



# Family Caregiving to the Older Population: Background, Federal Programs, and Issues for Congress

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## Summary

Family caregiving to older individuals in need of long-term care encompasses a wide range of activities, services, and supports. Caregiving can include assistance with personal care needs, such as bathing, dressing, and eating, as well as other activities necessary for independent living, such as shopping, medication management, and meal preparation. In addition, family caregivers may arrange, supervise, or pay for formal or paid care to be provided to the care recipient.

Family caregivers fulfill the majority of the need for long-term care by older persons with chronic disabilities in the United States. As a result of increases in life expectancy, as well as the aging of the baby-boom generation, demand for family caregiving to the older population is likely to increase. However, demographic trends such as reduced fertility, increased divorce rates, and greater labor force participation among women may limit the number of available caregivers to older individuals, as well as the capacity for caregivers to provide needed care.

Although many family caregivers find caregiving for an older family member a rewarding experience, other life circumstances, in addition to caregiving, may increase caregiver stress. For example, family members may not live in close proximity to the care recipient, they may face the competing demands of child care and elder care, and they may have to manage work with caregiving responsibilities. As a result, family caregiving can lead to emotional and physical strain and financial hardship. These effects are more likely to be felt among those caring for persons with high levels of disability or cognitive impairment. Caregiver stress has been linked to nursing home admission for the care recipient, thus interventions that can reduce stress may also reduce nursing home placement.

Recognizing family caregivers as an important part of the nation's long-term care delivery system, the federal government has established programs and initiatives that provide direct supports to caregivers, such as respite care, education and training, tax relief, and cash assistance. These benefits are targeted at family caregivers to reduce stress and financial hardship, and to improve caregiving skills, among other things. Other federal programs and initiatives provide home and community-based long-term care services and supports to the care recipient. These programs can indirectly benefit caregivers in relieving caregiver burden by either supplementing the informal care they are providing or substituting with paid support.

Three sets of policies that would provide direct assistance to family caregivers to older adults are briefly discussed in the last section of this report. These policy issues, which have been the subject of discussion among federal policymakers and other interested stakeholders, include the following: caregiver services and supports, flexible workplace accommodations and income security, and additional tax credits.

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## What Is Caregiving?

Caregiving encompasses a wide range of activities, services, and supports to assist persons who are limited in their capacity for self-care because of a physical, cognitive, or mental disability or condition that results in a functional impairment and dependence on others. Those in need of assistance over an extended period of time often require long-term care services and supports. Although the need for long-term care affects people of all ages, the likelihood of needing long-term care assistance increases with age.

Caregiving assistance to older persons with long-term needs can be provided in a variety of settings, including the care recipient's or caregiver's home; in a community residential setting, such as an assisted living facility; or in an institution, such as a nursing home. *Formal caregiving* refers to care that is provided by paid individuals who are employed by a long-term care service organization or agency, such as a nursing home or home health care agency, or who are self-employed. *Informal caregiving* refers to assistance provided by unpaid individuals, such as a family member, friend, or neighbor. This report focuses on family caregiving—informal care provided primarily by spouses and children—to the older population.

Family caregiving activities include assistance with personal care needs, or activities of daily living (ADLs), such as eating, bathing and showering, dressing, using the toilet, walking across a small room, and transferring (getting in and out of a bed or chair). They may also include assistance with activities that are necessary for independent living, or instrumental activities of daily living (IADLs), such as shopping for groceries or personal items, performing housework or yardwork, managing money, preparing meals, using a telephone, doing laundry, getting around outside the home, and taking medications.

Other family caregiver activities may include accessing the health care and social services systems, communicating with providers and insurers, and advocating for the care recipient. In addition to hands-on assistance, caregivers may arrange, supervise, or pay for formal care to be provided to the care recipient, either as temporary relief from the caregiver's responsibilities (i.e., respite care) or on a more permanent basis. As caregiving needs change over time, formal and informal care arrangements can also shift. Formal or paid care may supplement or substitute for the informal caregiving activities provided by a family member.

## Background

Family caregivers fulfill the majority of the need for long-term care by older persons with chronic disabilities in the United States. More than 90% of older care recipients receive informal care, either alone or in combination with formal care.<sup>1</sup> Demographic trends such as increases in life expectancy, as well as advances in medical care, have enabled persons with disabilities to live longer. As a result, the demand for informal care provided to older relatives can last many years. The aging of the baby-boom generation is also likely to increase demand for family caregiving to the older population. Moreover, most older individuals prefer to remain in their own homes and

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<sup>1</sup> Brenda C. Spillman and Kirsten J. Black, *Staying the Course: Trends in Family Caregiving*, AARP Public Policy Institute (Washington, DC, November 2005). This report is based on an analysis of the National Long Term Care Survey, 1999. (Hereinafter referred to as Spillman and Black, *Staying the Course: Trends in Family Caregiving*, 2005.)

live in the community for as long as possible.<sup>2</sup> Finally, the difficulty of recruiting and retaining paid long-term care workers has placed increased pressure on family caregivers.<sup>3</sup> The growing demand for care provided in the home has focused the attention of federal and state governments on efforts to expand programs that provide services and supports to family caregivers.

As demand for caregiving to older persons with disabilities is likely to increase, other demographic trends, such as smaller family sizes and increased divorce rates, may limit the number of available caregivers to older individuals, as well as the capacity for caregivers to provide needed care. Increased labor force participation among women, who traditionally have assumed the role of family caregiver, may make them unavailable to take on this role.<sup>4</sup> Also, family members who no longer live in close proximity may limit the direct-care assistance that families are able to provide.

Family caregivers are diverse in terms of gender, age, relationship to the care recipient, and life circumstances. For many, caregiving is a rewarding activity; however, some may face challenges associated with their caregiving responsibilities. Adult children caring for an elder parent might experience increasing stress or financial hardship as a result of the competing demands of work or child care. Others may experience increased physical and emotional strain sometimes associated with assisting a spouse or parent who has a disability or is cognitively impaired. Research indicates that, over time, a larger proportion of family caregivers were providing assistance to persons with higher levels of disability.<sup>5</sup> Moreover, technical advances in home care mean that caregivers are more likely to assist with medical equipment and medications that require more skilled forms of care in the home, including oxygen equipment, intravenous medications, and catheters.<sup>6</sup> These caregivers may have little training or formal assistance in providing such care.

The federal government has expressed an interest in directly supporting family caregivers who provide the majority of long-term care assistance to older individuals, as evidenced by the National Family Caregiver Support Program enacted under the Older Americans Act Amendments of 2000 (P.L. 106-501). Sustaining informal caregiving can offset the need for publicly financed care. However, demographic shifts that may affect the supply of family caregivers raise concerns about whether caregivers will be able to meet the potential increase in demand for long-term care assistance by older individuals in the future. A recent study projects that the disabled older population, even under the most optimistic scenario, will increase by 50% between 2000 and 2040.<sup>7</sup> Over this same period, the share of older adults receiving paid long-

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<sup>2</sup> AARP, *Beyond 50.5—A Report to the Nation on Livable Communities: Creating Environments for Successful Aging*, AARP Public Policy Institute (Washington, DC, May 2005).

