

## Supporting Family Caregivers Through Title III of the OAA

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*Since passage of the Older Americans Act (OAA) in 1965, the Administration on Aging (AoA) has supported the delivery of services to older Americans, helping them maintain independence and remain in their own homes. Through its Aging Services Network, including State Units on Aging (SUAs), Area Agencies on Aging (AAAs), tribal partners, and service providers, AoA works to provide services designed to mitigate the effects of declining physical health and functioning experienced by frail older adults. This brief, the fifth in a series that presents findings from AoA's National Survey of OAA Program Participants, focuses on the National Family Caregiver Support Program (NFCSP). Authorized under OAA Title III in 2000, the NFCSP provides caregivers with information or help so they can connect with services and resources; training, education, counseling, and support groups; respite care; and supplemental goods and services to help family and informal caregivers care for loved ones at home.<sup>1</sup>*

### Background

Family caregivers are a mainstay of home- and community-based long-term care in the United States. Research from the last decade has shown that family caregivers make an important economic contribution to the care of people needing long-term services and supports (estimated at \$450 billion in 2009 by Feinberg et al. 2011).<sup>2</sup> Without family caregivers, the cost and burden to the nation's long-term care system would be substantial. Many frail older adults who live at home receive assistance from family caregivers (61 percent), and the share of those who use paid supportive services and rely on help from family caregivers is even larger (72 percent) (Johnson and Weiner 2006). If family caregivers become unable to help as much as needed or in the ways needed, then nursing home care or paid in-home services may be the only long-term alternatives. These alternatives would likely require significant public financing, which is increasingly constrained.

When caregivers are supported in their roles, however, they may be able to provide better care for longer periods of time, to the benefit of their families and society as a

### What Is The Aging Services Network?

The Aging Services Network provides a range of community-based services—home-delivered and congregate meals, case management, transportation, and homemaker and caregiver support. Such services enhance both the quality of life and social interaction, and reduce the effects of disability for homebound and more active seniors. Funded under Title III of the OAA, services are available to individuals age 60 and older, though delivery is targeted to the most vulnerable elderly.

whole. The NFCSP recognizes caregivers as consumers and provides services and supports that help them care for relatives at home.

The Aging Services Network has been involved with both frail older adults and family caregivers for a long time; however, the authorization of the NFCSP in 2000 brought more attention and resources to the development of a multifaceted system of support services for caregivers. Annually, more than 600,000 caregivers receive NFCSP services (AoA). These services include help or information so caregivers can access long-term care services in their communities, training and education to help them address problems and make decisions, respite to provide breaks from caregiving, and supplemental goods and services to help them continue providing care.

<sup>1</sup>Persons eligible for NFCSP services include informal (unpaid) caregivers of people age 60 or older; adult caregivers of individuals of any age with Alzheimer's disease or related illness; and grandparents or other nonparent relatives, age 55 or older, caring for an adult age 18 to 59 with a disability or a child younger than 18.

<sup>2</sup>Gibson and Houser (2007) describe the factors used to estimate the economic value of the unpaid contributions of family caregivers, including the number of such caregivers in the United States under various definitions and the number of hours spent providing care.

This research brief draws data from the Fifth National Survey of OAA Program Participants to describe NFCSP caregivers who help frail older relatives.<sup>3</sup> It describes the types and amount of care the caregivers provide, the services caregivers receive from the NFCSP, and the benefits they report deriving from NFCSP services. Data were examined separately for spouses, adult children, and other caregivers because members of these groups were expected to have different characteristics and circumstances and, perhaps, different experiences as caregivers. Key similarities and differences between and among these caregiver groups are noted throughout the brief.

## Caregiver Characteristics and Circumstances

NFCSP caregivers are a diverse group. Forty-seven percent are adult children caring for a parent; 39 percent are spouses caring for a spouse; and 14 percent are grandchildren, nieces or nephews, daughters- or sons-in-law, or other relatives or friends.

Spouses, adult children, and other caregivers have notably different characteristics and personal circumstances. Compared to adult children and other caregivers, spouse caregivers are more likely to be men, to be older than 70, to be in fair or poor health themselves, and to report having a health problem that affects caregiving (Table 1). Spouse caregivers have less education and lower income, on average, than adult children and other caregivers. Virtually all spouse caregivers live with their care recipients. Conversely, adult children and other caregivers are more likely than spouse caregivers to be in the workforce and they are less likely than spouses to live with their care recipient. Such diverse personal circumstances may affect caregivers' availability, physical ability to help with personal and household tasks, and experience of stress and strain.

