

## Services

*"There is a growing recognition within the policy arena of the importance of caregiver support services as a preventive service. The more you provide in terms of services and infrastructure for caregiver support, the better off the state will be in future expenditures."*

--Medicaid waiver respondent

*"Respite is frequently identified as the number one need, but once the family caregiver starts having regular respite, there is usually the recognition that they need information, support and links to other services and supports."*

--State-funded program respondent

Family members and friends may have different needs and preferences at different times during their caregiving experience. A variety of services can bolster them in providing care to a loved one. We asked state program administrators to identify each service that their program provides specifically to family caregivers. The programs in this survey offer a broad array of services that either directly or indirectly assist caregivers. Table 4 shows which of 18 services each program in this survey provides to caregivers.

Definitions for services vary across programs and across states. Because service categories, names and availability fluctuate, they challenge efforts to track and classify them. At a practical level, these variations make it more difficult for a caregiver to access needed help. For example, under the NFCSP, states can provide the service category of "supplemental services", as defined by the state, to complement the care provided by caregivers. By definition, supplemental services are intended to benefit caregivers and be flexible enhancements to the caregiver support programs (Lewin Group, 2002). Services can include home modifications, assistive technology, emergency alarm response systems, consumable supplies, or any service or service option as defined by the state. Neither the Medicaid waiver nor the state-funded programs have such a broad service category.

Similarly, definitions of the term "respite" vary widely from program to program. As one state-funded program respondent said, *"Respite means different things to different people."* Some program administrators view respite as a specific service; others view it as an outcome of providing other out-of-home or in-home services, such as personal care or homemaker/chore services. Some state-funded and Medicaid waiver programs consider in-home services such as homemaker/chore and personal care to be "respite" for the family caregiver, even though it is often not tracked as such and this care directly benefits the older person or adult with disabilities.

## Caregiver Support Services

Figure 11 illustrates the types of services provided by programs in this study to support family and informal caregivers. Figure 12 shows the percentage of state programs surveyed by program type providing selected caregiver support services.

**State-administered programs offer an array of services to support family and informal caregivers; respite care tops the list.**

- At least half of all programs in this survey (76 out of 150 programs) provide one or more of the following eight services: respite care (95%), information and assistance (69%), education and training (62%), care management/family consultation (58%), homemaker/chore/personal care (58%), assistive technology/emergency response systems (54%), individual and/or family counseling (52%), and home modifications (51%).
- Most, but not all, programs in this survey offer multiple services to caregivers, generally respite care and one or more other services. In 14 programs<sup>23</sup> in ten states (six state-funded programs; eight Medicaid waivers) respite care is the only service identified specifically for family caregivers.

**The NFCSP is emerging both as a key program to enhance the scope of services available to caregivers and fueling innovation.**

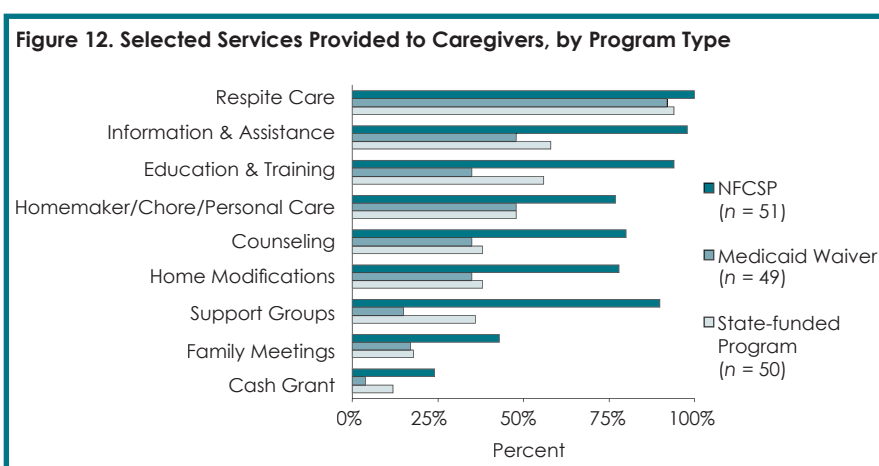
Many services now available to support caregivers come mainly through the NFCSPs, as shown below.