<sup>3</sup> National Commission for Quality Long-Term Care, *The Long-Term Care Workforce: Can the Crisis Be Fixed?* Institute for the Future of Aging Services (Washington, DC, January 2007).

<sup>4</sup> Bureau of Labor Statistics, *Changes in Men's and Women's Labor Force Participation Rates*, accessed at <http://www.bls.gov/opub/ted/2007/jan/wk2/art03.htm> on October 8, 2008.

<sup>5</sup> Mary Jo Gibson, *In Brief—Staying the Course: Trends in Family Caregiving*, AARP Public Policy Institute (Washington, DC, November 2005).

<sup>6</sup> AARP, "Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving," AARP Public Policy Institute (Washington, DC, June 2007). (Hereinafter referred to as AARP, *Valuing the Invaluable*, 2007.)

<sup>7</sup> Richard W. Johnson et al., *Meeting the Long-Term Care Needs of the Baby Boomers: How Changing Families Will Affect Paid Helpers and Institutions*, The Retirement Project, Discussion Paper 07-04, The Urban Institute (Washington, DC, May 2007).

term care is projected to increase (from about 22% to 26%), while those receiving unpaid assistance from an adult child will fall (from 28% to 24%).<sup>8</sup>

Recognizing family caregivers as an important part of the nation's long-term care delivery system, the federal government has established programs and initiatives that provide direct support to caregivers. Direct supports such as respite care, education and training, tax relief, and cash assistance are targeted at caregivers to reduce stress and financial hardship, and to improve caregiving skills, among other things. Other federal programs and initiatives provide home and community-based long-term care services and supports to the care recipient. These programs can indirectly benefit caregivers in relieving caregiver burden by either supplementing the informal care being provided or substituting some informal care with paid support. Services provided to care recipients that can indirectly assist caregivers may include formal personal care services, assistive devices, and home modifications, among other things. Access to federal services that provide direct and indirect benefits to caregivers have different eligibility criteria and benefits. As a result, these services are often limited and may be insufficient in terms of the scope and duration of benefits.

## Who Receives Care?

About 5.5 million adults aged 65 and older—about 16% of the U.S. population aged 65 and older—receive long-term care services and supports. Of those receiving services, the majority (70%, or 3.8 million) live in the community; the remaining 30% (1.7 million) live in institutional settings.<sup>9</sup>

Generally, those individuals who live in long-term care facilities are the most impaired; however, many older individuals with fairly significant limitations live in the community. Eligibility for assistance through publicly and privately financed long-term care benefits typically requires people to have limitations in or need supervision with at least two or more ADLs. Of those aged 65 and older who live in the community and receive long-term care, more than half (55.6%) have three or more limitations in ADLs, 29.3% have limitations in one or two ADLs, and 15.1% have less intensive needs, requiring assistance only with IADLs (see **Table 1**).

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<sup>8</sup> Ibid.

<sup>9</sup> CRS calculations based on unpublished tabulations from the 1999 National Long Term Care Survey by Brenda C. Spillman, the Urban Institute, 2003. For further information, see CRS Report RL33919, *Long-Term Care: Consumers, Providers, Payers, and Programs*, by (name redacted) et al.

**Table 1. Distribution of Those Non-Institutionalized Aged 65 and Older Receiving Care, by Level of Disability**

	Total	
	Number (in thousands)	Percent
IADLs only	558	15.1
1-2 ADLs	1,086	29.3
3-4 ADLs	990	26.7
5-6 ADLs	1,068	28.9
<b>Total</b>	<b>3,701</b>	<b>100.0</b>

**Sources:** Federal Interagency Forum on Aging-Related Statistics, "Older Americans 2004: Key Indicators of Well-Being," Table 37b (Washington, DC: U.S. Government Printing Office, November 2004), p. 115; Data are from the 1999 National Long Term Care Survey.

**Notes:** Data refer to Medicare enrollees living in the community who report receiving personal care from a paid or unpaid helper for a chronic disability.

Among those older individuals who live in the community and receive long-term care, the vast majority receive some form of informal care. For two-thirds of this group (65.5%), informal care is the only source of care provided in the home; another quarter (25.9%) receive some combination of informal and formal care, and the remainder (8.5%) receive formal care alone. Although the presence of formal care is more likely to increase as a care recipient's level of disability increases, half of those most severely impaired with five or six ADLs (50.6%) rely on informal caregivers alone for their personal care needs (see **Table 2**).

**Table 2. Distribution of Those Non-Institutionalized Aged 65 and Older Receiving Care, by Type of Care and Level of Disability**

	Informal Care Only	Informal and Formal Care	Formal Care Only	Total	Total
	Percent Distribution				Number (in thousands)
IADLs only	80.1	12.8	7.1	100.0	558
1-2 ADLs	75.8	16.1	8.1	100.0	1,086
3-4 ADLs	62.2	28.1	9.7	100.0	990
5-6 ADLs	50.6	40.8	8.6	100.0	1,068
<b>All</b>	<b>65.5</b>	<b>25.9</b>	<b>8.5</b>	<b>100.0</b>	<b>3,701</b>

**Sources:** Federal Interagency Forum on Aging-Related Statistics, "Older Americans 2004: Key Indicators of Well-Being," Table 37b (Washington, DC: U.S. Government Printing Office, November 2004), p. 115; Data are from the 1999 National Long Term Care Survey.

**Notes:** *Informal care* refers to unpaid assistance provided to a person with a chronic disability living in the community. *Formal care* refers to paid assistance. Data refer to Medicare enrollees living in the community who report receiving personal care from a paid or unpaid helper for a chronic disability. Figures may not add to 100.0% due to rounding.



Other factors, such as gender and living arrangement, influence the type and amount of informal care received. Research findings indicate that women are more likely than men to receive any help, but that men receive a greater amount of care.<sup>10</sup> Older men typically receive assistance from one caregiver, primarily their spouses, whereas older women are more likely to have multiple caregivers. Variation in the amount of care may be related to gender differences in the types of care received. For example, men are more likely to receive help with personal care, housekeeping, and meal preparation activities, whereas women are more likely to receive help with transportation, shopping, and home repairs. Those who live with someone else receive a substantially greater amount of informal care than those who live alone. Alternatively, research has found that those who live alone, are not married, and live in public housing are more likely to use paid care.<sup>11</sup>

Income of the care recipient may also influence the type of care received. Data from a 2002 nationally representative study of the older population found that poor and near poor older care recipients living in the community with severe disabilities (i.e., three or more ADLs) were more likely to receive paid personal care assistance than those with incomes greater than 125% of the federal poverty level (FPL).<sup>12</sup> Greater reliance on paid help among the poor elderly most likely reflects assistance from Medicaid and other public support programs. The same study found that those with incomes between 125% and 400% of the FPL were more likely to rely on unpaid assistance only and received less paid support than those with lower incomes. These individuals are less likely to meet income eligibility requirements for public benefits, such as Medicaid, and may be unable to afford the costs of privately paid care.

