The unclaimed payments revert back to the state and the funds are then set aside for designated health-related programs.

Although most states experienced severe budget crises between 2001 and 2003, funding levels for family caregiver programs generally held their own—either increased or remained about the same.

Program administrators in Alabama, Arizona, Connecticut, Delaware, the District of Columbia and Florida (for the NFCSP), and Iowa, Massachusetts, Montana, New Mexico, Oklahoma, Pennsylvania, Utah, Virginia, Washington, West Virginia and Wyoming (for the state-funded program in general or the state respite program in particular) report either stable funding or slight increases between fiscal years 2002 and 2003 and project increases for fiscal year 2004. For many, modest increases in federal NFCSP allocations account for the growth. Program respondents also expect to see an increase in demand for services from family and informal caregivers due to budget pressures on other aging and disability supportive services.

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