- Caregiver education and training is offered by nearly two out of three (62%) programs surveyed. Education and training can include conferences or classes covering a broad range of topics of interest to family caregivers, or can teach caregivers “hands-on” skills and knowledge to improve confidence and competence in the caregiving role (e.g., training for lifting or bathing a person, techniques for managing behavioral problems, methods of coping with stress). Caregiver education and training is much more commonly offered by the NFCSPs (94%) than the state-funded (56%) or Medicaid waiver programs (35%).

**Figure 11. Types of Caregiver Support Services Provided by State Programs**

	Program responses*	
	n	%**
Respite Care	143	95%
Information & Assistance	102	69%
Education & Training	93	62%
Care Management/Family Consultations	87	58%
Homemaker/Chore/Personal Care	86	58%
Assistive Technology/Emergency Response	80	54%
Counseling (individual and/or family)	77	52%
Home Modifications	76	51%
Support Groups	71	48%
Transportation	66	44%
Consumable Supplies	51	34%
Legal/Financial Consultations	48	32%
Family Meetings	39	26%
Other Services	22	15%
Cash Grant	20	13%
eHealth Applications (excluding read-only websites)	10	7%

Note. \*N=150. \*\*Percentages are based on total number of responses.



<sup>23</sup>State-funded programs (California’s Adult Day Health Care, Michigan’s State/Escheat Respite, Nebraska’s Respite Subsidy Across the Lifespan, Oklahoma’s Respite Resource Network, Washington’s Respite Care Services and Wyoming’s Community-Based In-Home Services Program). Medicaid waivers in Arkansas, California, Illinois, Nebraska, Oklahoma, Texas, Vermont and Wyoming.

- ♦ *Care management or family consultations* are covered by well over half (58%) the programs in this study, and are considerably more common among the NFCSPs (84%), as compared to the Medicaid waiver (47%) or state-funded programs (42%). These services assist families in making a care plan, identifying and arranging needed services, locating other resources, and assisting caregivers with both everyday and long-term choices and decisions.
- ♦ *Individual and/or family counseling* to address specific caregiving needs and psychological well-being are offered by over half (52%) of the programs surveyed. Counseling is twice as likely to be a covered service under the NFCSP as compared to the other programs in the study (NFCSP, 80%; state-funded, 38%; and Medicaid waiver programs, 35%).
- ♦ *Caregiver support groups* are available through fewer than half (48%) of the programs. Support groups are provided by almost all the NFCSPs (90%). Support groups are especially uncommon among Medicaid waivers (15%) and offered by a little over one-third of the state-funded programs (36%).

In several emerging, or innovative, service areas the NFCSP is leading the way:

- ♦ *Family meetings*, offered by only 26 percent of programs in this study, help resolve caregiving issues and improve communication among family members about difficult subjects. NFCSPs are twice as likely to offer this service (43%) as compared to the state-funded (18%) or Medicaid waiver programs (17%).
- ♦ *Cash grants* to purchase goods (e.g., incontinence products, ramps, grab bars) and/or services (e.g., respite care) help offset the often high costs of providing care and, for some, may enable the family to continue to provide care. Cash grants are available through only 20 of the programs surveyed (13%) in 18 states and the District of Columbia, mostly through the “supplemental services” category of the NFCSPs. The NFCSPs are at least twice as likely to offer this option as are the other programs in this study (24% NFCSP, versus 12% of state-funded programs and just 4% of waiver programs, i.e., those in Alabama and Minnesota).
- ♦ *eHealth applications* (e.g., telemedicine, interactive websites) include information and services delivered or enhanced through the Internet and related technologies. Although this offering for family caregivers is still rare (by just 10 programs<sup>24</sup> in eight states overall), NFCSPs account for more than half.

### Respite Care

Respite care addresses one of the most pressing needs identified by caregiving families. Although some programs consider “respite” to be a broad concept that includes almost anything if it improves the caregiver’s quality of life (Feinberg & Pilisuk, 1999), respite care is generally defined as temporary, short-term help provided to the care receiver that enables caregivers to take a break.

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<sup>24</sup> NFCSPs (Arkansas, Idaho, Maine, Missouri, New York and Oregon); state-funded programs (California Caregiver Resource Centers, Minnesota Alternative Care Program) and Medicaid waivers (Minnesota, Oregon).