## Who Provides Care?

### How Many Caregivers Are There?

Estimates of the number of informal caregivers range from 7 million to 54 million (see **Table 3**). There is wide variation in these estimates for several reasons, including differences in the definitions of caregiver and care recipient, the amount and intensity of care provided, and the data collection methodology. Methodological considerations include whether the respondent is asked to identify themselves as a caregiver or whether the care recipient identifies those who provide care, the time frame for reporting caregiving activities (i.e., past year or no recall period), and the

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<sup>10</sup> Sharon Tennstedt, *Family Caregiving in an Aging Society*, presented at the U.S. Administration on Aging Symposium, Baltimore, MD, March, 1999, accessed at <http://www.aoa.gov/prof/research/famcare.pdf> on October 8, 2008.

<sup>11</sup> Ibid.

<sup>12</sup> Richard W. Johnson and Joshua M. Wiener, *A Profile of Frail Older Americans and Their Caregivers*, The Retirement Project, Occasional Paper Number 8, The Urban Institute (Washington, DC, February 2006). (Hereinafter referred to as Johnson and Wiener, *A Profile of Frail Older Americans and Their Caregivers*, 2006.) The authors' estimates are based on data from the 2002 Health and Retirement Study, a nationally representative survey of older Americans aged 55 and older and living in the community. The study classified respondents as disabled if they reported any difficulty because of health or memory problems with at least one ADL (bathing, getting in and out of bed, eating, dressing, walking across the room, and using the toilet) or IADL (shopping for groceries, preparing hot meals, using the telephone, taking medications, and managing money). Respondents were not considered disabled if they expected their limitations to last less than three months. The analysis is restricted to those aged 65 and older and living in the community in 2002. In this analysis, "poor" refers to care recipients with incomes less than 100% of the federal poverty level; "near poor" refers to care recipients with incomes between 100% and 125% of the poverty level.

sample size. These differences in methods make it very difficult to compare estimates across surveys.

**Table 3** shows the range of estimates of the number of caregivers from selected national surveys, as well as a comparison of survey characteristics and methodology. Estimates at the high end of the range include those individuals who provide care to the adult-disabled or to individuals of all ages and use a less restrictive measure of disability that may also include short-term disability or acute spells of illness.

Data from the 1999 National Long Term Care Survey (NLTCS)—the only national survey that estimates the number of persons providing care to an older population (aged 65 and older)—estimated that 7 million individuals were providing care to individuals aged 65 and older. This estimate is more conservative than other survey estimates in part because a care recipient's functional status or disability is measured as receiving help with ADLs or IADLs for at least three months, a more restrictive definition that measures chronic disability, defined as ADL or IADL impairments lasting at least three months, among the older population.

**Table 3. Alternative Estimates of Number of Caregivers**

Survey	NSFH	NLTCs		SIPP		NCOA/PEW	NFCA	NAC/AARP	
Year	1992	1994	1999	1997, 1996 Wave 5	1998, 1996 Wave 7	1997	2000	1997	2003
Caregivers (in millions)	52.0	7.1	7.0	13.0	9.5	7.0	54.0	22.4	44.4
Unit of observation	Individuals	Individuals		Individuals	Individuals	Individuals	Individuals	Households	Individuals
Care Recipient Characteristics									
Age	All ages	65+		15+	All ages	55+	All ages	50+	18+
Functional status	Physical or mental condition, or disability	ADL or IADL impairments of 3+ months <sup>a</sup>		ADL or IADL <sup>a</sup> impairment	Long-term illness or disability	Unspecified	Disability or chronic illness	Need help to take care of self	Need help to take care of self
Methodological Considerations									
Timeframe for reporting	Past 12 months	Not specified		Not specified	Past month	NA	NA	Past 12 months	Past 12 months
Caregiver designation	Self-identified	Care recipient identified up to five helpers		Care recipient identified up to two helpers	Self-identified	Self-identified	Self-identified	Self-identified	Self-identified
Sample size	10,005 individuals; about 3,000 caregivers	About 6,000 aged 65+ individuals with disabilities		36,700 households; about 60,000 individuals; about 2,500 with ADLs or IADLs	36,700 households; about 60,000 individuals; 2,829 caregivers	200 caregivers	1,000 individuals; 266 caregivers	1,509 caregivers	6,139 individuals; 1,247 caregivers

**Source:** Adapted by CRS from Administration on Aging, "The National Family Caregiver Support Program, Resource Guide," prepared by The Lewin Group, Inc. (Washington, DC, August 2002), at <http://www.lewin.com/content/publications/2479.pdf>, accessed on October 8, 2008.

**Notes:** *National Survey of Families and Households (NSFH)*, 1992: Administration on Aging (AoA) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE), *Informal Caregiving: Compassion in Action*, 1998, at <http://aspe.hhs.gov/daltcp/reports/carebro2.pdf>, visited October 8, 2008.

*National Long Term Care Survey (NLTCs)*, 1994: AoA and ASPE, *Informal Caregiving: Compassion in Action*, 1998, at <http://aspe.hhs.gov/daltcp/reports/carebro2.pdf>, visited October 8, 2008; *NLTCs*, 1999, tabulated by The Lewin Group.

*Survey of Income and Program Participation (SIPP)*, 1997, 1996, Wave 5, Adult Disability Topical Module, tabulated by The Lewin Group; *SIPP*, 1998, 1996, Wave 7 Home Care (Caregiver) Topical Module, tabulated by The Lewin Group.

*National Council on Aging (NCOA) and Pew Charitable Trusts (PEW)*, 1997: Donna L. Wagner, "Long-Distance Caregiving for Older Adults," *Healthcare and Aging*, National Council on the Aging, 1997.

*National Family Caregivers Association (NFCA)*, 2000: NFCA, *Caregiver Survey-2000*, Kensington, MD, 2000.

*National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP)*, 1997: NAC and AARP, *Family Caregiving in the U.S.: Findings from a National Survey*, Washington, DC: AARP, 1997; NAC and AARP, 2003: NAC and AARP, *Caregiving in the U.S.*, Washington, DC: NAC and AARP, 2004.

- a. ADLs refer to activities of daily living, such as bathing, dressing, toileting, transferring from a bed to a chair, and eating; IADLs refer to instrumental activities of daily living, such as shopping, money management, preparing meals, and doing laundry.

## What Are Their Characteristics?

Spouses and adult children are the most common source of informal care to the older population with long-term care needs. A nationally representative survey of older Americans found that among older disabled persons receiving informal care in the community in 2002, more than 80% received some care from a spouse or adult child, 13% received care from another relative, and almost 7% received care from a non-relative.<sup>13</sup> In addition, family caregiving activities are highly concentrated; more than two-thirds of care recipients received informal help from one caregiver.<sup>14</sup>

Marital status plays a large role in determining the caregiver relationship (see **Table 4**). Married care recipients were more likely to receive help from one adult caregiver, primarily their spouse. Unmarried care recipients were more likely to receive help from more than one helper, most often from their adult children.

**Table 4. Relationship of Caregivers to Care Recipients, 2002**

	Marital Status of Care Recipient		
	All Care Recipients	Married Care Recipients	Unmarried Care Recipients
Spouse	27.6	66.7	n/a
Daughter/daughter-in-law	36.4	18.5	49.1*
Son/son-in-law	16.4	7.3	22.9*
Grandchild	6.4	3.3	8.6*
Other relative	6.6	2.0	9.7*
Friend/neighbor	6.6	2.1	9.8*
<b>All caregivers</b>	<b>100.0%</b>	<b>100.0%</b>	<b>100.0%</b>

**Sources:** Johnson and Wiener, *A Profile of Frail Older Americans and Their Caregivers*, Table 5.1, 2006; data are from the 2002 Health and Retirement Study.