NFCSP caregivers help frail older relatives who have a range of conditions and needs. Many help someone who may be at risk for nursing home entry. Fifty-nine percent care for someone with Alzheimer's disease, dementia, or other memory-related illness, and 67 percent care for someone with at least three limitations in activities of daily living (ADLs) (not shown). Fifty-five percent of NFCSP caregivers say the person they care for needs someone nearby almost always to be safe (reported by 63 percent of spouses, 51 percent of adult children, and 45 percent of other caregivers).

<sup>3</sup>The Fifth National Survey of OAA Program Participants included only caregivers of adults. The grandparents and other relatives caring for children were not included.

**Table 1. NFCSP Caregivers Have Diverse Characteristics and Circumstances (Percentages)**

Characteristic	Adult Child	Spouse	Other
<b>Female</b>	77.6	66.1	81.3
<b>Age</b>			
60 or younger	61.5	5.6	49.8
61 to 70	34.5	22.4	29.4
71 to 80	3.9	43.8	11.3
81 or older	0.2	28.1	9.6
<b>At Least Some College</b>	70.4	51.1	52.3
<b>Employment Status</b>			
Working full or part time	51.4	9.8	40.0
Retired	26.4	78.6	36.4
Not working	22.2	11.6	23.5
<b>Annual Household Income</b>			
At or below \$20,000	20.4	21.7	34.1
\$20,001 to \$50,000	41.5	65.6	42.7
Above \$50,000	38.1	12.7	23.2
<b>Self-Rated Health Status</b>			
Excellent or very good	38.4	27.5	37.6
Good	34.4	36.1	42.0
Fair or poor	27.2	36.4	20.4
<b>Health Problem or Disability Affects Caregiving</b>	35.0	51.1	25.3
<b>Lives with Care Recipient</b>	57.0	98.8	50.1
<b>Number of Respondents</b>	<b>831</b>	<b>715</b>	<b>246</b>

Source: Calculations based on the Fifth National Survey of OAA Program Participants, 2009.

Finally, the advanced age of NFCSP caregivers is striking. Sixty-eight percent of all NFCSP caregivers are older than 60 and care for someone 85 or older. The majority of spouses (61 percent) who care for someone 85 or older are themselves older than 80 (not shown).<sup>4</sup> Therefore, in addition to NFCSP services, these caregivers are eligible for other OAA services to help them maintain their own independence. These services may include home-delivered or congregate meals, case management, homemaker services, and transportation.

## Amount and Types of Assistance Provided by Caregivers

Seven in 10 NFCSP caregivers say they provide at least 40 hours of care per week—the equivalent of a full-time job. A

<sup>4</sup>Compared with the general U.S. population of family caregivers and care recipients, NFCSP caregivers in the survey sample are more likely to be 75 or older (22 versus 5 percent) and to care for someone who is 75 or older (87 versus 63 percent) (Link and Klocinski 2010).

sizable proportion of spouses (38 percent) and some adult children and other caregivers (18 and 15 percent, respectively) say they provide round-the-clock care (not shown).

Spouses, adult children, and other caregivers provide similar types of care. At least three-quarters of caregivers in each group say they help with each of five instrumental activities of daily living (IADLs)—laundry, meal preparation, and cleaning; local trips for shopping or medical appointments; arranging for services from others; handling medical needs; and managing household finances (not shown). Somewhat smaller proportions of caregivers (at least two-thirds of spouses, adult children, and other caregivers) help with one or more of four activities of daily living—dressing, eating, bathing, and using the toilet.