In this survey, we found that respite is offered in varying degrees, by all types of programs and in all 50 states. It is provided under the NFCSP; as a state-funded, single purpose program; as part of state-funded HCBS multi-component programs; and also as a specific benefit under Medicaid HCBS waiver programs. In the NFCSP, respite is a specific part of the core package of services to caregivers. In Medicaid waiver and state-funded HCBS programs, however, respite may not be an explicitly covered benefit or service. Administrators of these programs often see respite as a by-product of other in-home (e.g., homemaker/chore/personal care) or out-of-home services (e.g., adult day services). Some say that cash grants to care receivers to purchase in-home services or home modifications, for example, provide respite and relief for the family caregiver, although their purpose is to benefit the care receiver.

***Respite is the service strategy most commonly offered to support caregivers and is available in all 50 states, although the amount of respite to family members varies substantially from state to state and program to program within states.***

- Nearly all (95%) of the programs in this survey (143 out of 150) report providing respite care, regardless of funding source.
- All states and the District of Columbia (100%) offer respite care to caregivers under the NFCSP.
- All but four states<sup>25</sup> report including respite as an explicit service under their Aged/Disabled Medicaid HCBS waiver.
- In two states, Tennessee and Nevada, a state-funded HCBS program does not offer respite or other in-home services.

As shown in Table 5, respite care takes many forms. The most common types of respite offered in the state programs surveyed are in-home respite, adult day services and overnight respite in a facility. Figure 13 shows the prevalence of various types of respite service options available in the states.

- The great majority (71%) of the programs offering respite assistance do not require that the caregiver live with the care receiver, enabling adult children or other relatives to qualify for respite services even if they live in separate households.
- This broader eligibility criteria exists more often in the NFCSPs (80%) and the state-funded programs (75%), than in the Medicaid waiver programs (58%) (see Table 5).

To control costs and distribute services equitably, given limited program budgets, programs cap cost or service utilization. We were particularly interested in better understanding how caps are used for respite care in the states and who decides how to formulate the caps.

- Sixty-six programs (46%) in 38 states and the District of Columbia that offer respite assistance utilize a respite cap of some type to contain

Types of Respite Care	Program responses*	
	n	%**
In-home	136	91%
Adult Day Services	131	87%
Overnight in Facility	113	75%
Weekend/Camp	86	57%
Other	17	11%

Note. \*N=150. \*\*Percentages are based on total number of responses.

<sup>25</sup>The Aged/Disabled Medicaid HCBS waiver programs in Alaska, Kentucky and New York did not respond to this survey. The waiver programs that do not report including respite as an explicit service are located in Louisiana, Rhode Island, Washington and West Virginia, although the waiver in Louisiana includes homemaker/chore/personal care that can provide some respite to family caregivers.

costs. Considerable variation exists within the limits imposed. In a majority of these programs (49 out of 66; 74%), the respite cap is applied uniformly across each program site, with Medicaid waiver (96%) and state-funded programs (88%) most likely and the NFCSPs least likely (48%) to do so.

- ♦ In nearly two-thirds (62%) of these 66 programs, the administering state agency decides how to formulate the cap. Medicaid waivers (91%) and state-funded programs (71%) are much more likely than the NFCSPs (33%) to set policy through the state agency.
- ♦ Less than one-third (30%) of the respite caps overall are set by local administering agencies. However, where the NFCSP has a cap for respite, the majority (59%) rely on their AAAs to set it. In contrast, a minority of state-funded (18%) and Medicaid waiver programs (5%) let the local agency do this.
- ♦ Half (50%) of the programs with a respite cap utilize a cost cap. Nearly as many (47%) use a utilization cap, typically a ceiling on the number of allowable hours of respite per year.
- ♦ Caps vary widely. Some use monthly limits, while others calculate caps on an annual basis.