**Notes:** Estimates are based on a sample of 2,427 caregivers to frail adults aged 65 and older living in the community, of which 1,044 assisted married adults and 1,383 assisted unmarried adults. An asterisk indicates that the estimate differs significantly ( $p < .10$ ) from the estimate for married recipients. Figures may not add to 100.0% due to rounding.

Women are the majority of informal caregivers to older adults. Because women have longer life expectancies than men and caregiving is still viewed by many as a woman's responsibility, wives are more likely to care for their husbands and older widows are more likely to be cared for by their daughters. In the 2002 Health and Retirement Survey (HRS), daughters were more than twice as likely than sons to provide care to their parents, regardless of the parent's marital status. However, the percentage of male caregivers has increased during the past few decades. Using data from the NLTCs, researchers reported a 50% increase in men reporting they were primary caregivers from 1984 to 1994.<sup>15</sup> Male caregivers were more likely to be spouses and least likely

<sup>13</sup> Johnson and Wiener, *A Profile of Frail Older Americans and Their Caregivers*, 2006.

<sup>14</sup> Ibid.

<sup>15</sup> Brenda C. Spillman and Liliana E. Pezzin, "Potential and Active Family Caregivers: Changing Networks and the 'Sandwich' Generation," *The Milbank Quarterly*, 78(3):347-374, 2000. (Hereinafter referred to as Spillman and Pezzin, (continued...))

to be friends or neighbors. However, women are more likely to engage in the more physically demanding aspects of caregiving. A MetLife study of working men and women caregivers found that while men were just as likely as women to provide assistance with IADLs, such as managing medications, shopping, and transportation, women reported more involvement with personal care tasks or ADLs, such as bathing, dressing, and toileting.<sup>16</sup>

Caregivers can be of any age and face particular challenges based on their own life circumstances, including the competing demands of work, child care responsibilities, and chronic illness and decline in their own personal health. Most spouses who provide care to their disabled elderly spouse are aged 65 and older, with 44% of spouse caregivers in their 70s and about one-quarter in their 80s.<sup>17</sup> Because of advanced age and chronic illness, spouse caregivers may be in poor health themselves. About one-third described themselves to be in fair or poor health, more than 20% reported one or more limitations with ADLs or IADLs, and 17% reported poor mental health, measured by the presence of depressive symptoms. Only a small fraction of spouse caregivers reported they were employed full-time (6%); another 10% reported working part-time.<sup>18</sup>

Adult children providing care to their older parents are most likely to be in their 40s and 50s (68%). The greatest proportion of adult child caregivers live separately from their older parent (68%). About one-third (32%) of adult child caregivers live with their parent. More than half of adult children providing care to their older parents worked full-time (53%), another 10% worked part-time.<sup>19</sup>

## **Long-Distance Caregiving**

Observers have expressed concern that family caregiving may be affected by a more mobile society, resulting in greater long-distance caregiving and a reduced supply of family caregivers.<sup>20</sup> However, some researchers have questioned this notion, suggesting instead that our society is actually less mobile than in previous decades.<sup>21</sup> Data from the 2002 HRS indicate that the majority (63%) of frail older adults have at least one adult child living in close proximity to them (defined as within 10 miles); almost 20% have two or more adult children nearby.<sup>22</sup>

A study by MetLife found that half of long-distance caregivers, defined as living more than one hour from the care recipient, reported that they played a secondary helper role, typically to another sibling who lived near the care recipient. Although primary caregivers may be more

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(...continued)

*Potential and Active Family Caregivers*, 2000.)

<sup>16</sup> MetLife Mature Market Institute, *The Metlife Study of Sons at Work: Balancing Employment and Eldercare* (New York: Metropolitan Life Insurance Company, 2003).

<sup>17</sup> Johnson and Wiener, *A Profile of Frail Older Americans and Their Caregivers*, 2006.

<sup>18</sup> Ibid.

<sup>19</sup> Ibid.

<sup>20</sup> MetLife Mature Market Institute, *Miles Away: The Metlife Study of Long-Distance Caregiving* (New York: Metropolitan Life Insurance Company, 2004). (Hereinafter referred to as MetLife Mature Market Institute, *Miles Away*, 2004.)

<sup>21</sup> Douglas A. Wolf and Charles F. Longino, Jr., "Our 'Increasingly Mobile Society'? The Curious Persistence of a False Belief," *The Gerontologist*, vol. 45, no. 1 (February 2005), pp. 5-11).

<sup>22</sup> Johnson and Wiener, *A Profile of Frail Older Americans and Their Caregivers*, 2006.

likely to live in close proximity to the care recipient, the same study found that a sizeable group of long-distance caregivers (23%) were the primary or only care provider. Both primary and secondary long-distance caregivers reported living an average distance of 450 miles away. The majority reported managing needed services, helping with IADLs such as shopping and managing finances, and visiting at least a few times a month. These activities were not only time consuming, with half spending the equivalent of one full day a week managing care from a distance, but added a substantial financial burden in terms of travel costs. Long-distance caregivers reportedly spent an average of \$392 per month on travel and out-of-pocket expenses. Nearly 80% of the caregivers surveyed were employed either full- or part-time.<sup>23</sup>

## **The Sandwich Generation**

Many researchers have focused attention on the “sandwich generation” of caregivers—those caught between the demands of caring for their aging parents and supporting their dependent children. Some have expressed concerns that delayed fertility among women will lead to greater caregiving burden, with demand for caregiving only increasing as the baby-boom population ages. Approximately 3.5 million individuals, primarily women, were potentially responsible for both an aging parent and a dependent child.<sup>24</sup> According to a 2004 survey of all family caregivers, including those caring for individuals under age 65 with disabilities, more than one-third reported the presence of a child under the age of 18 living at home. Adult caregivers under the age of 50 were more likely to have a child in their home, compared with caregivers aged 50 and older. More than half (52%) of caregivers between the ages of 18 to 34 and almost 6 in 10 (57%) caregivers between the ages of 35 to 49 had a child under age 18 living in the household.<sup>25</sup>

Although data suggest that many caregivers have been squeezed into the “sandwich generation,” other research suggests that only a small subset of this group are simultaneously providing support to a dependent child and parent. For this reason, some researchers disagree about the caregiving demand and burden faced by the “sandwich generation,” arguing that the phenomenon is an exception rather than the norm. These researchers maintain that child care activities and eldercare activities more often occur sequentially rather than simultaneously.<sup>26</sup> Moreover, the types of activities and support provided to a dependent child may be very different from those provided to a disabled parent.

Data from the National Longitudinal Survey of Young Women found that about 1% of women aged 45 to 56 years old have both a parent and a child living in the household.<sup>27</sup> Broadening the definition of the “sandwich generation” of caregivers to include those who are providing either financial support of more than \$1,000 or caregiving support of more than 500 hours to both a

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<sup>23</sup> MetLife Mature Market Institute, *Miles Away*, 2004.