### Self-Reported Strain

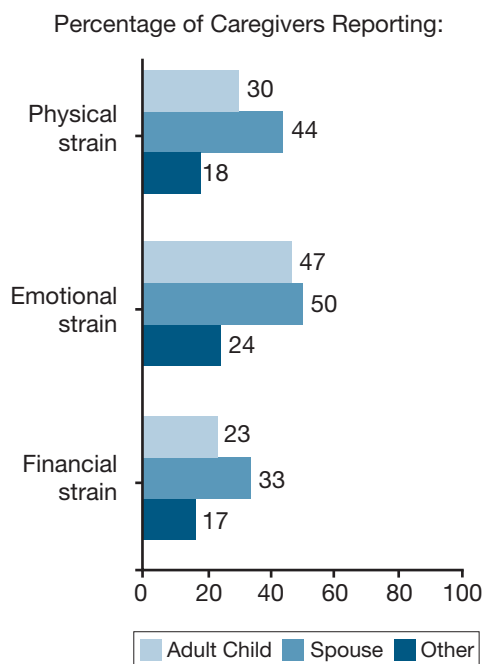
Caregiving results in emotional, physical, and financial strain for some NFCSP caregivers. This is especially pronounced among spouse caregivers. Overall, emotional strain is the most commonly reported type of strain, but it affects about twice as many spouses and adult children (roughly half) as other caregivers (roughly one-quarter) (Figure 1). In addition, 44 percent of spouses say caregiving causes

physical strain, compared with 30 percent of adult children and 18 percent of other caregivers. Similarly, 33 percent of spouses say they experience financial strain as a result of caregiving, compared with 23 percent of adult children and 17 percent of other caregivers. Among caregivers who report having a health problem or disability themselves, half said caregiving worsens the problem (not shown).

### Receipt of NFCSP Services

The NFCSP is designed to alleviate the emotional, physical, and financial strain of caregiving through the types of services it provides. Which service types do caregivers most commonly receive, and how do they say they benefit? Eighty percent of caregivers say they receive information about or help accessing services or resources; about 60 percent report getting supplemental goods and services, such as canes or walkers, emergency response systems, or nutritional supplements for the care recipient; half say they receive respite services; and a third participate in training, education, counseling, or support groups (Figure 2). There is little variation in the percentages of spouses, adult children, and other caregivers who receive each of these services. Three-quarters of caregivers said they receive two or more types of services (not shown).

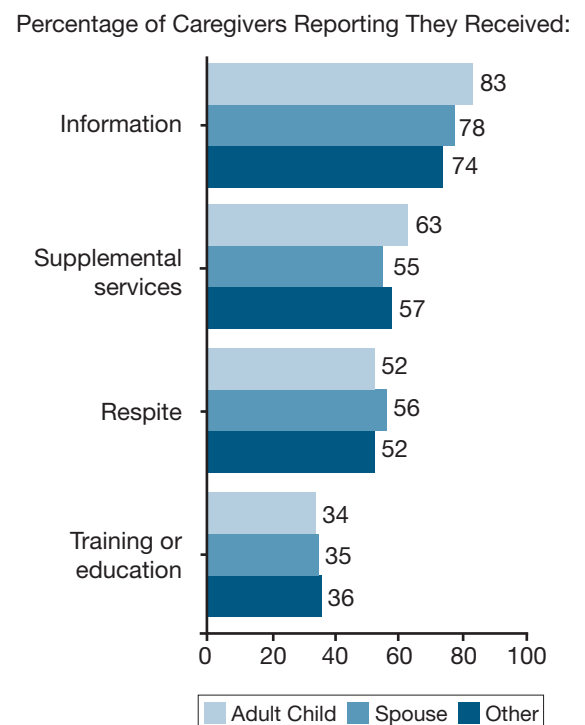
**Figure 1. Spouses Are Most Likely to Say Caregiving Leads to Strain**



Source: Calculations based on the Fifth National Survey of OAA Program Participants, 2009.

Note: The figure shows the share of respondents who rate their stress as 4 or 5 on a scale from 1 (no strain at all) to 5 (very much of a strain).

**Figure 2. Receipt of NFCSP Services Is Similar Across Caregiver Types**



Source: Calculations based on the Fifth National Survey of OAA Program Participants, 2009.

When asked to name the most useful of the NFCSP services they received, 72 percent of those who received respite care (temporary relief from caregiving responsibilities) said that it was the most useful service (not shown). Among those not receiving respite, 43 percent said help or information about connecting to resources was most useful; followed by those citing supplemental goods and services (32 percent); and training, education, counseling, or support groups (25 percent). In general, spouses were more likely than adult children to say training, education, counseling, or support groups was the most useful service.

### Self-Reported Program Benefits

Caregivers are highly satisfied with NFCSP services; 80 percent rated the services as excellent or very good (not shown). Moreover, large majorities report deriving important benefits from those services. For example, 80 percent say the services help them provide care longer than they could otherwise, 76 percent say the services help them feel less stress, and 77 percent say NFCSP services help them deal with the difficulties of caregiving. These proportions vary little across spouses, adult children, and other caregivers.