Figure 14. Use and Amount of Respite Cost Caps by State Programs	Number of Programs
None	73
\$100 - \$200/mo	1
\$501 - \$600/mo	3
\$1,000/mo	1
< \$500/yr	3
\$501 - \$1,000/yr	7
\$1,001 - \$2,000/yr	5
\$2,000 - \$3,000/yr	1
\$3,001 - \$4,000/yr	6
> \$4,000/yr	1

- In the NFCSPs, most capped programs (19, 70%) refer to dollars, not utilization. The caps range from \$250-\$500 per year (Colorado) to \$4,000 per year (District of Columbia) and average \$1,300 per year.
- Medicaid waiver programs more often use a utilization cap, with these ranging from 168 hours per year (Maryland) to 6,480 hours per year (South Dakota) and averaging 937 hours annually.
- State-funded programs are slightly more likely to use cost (59%) than utilization (41%) caps. These caps range from \$1,500 per year (Nebraska's Lifespan Respite) to \$7,200 per year (New Jersey's Assistance for Community Caregiving) and average \$3,844 annually. The average utilization cap across state-funded programs was 300 hours per year.

- ♦ Among the programs reporting dollar amounts for their respite caps, Colorado's Family Caregiver Support Program has the lowest (\$250-\$500 per year) and New Jersey's Enhanced Community Options (ECO) Medicaid waiver program the highest (\$1,000 per month). The variation in the 29 programs reporting the amount of their respite caps is shown in Figure 14.

## Access to Information and Services

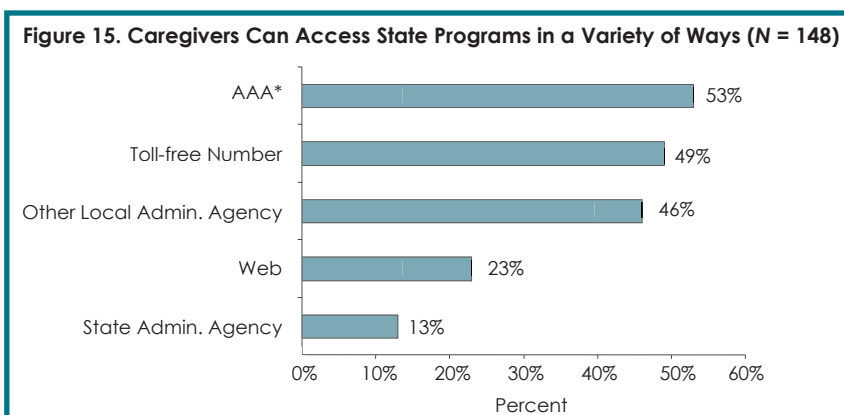
**Access to program information or services varies by program type; even within the same state, caregivers typically do not find the same package of services to be available.**

Fragmented services, confusing service delivery systems, and inaccessible information about community resources can compromise the family member's ability to care for their relative and adversely affect the caregiver's own health and quality of life. We asked state program administrators to describe the best way for a caregiver to access their program either for information or for services. As shown in Figure 15, over half (53%) of the program respondents, regardless of type of program, point to the local AAA. Nearly half (49%) indicate the state's toll-free telephone number. Programs in this survey suggest various ways for caregivers to access information or services:

- ♦ for the NFCSP, officials cite first the local AAA (69%), then the state's toll-free telephone number (55%)
- ♦ for the Medicaid waivers, respondents see the top method to be the local administrative toll-free number (40% each)
- ♦ for state-funded programs, respondents say to call the toll-free number or the local AAA (51%)
- ♦ relatively few program administrators mention the Web as a way to access programs (31%, state-funded; 25%, NFCSP; 13%, Medicaid waiver).

We asked respondents whether or not all family caregivers in their state have access to the same package of services within their program. In about half (49%) the programs, respondents said "No." The NFCSPs were the least likely of all three program types to respond affirmatively; more than three out of four (77%) report that caregivers in their state don't have access to the same program services, followed by state-funded programs (44%) and the Medicaid waivers (18%).

- ♦ Under the NFCSP, only 21 states<sup>26</sup> (42%) report that all of their state's AAAs offer each of the five specified service components (information, assistance, counseling/support groups/education and training, respite and supplemental services).



<sup>26</sup>Alabama, Connecticut, Florida, Georgia, Hawaii, Kentucky, Louisiana, Massachusetts, Maryland, Maine, Michigan, New Hampshire, New York, Ohio, Pennsylvania, South Dakota, Tennessee, Texas, Utah, Washington, Wyoming. Note: 4 states (Alaska, Delaware, Rhode Island, Wisconsin) and the District of Columbia responded "not applicable." All but Wisconsin do not have AAAs; the state or district acts as the single planning and service area.