<sup>24</sup> Spillman and Pezzin, *Potential and Active Family Caregivers*, 2000. This report is based on an analysis of the National Long Term Care Survey, 1994.

<sup>25</sup> National Alliance for Caregiving and AARP, *Caregiving in the U.S.*, 2004.

<sup>26</sup> Christine Himes, “Parental caregiving by adult women: A demographic perspective,” *Research on Aging*, vol. 16 (2004), pp. 191-211; L.S. Loomis and A. Booth, “Multigenerational caregiving and wellbeing: The myth of the beleaguered sandwich generation,” *Journal of Family Issues*, vol. 16 (2005), pp. 131-148.

<sup>27</sup> Charles R. Pierret, “The ‘sandwich generation’: women caring for parents and children,” *Monthly Labor Review*, September 2006. This report is based on analyses of the 1997 and 1999 waves of data from the National Longitudinal Survey of Young Women.

child and a parent, neither of whom necessarily live in the same household, increases the percentage of women in the “sandwich generation” to 9%.<sup>28</sup>

## **Work and Caregiving**

A substantial share of caregivers are balancing work with caregiving responsibilities. In a 2002 survey conducted by the Families and Work Institute, more than one-third (35%) of workers indicated they provided care for a relative or in-law aged 65 or older in the past year.<sup>29</sup> However, those working full-time are less likely to be shouldering the primary caregiving responsibility. A 2004 national survey conducted by the National Alliance for Caregiving (NAC) and AARP found that those who have a lower caregiving burden were more likely to be employed full-time.<sup>30</sup>

Employed caregivers often make workplace adjustments to care for older family members, such as changing their daily work schedules, reducing their work hours, or taking a leave of absence to care for an older relative.<sup>31</sup> Workplace policies that can assist family caregivers to older adults include flexible work schedules, part-time hours, job-sharing, paid and unpaid leave policies, telecommuting, and worklife benefits such as counseling and information and referral services. The 2002 Families and Worklife Institute survey found that elder care resource and referral services have increased significantly in the past decade. In 2002, almost one-quarter of employees reported they had access to this benefit, an increase from 11% in 1992.<sup>32</sup> Federal initiatives such as the Family and Medical Leave Act provide a limited amount of job-protected unpaid leave to qualifying employees. Also, some current law tax provisions assist family caregivers with an older relative who is a qualifying dependent. However, these federal provisions (discussed in the next section) are not widely used for the purpose of caring for an older frail family member.<sup>33</sup>

## **How Much Care Do They Provide?**

Family caregivers who are the primary source of care to an older disabled relative spend a significant amount of time providing assistance. Primary ADL caregivers helped the most by providing, on average, about 46 hours of care per week (or 201 hours per month)—more hours than a typical full-time job. Those providing primary IADL assistance averaged fewer hours of care, with about 83 hours per month, or just over 19 hours on average per week. Spouses, who typically assume the role of a primary caregiver, provided the most hours of care to a disabled older spouse, followed by daughters, then sons (**Table 5**).

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<sup>28</sup> Ibid.

<sup>29</sup> James T. Bond et al., *Highlights of the 2002 National Study of the Changing Workforce*, Families and Work Institute, 2002.

<sup>30</sup> National Alliance for Caregiving and AARP, *Caregiving in the U.S.*, 2004.

<sup>31</sup> For further information, see CRS Report RL31755, *Family Caregiving to the Elderly by Employed Persons: The Effects on Working Caregivers, Employers, and Federal Policy*, by (name redacted).

<sup>32</sup> James T. Bond et al., *Highlights of the 2002 National Study of the Changing Workforce*, Families and Work Institute, 2002.

<sup>33</sup> See CRS Report RL31755, *Family Caregiving to the Elderly by Employed Persons: The Effects on Working Caregivers, Employers, and Federal Policy*, by (name redacted).



**Table 5. Monthly Hours of Help Provided by Informal Caregivers to Noninstitutionalized Frail Older Adults, by Type and Relationship, 2002**

	Mean Hours per Month	Median Hours per Month
<b>Caregiver Type</b>		
Primary ADL	201	90
Primary IADL	83	31
Other Caregivers	53	16
<b>Relationship</b>		
Spouse	153	61
Daughter/daughter-in-law	98	31
Son/son-in-law	71	30
Other	83	20

**Source:** Johnson and Wiener, A Profile of Frail Older Americans and Their Caregivers, Table 5.2, 2006.

**Notes:** Data from the 2002 Health and Retirement Study. Estimates are based on a sample of 2,427 caregivers to frail adults aged 65 and older living in the community, which includes 738 primary ADL caregivers, 736 primary IADL caregivers, and 953 other caregivers and helpers.

**Table 5** also shows that the median hours of care per month, regardless of relationship or caregiver type, is substantially lower than the average or mean hours of care per month. The 2002 HRS data suggest that the distribution of informal caregiving hours is highly skewed. Thus, there is likely to be wide variation in the amount of hours of informal care that caregivers reported providing to an older care recipient. Indeed, the NAC/AARP 2004 survey of caregivers found that almost half of caregivers to individuals of all ages reported providing up to 8 hours of care per week (48%), whereas almost one-fifth of caregivers (17%) provided more than 40 hours of care per week. These data reflect the wide variation in amount of care and a much greater intensity of caregiving for a relatively smaller but sizeable portion of the caregiving population.<sup>34</sup>

Further research indicates that the amount of time spent caring increases substantially for older persons with varying degrees of cognitive impairment. Individuals aged 70 and older with no dementia received 4.6 hours of informal care per week, compared with 13.1 hours per week for those with mild dementia, 22.0 hours per week for those with moderate dementia, and 46.1 hours per week for those with severe dementia.<sup>35</sup>

Many family caregivers devote significant time assisting older adults during the course of a year; however, caring for the long-term needs of an older frail family member can continue for many years. In the 2004 NAC/AARP survey of caregivers, the average duration of care was 4.3 years. Almost 30% of caregivers reported assisting the recipient for five years or more. Older caregivers

<sup>34</sup> National Alliance for Caregiving and AARP, *Caregiving in the U.S.*, April 2004.

<sup>35</sup> Kenneth M. Langa et al. "National Estimates of the Quantity and Cost of Informal Caregiving for the Elderly with Dementia," *Journal of General Internal Medicine*, vol. 16 (November 2001), pp.770-778.

were more likely to have been providing care for 10 years or more, compared with caregivers under age 50.<sup>36</sup>

## The Effects of Family Caregiving

### The Physical, Emotional, and Financial Effects of Caregiving

While many family members find caregiving a rewarding and satisfying activity, caregivers may also face increased physical strain, emotional stress, and financial hardship as a result of caregiving responsibilities. Moreover, caregiver satisfaction and caregiver strain may be experienced simultaneously. Some caregivers find personal satisfaction from forming a close relationship with a family member. They may find caregiving fulfills a sense of duty to the recipient. Also, they may find satisfaction from their personal belief that they can provide the best care to the recipient.<sup>37</sup> One factor associated with caregiver stress is whether the caregiver had a choice in taking on caregiving responsibilities. Other factors associated with high caregiver stress and strain include poor caregiver health and heavy caregiving burden. One study found that those caregivers experiencing high levels of stress because of heavy caregiving burden were more likely to provide more than 20 hours of care per week, to provide care to a recipient with more than three ADLs, to have little to no backup assistance, and to experience problems providing care (e.g., sleep interruption, disruptive behavior by the care recipient).<sup>38</sup>