The more types of services caregivers receive from the NFCSP, the more likely they are to report benefits. As Figure 3 illustrates, 92 percent of caregivers who say they received all four types of services also say the services help them deal with the difficulties of caregiving. In contrast, 61 percent of caregivers receiving only one type of service report the same benefit. The relationship between number of services received and the share of caregivers reporting a benefit holds for every benefit the survey asks about (a total of 12 benefits).

### Summary

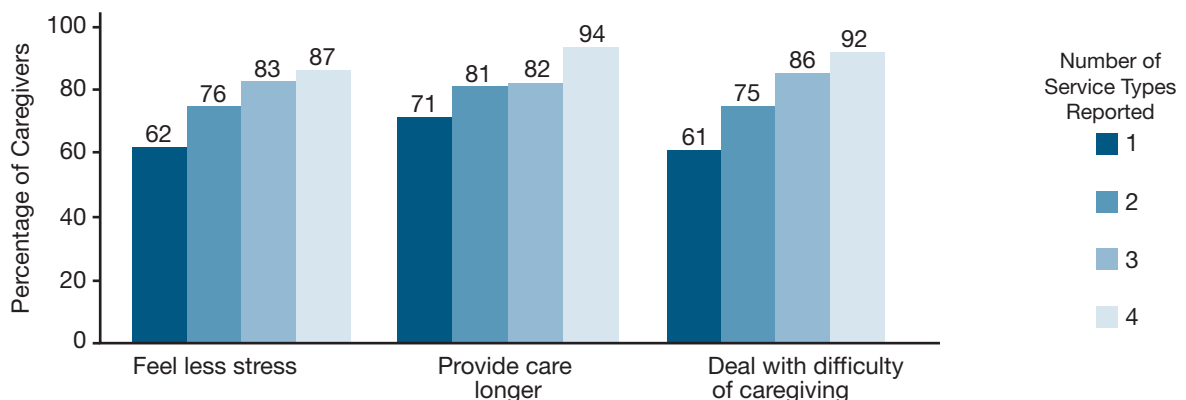
NFCSP caregivers who help frail older relatives are in distinct groups: adult children caring for a parent are the largest group, spouses caring for a spouse are a slightly smaller group, and other relatives are a much smaller group. More than half of all caregivers say they devote at least 40 hours each week to a variety of personal and household tasks. On average, spouses and adult children are more likely than other caregivers to say they experience emotional strain as a result of caregiving. Spouses are more likely than caregivers in the other groups to say caregiving leads to physical and financial strain. They are also more likely to report that they provide round-the-clock care.

Despite differences in their personal circumstances and caregiving-related strain, caregivers in the survey sample use similar NFCSP services and report similar benefits. Among those who receive it, respite is cited as a key NFCSP service, surpassing information, training and education, and other services or goods. Across all caregivers in the survey sample, 8 in 10 say NFCSP services are excellent or very good, and the same proportion of caregivers say the services help them provide care for longer than they could otherwise. The more types of services caregivers receive, the more likely they are to report these and other benefits, such as feeling less stress.

### Data

Information on Title III participants was drawn from the Fifth National Survey of OAA Program Participants. Westat Inc. conducted the telephone survey in 2009,

**Figure 3. Share of Caregivers Reporting Benefits Rises with Number of NFCSP Services Received**



Source: Calculations based on the Fifth National Survey of OAA Program Participants, 2009.

administering it to more than 5,000 people who reported receiving OAA Title III services. The survey used a two-stage sampling design, first selecting a sample of AAAs and then randomly sampling participants from each selected AAA by service type. The number of participants selected from each AAA was proportional to the number of participants who received that particular service from the sampled AAA. This brief includes data for participants in the caregiver module of the survey (1,793 respondents), which is cross-sectional and based upon participants' self-report. All analyses in this brief apply sample weights to account for this design. Additional data from and more detailed documentation for the Fifth National Survey and other AoA data sources are available on the interactive AGing Integrated Database (AGID) at <http://data.aoa.gov>.

## References

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### About This Series

This series is funded by AoA, and presents analyses conducted by Mathematica Policy Research using data from AoA's National Surveys of Program Participants. These surveys collect information from Title III participants about their demographics, socioeconomic status, health, and functioning, as well as their service use and client-reported service impact and quality.

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