Most caregivers report they are in good health. However, factors such as age, gender, education, income, and whether or not the caregiver lives with the recipient are associated with the caregiver's health.<sup>39</sup> Caregivers with increased caregiving responsibilities face greater levels of caregiver stress, which may place their physical health at risk. Researchers have documented several adverse health outcomes related to caregiving, including elevated blood pressure, impaired immune systems, and potential increased risk for cardiovascular disease.<sup>40</sup> Older spouse caregivers who experienced caregiver-related stress had higher mortality rates than non-caregivers of the same age.<sup>41</sup> Research has also linked high levels of caregiver stress to nursing home entry of the care recipient, where having a highly stressed caregiver increases the likelihood that a chronically disabled older adult will enter a nursing home by 12 percentage points within one year and 17 percentage points over a two-year follow-up period.<sup>42</sup> The same study concluded

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<sup>36</sup> National Alliance for Caregiving and AARP, *Caregiving in the U.S.*, April 2004.

<sup>37</sup> M. Nolan et al., *Understanding Family Care: A Multidimensional Model of Caring and Coping*, (Philadelphia: Open University Press, 1996).

<sup>38</sup> Brenda C. Spillman, "Primary Informal Caregivers: Factors Associated with High Stress," presented at Conference on Caregiver Health as a Public Health Issue, Urban Institute, Washington DC, September 26, 2006. (Hereinafter referred to as Spillman, *Primary Informal Caregivers*, 2006.)

<sup>39</sup> National Alliance for Caregiving and AARP, *Caregiving in the U.S.*, 2004.

<sup>40</sup> Sunmin Lee et al., "Caregiving and Risk of Coronary Heart Disease in U.S. Women: A Prospective Study," *American Journal of Preventive Medicine*, vol. 24, pp. 113-119.

<sup>41</sup> Richard Schulz and Scott R. Beach, "Caregivers as a Risk Factor for Mortality: The Caregiver Health Effects Study," *Journal of the American Medical Association*, vol. 282, no. 23 (1999), pp. 2215-2219.

<sup>42</sup> Brenda C. Spillman and Sharon K. Long, "Does High Caregiver Stress Lead to Nursing Home Entry?" Office of Disability, Aging and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, January 26, 2007.

that initiatives to reduce stress among caregivers would also reduce the rate of nursing home admission.

Providing care to an older person can also affect a caregiver's mental health. Several studies have documented high levels of depressive symptoms and other mental health problems among those who provide care compared with those who do not.<sup>43</sup> In particular, higher levels of depression are associated with caregivers assisting those individuals with dementia. Studies have shown that about 30% of dementia caregivers suffer from depression, and more than 40% report high levels of emotional stress as a result of caregiving.<sup>44</sup>

Research on caregiver burden indicates that caregivers need more assistance and information on where to find supportive services. A national study of caregivers to adults aged 60 and older found that more than one-third (35%) expressed a need to find time for themselves. However, the same study reported that almost one-third of caregivers said they did not know where they would turn for information on either short- or long-term care for the care recipient.<sup>45</sup> Another study found that high-stress caregivers are more likely to say they need help with caregiving, time-off or a break from caregiving responsibilities, and some form of financial assistance such as cash, a tax break, or a subsidy for caregiving.<sup>46</sup>

Caregivers who do report using supportive services are more likely to be in high-stress caregiving situations. In the 2004 NAC/AARP survey, caregivers were more likely to report using supportive services if they assisted someone with Alzheimer's or dementia, lived with the person they also cared for, or were older themselves (i.e., aged 50 and older). Furthermore, those assisting individuals with high levels of disability are more likely to report experiencing financial hardship and requesting information about how to get financial help for the care recipient.<sup>47</sup>

Research comparing high-stress and low-stress caregivers found that caregivers rating their stress level as 6 or higher on a scale of 1 to 10 were more likely to have ever used paid help for ADLs, adult day care, or respite. The overwhelming majority of low-stress caregivers reported that they did not use these services because they did not need them. However, high-stress caregivers were four times more likely than low-stress caregivers to indicate they have not used these services because they were unaware of them, and 20 times more likely to report not using these services because they could not afford them.<sup>48</sup>

For some family caregivers, providing care to an older relative can pose a significant financial burden. A 2007 study by Evercare and NAC looked at the extent to which family caregivers to

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<sup>43</sup> Carolyn C. Cannuscio et al., "Reverberation of Family Illness: A Longitudinal Assessment of Informal Caregiver and Mental Health Status in the Nurses' Health Study," *American Journal of Public Health*, vol. 92, issue 8, pp. 1305-1311; Nadine Marks et al., "Transitions to Caregiving, Gender, and Psychological Well-Being: A Prospective U.S. National Study," *Journal of Marriage and Family*, vol. 64, no. 3, pp. 657-667.

<sup>44</sup> Kenneth E. Covinsky et al., "Patient and Caregiver Characteristics Associated with Depression in Caregivers of Patients with Dementia," *Journal of General Internal Medicine* vol. 18 (2003), pp. 1006-1014; Alzheimer's Association, *Alzheimer's Disease Facts and Figures* (Chicago, IL, 2007).

<sup>45</sup> Sarah L. McKune et al., *Caregiving: A National Profile and Assessment of Caregiver Services and Needs*, Rosalynn Carter Institute and the University of Florida, 2006.

<sup>46</sup> Spillman, *Primary Informal Caregivers*, 2006.

<sup>47</sup> National Alliance for Caregiving and AARP, *Caregiving in the U.S.*, 2004.

<sup>48</sup> Spillman, *Primary Informal Caregivers*, 2006.

older individuals pay for the goods and services provided to their care recipients.<sup>49</sup> According to the study's findings, family caregivers reported an average annual out-of-pocket expense of \$5,531, more than 10% of the median income of the survey group, which was \$43,026. Long-distance caregivers reported the highest average annual expenses (\$8,728) compared to caregivers who lived in the same household as the care recipient (\$5,885) and those who cared for someone nearby but not in the same household (\$4,570). The most common expense categories that respondents reported they may have had as a result of the help and support they provided were: household goods, food and meals (42% reporting), travel and transportation costs (39%), and medical care co-pays and pharmaceuticals (31%).

However, it is often difficult to differentiate those household expenses that are care related expenses from those that are general household expenses, particularly when a caregiver co-resides with the care recipient. For example, co-resident households may have certain shared household expenses such as groceries, certain household items, and transportation. In the Evercare study 45% of respondents co-resided with the care recipient, and caregiver related expenses may have been paid for with the caregiver's own money or with household money.

## The Economic Value and Costs of Caregiving

The total value (non-economic as well as economic) of caregiving to older persons with disabilities can be substantial. Some researchers have attempted to document the economic value associated with family caregiving. Generally, the economic value of informal care is measured as the cost of replacing informal (unpaid) care with formal (paid) care. Estimates of the value of informal care vary widely, depending on the identified caregiving population, the number of caregivers or caregiving hours counted, and the estimated hourly wage rate for caregivers' time. These studies provide the following estimates:

- Annual cost of replacing informal caregiving with paid home care at \$45 billion to \$94 billion.<sup>50</sup>
- Imputed value of informal caregiving at \$168 billion (18.7 billion hours of caregiving at \$9 per hour).<sup>51</sup>
- Economic value of caregiving using a range of three estimates—from a low estimate of \$149 billion (27 million caregivers each providing 20.5 hours of care per week at \$5.15 per hour) to a mid-range estimate of \$306 million (28.9 million caregivers each providing 20.5 hours of care per week at \$9.92 per hour) to a high estimate of \$483 billion (30.7 million caregivers each providing 20.5 hours of care per week at \$14.68 per hour).<sup>52</sup>

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<sup>49</sup> Evercare and National Alliance for Caregiving, "Family Caregivers - What They Spend, What They Sacrifice?" November, 2007.

<sup>50</sup> Department of Health and Human Services, *Informal Caregiving: Compassion in Action*, Administration on Aging, at <http://aspe.hhs.gov/search/daltcp/reports/Carebro2.pdf>.

<sup>51</sup> Mitchell Laplante et al., "Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living Provided to Adults Living at Home," *Health Services Research*, vol. 37, no. 2 (April 2002).

<sup>52</sup> Peter S. Arno, *Economic Value of Informal Caregiving: 2004*, presented at the Care Coordination and the Caregiver Forum, Department of Veterans Affairs, National Institutes of Health, Bethesda, MD, January 25-27, 2006. This research is based on previous research by the author and other researchers.

- Economic value of unpaid caregiving activities in 2006 to be \$354 billion, assuming 34 million caregivers each providing 1,080 hours of care per year (about 21 hours of care per week) at a cost of \$9.63 per hour.<sup>53</sup>

Other researchers, however, have cautioned that some estimates may overstate the economic costs of informal caregiving.<sup>54</sup> For example, some estimates may include the time family members spend performing activities that they would have done regardless of the care recipient's disability status (e.g., meal preparation, shopping, housework).

Some researchers have attempted to quantify the economic costs to family caregivers and to employers that can be associated with caregiving. Caregivers that take time out of the work force to care for a family member not only lose wages but fail to accrue savings and benefits, which may place them at economic risk over their lifetimes. Another measure of economic cost looks at lost economic productivity resulting from caregiving activities. In a small, nonrepresentative study of family caregivers, MetLife found that as a result of caregiving, informal caregivers lost a lifetime estimated average of \$566,433 in pre-taxable wage wealth, \$25,494 in Social Security wealth, and \$67,202 in pension wealth.<sup>55</sup> Combined, the result is a loss in total pre-taxable wealth of approximately \$659,000 per person over a lifetime.<sup>56</sup> Another study by MetLife and NAC estimated that the aggregate costs of caregiving in lost productivity to U.S. businesses for full-time employees was between \$17.1 and \$33.6 billion annually, based on NAC's 2004 survey of caregivers.<sup>57</sup>

## Federal Government Initiatives to Assist Caregivers

The federal government has established programs and initiatives that provide direct support to family caregivers, including grant programs authorized under the Older Americans Act and Title XX of the Social Security Act (the Social Services Block Grant program). These programs provide family caregivers with information and referral, respite care, and training. In addition, some states' Medicaid home and community-based waivers offer respite care as a covered service. Recently, some states began allowing family caregivers to be hired by the Medicaid beneficiary, giving some cash assistance to caregivers. Other initiatives that offer direct assistance to caregivers include the Family and Medical Leave Act, which provides unpaid leave to eligible employees in order to care for a spouse, parent, or child with a serious health condition. Furthermore, tax provisions in current law offer caregivers some direct tax relief.

Other federal programs and initiatives provide home and community-based long-term care services and supports to the care recipient. These programs can indirectly benefit caregivers by relieving caregiver burden through supplementing the informal care being provided by caregivers

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<sup>53</sup> AARP, *Valuing the Invaluable*, 2007.

<sup>54</sup> Douglas A. Wolf, "Valuing Informal Elder Care," in *Family Time: The Social Organization of Care*, edited by Nancy Folbre and Michael Bittman.

<sup>55</sup> *Wage wealth* is defined as the present value of lifetime wages calculated as of the date of retirement; *Social Security wealth* is defined as the respondent's total estimated Social Security benefits; *pension wealth* is defined as the respondent's estimated average annual pension benefits accumulated in retirement.

<sup>56</sup> MetLife Mature Market Institute, *The MetLife Juggling Act Study: Balancing Caregiving with Work and the Costs Involved* (New York: Metropolitan Life Insurance Company, 1999).

<sup>57</sup> MetLife Mature Market Institute and National Alliance for Caregiving, *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Businesses* (Westport, CT: MetLife Mature Market Institute, July 2006).

or substituting it with paid support. Services provided to care recipients that can indirectly assist caregivers include formal personal care services, adult day health care, assistive devices, transportation, and nutrition services (i.e., home-delivered meals). Many of these services are offered through the same programs mentioned above (i.e., Older Americans Act, Social Services Block Grant, and Medicaid waivers).

Access to benefits that directly assist caregivers are often limited by program funding and may be insufficient in coverage and duration. Furthermore, coverage for direct benefits to caregivers may be uneven across states. Federal programs that provide long-term care services to care recipients that, as a result, indirectly assist caregivers are often limited to those recipients who meet certain age requirements and financial and functional eligibility criteria (e.g., limitations with two or more ADLs). In addition, some states use state-funds to provide programs and services, such as respite care, or offer state tax benefits to assist family caregivers. These state initiatives are outside of the scope of this report. The following describes the various federal government initiatives and programs. A summary table of these federal programs and initiatives is provided in the **Appendix**.

## **Programs and Services**

### **Older Americans Act (OAA)**

The OAA (P.L. 89-73, as amended; 42 USC. § 3001 et seq.) funds a number of programs and activities to support family caregivers of older individuals (aged 60 and older) directly through information and referral services, respite, and caregiver training and support. The OAA also provides indirect services that can assist caregivers through the delivery of other home and community-based services and supports.

#### ***National Eldercare Locator Service***

Title II of the OAA requires the U.S. Administration on Aging (AoA) to develop the National Eldercare Locator Service. The Eldercare Locator Service allows caregivers and older adults to connect with state and local area agencies on aging and community-based organizations that provide services to older individuals. By calling a nationwide toll-free number (1-800-677-1116, weekdays, 9:00 a.m. to 8:00 p.m., EST) or accessing the website at <http://www.eldercare.gov>, individuals can access the resources of state and local OAA information and referral programs and other service providers identified for every ZIP code across the nation.

The National Eldercare Locator Service can help caregivers identify local resources and enables long-distance caregivers to access information about services available to family members in other parts of the country. The Eldercare Locator Service can connect individuals to more extensive information sources for a variety of services, including transportation, home-delivered meals, housing options, Alzheimer's hotlines, adult day care, respite services, home health services, long-term care ombudsmen, and legal assistance.

In FY2007, approximately 115,000 callers received information and referral services through the toll-free number, down from 131,000 and 132,000 callers in FYs 2005 and 2006, respectively. However, the number of Eldercare Locator web contacts has increased 43% over a two-year

period, from 188,000 in FY2005 to 269,000 in FY2007.<sup>58</sup> For FY2008, overall funding available for National Eldercare Locator Service program activities is approximately \$800,000.<sup>59</sup>

### ***Aging and Disability Resource Centers (ADRCs)***

Another federal initiative to provide family caregivers and individuals with information and improve access to public and private long-term care services and supports at the community level is the Aging and Disability Resource Center (ADRC) program. A collaborative effort of the AoA and the Centers for Medicare and Medicaid Services (CMS), the ADRC initiative provides grants to support states' efforts to streamline information and access to public and private long-term care services at the community level. ADRCs are designed to be single points of entry to publicly administered long-term care benefits funded under Medicaid, the OAA, and state programs. The vision of AoA and CMS is for ADRCs to serve as highly visible places where people can turn to for information and support on long-term care in every community.

The OAA Amendments of 2006 (P.L. 109-365) authorized AoA to award funds for ADRCs in all states.<sup>60</sup> As of February 2008, approximately 140 ADRC pilot sites operating in 40 states, the District of Columbia, and two territories (Guam and the Commonwealth of the Northern Mariana Island) have received grant funding through the joint AoA/CMS ADRC program initiative: 12 in FY2003, 12 in FY2004, and 19 in FY2005.<sup>61</sup> For FY2007 AoA provided continued support to the 12 states that received FY2004 funding. From FY2003 through FY2007, the AoA and CMS have awarded over \$42 million in grants to states. In addition, CMS has made investments of \$8 million in FY2008 to 7 states through its Real Choice Systems Change grants to develop person-centered hospital discharge planning models using ADRCs.<sup>62</sup>

### ***National Family Caregiver Support Program (NFCSP)***

The NFCSP provides direct services for caregivers in five core service areas:

- Information about health conditions, resources, and community-based services.
- Assistance with accessing available services.
- Individual counseling, support groups, and caregiver training.
- Respite care services to provide families temporary relief from caregiving responsibilities.
- Supplemental services on a limited basis that would complement care provided by family and other informal caregivers (e.g., adult day health care, home care,

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<sup>58</sup> Administration on Aging, *Fiscal Year 2009: Justification of Estimates for Appropriations Committees*, Department of Health and Human Services, 2008.

<sup>59</sup> Personal communication with Administration on Aging, October 9, 2008.

<sup>60</sup> For further information, see CRS Report RL31336, *The Older Americans Act: Programs, Funding, and 2006 Reauthorization (P.L. 109-365)*, by (name redacted) and (name redacted).

<sup>61</sup> For further information on location of ADRCs, see the ADRC Technical Assistance Exchange at <http://www.adrc-tae.org/tiki-index.php?page=PublicHomePage>, visited on October 6, 2008.

<sup>62</sup> Personal communication with Administration on Aging, October 17, 2008.

home modifications, incontinence supplies, nutritional supplies, assistive devices).

Priority for NFCSP services is given to caregivers aged 60 and older. Services are intended to be distributed to individuals with the greatest economic or social need; particular attention is given to low-income older individuals. However, the law also clarifies that priority is to be given to older individuals who are providing care to those with severe disabilities (including children with severe disabilities). Among other things, the OAA Amendments of 2006 (P.L. 109-365) included additional provisions giving priority for NFCSP services to those caregivers who provide assistance to older persons with Alzheimer's disease and related neurological disorders. For FY2008, NFCSP funding accounts for \$153.4 million, or 8% of total OAA expenditures.<sup>63</sup>

**Table 6** shows the number of caregivers who received assistance by service type for selected NFCSP services in FY2006. Using the most conservative national estimate of caregivers to the chronically disabled elderly (7.1 million from the NLTCS 1999 survey; see **Table 3**), it is estimated that approximately 15.5% of caregivers received assistance in locating services from both private and voluntary agencies, 2.0% received counseling and training services, and 1.0% received respite care. Thus, it appears that these services assist only a relatively small percentage of family caregivers. However, because data sources vary by year and defined population, these estimates should be interpreted with caution.

**Table 6. Selected National Family Caregiver Support Program Services, by Number and Percent of Caregivers Receiving Service, FY2006**

Service Type	Number of Caregivers Receiving Service	Percent of Caregivers Receiving Service
Access assistance	1,100,000	15.5
Counseling and training	148,000	2.0
Respite care	69,000	1.0

**Source:** Administration on Aging, *Fiscal Year 2009: Justification of Estimates of Appropriations Committees*, Department of Health and Human Services, 2008; CRS estimates based on source cited.

**Notes:** Data on services is for FY2006 from AoA administrative sources; the denominator used to calculate the number of caregivers (7.1 million) is from the 1999 NLTCS. Priority for OAA services is given to older care recipients, defined as being aged 60 and older, and their families. The NLTCS is based on a population of Medicare recipients, aged 65 and older.

### *Home and Community-Based Supportive Services*

Title III home and community-based services provide for a broad array of supportive services to assist caregivers indirectly by helping older adults remain in their own homes for as long as possible. These services include transportation; case management; in-home services, such as personal care, chore, and homemaker services; and community services, such as adult day health care and senior center activities. These services can assist caregivers indirectly by allowing them to continue working, and directly by providing brief respite from caregiver responsibilities or helping to alleviate caregiver burden.

<sup>63</sup> See CRS Report RL33880, *Older Americans Act: FY2008 Funding and FY2009 Funding Proposals*, by (name redacted).



In FY2005, transportation services provided more than 36.5 million rides to doctors' offices, grocery stores, senior centers, meal sites, and other critical daily activities. Personal care, homemaker, and chore services provided over 20 million hours of assistance to older adults to perform both ADLs and IADLs.<sup>64</sup> Case management services provided almost 4 million hours of assistance conducting needs assessment, developing care plans, and arranging services for older adults and their caregivers. Moreover, adult day health care provided over 7 million hours of care for dependent adults in a group setting for some portion of the day. For FY2008, funding for OAA supportive service programs is \$351.3 million.<sup>65</sup>

## **Ask Medicare**

In September of 2008, CMS launched a new initiative to assist family caregivers to Medicare beneficiaries titled "Ask Medicare." The initiative provides caregivers with easy access to useful information about Medicare and other essential health care information about services and available resources. This information can be accessed through a web-site for caregivers at <http://www.medicare.gov/caregivers>.□

## **Alzheimer's Disease Demonstration Grants to States (ADDGS)**

The Alzheimer's Disease Demonstration Grants to States (ADDGS) program provides competitive grants to help states plan and coordinate demonstration programs that address the specific needs of Alzheimer's patients, with particular focus on hard-to-reach and underserved persons with the disease. The program's mission is to expand the availability of diagnostic and support services for person's with Alzheimer's disease, their families, and caregivers. States may use funds to deliver respite care services that can directly benefit family caregivers, as well as supportive services (i.e., home health, personal care, day care, and companion services) that can indirectly benefit caregivers. The program is administered by the Administration on Aging (AoA) of the U.S. Department of Health and Human Services (HHS).

The program grant to states was created under the Older Americans Act (OAA) Amendments of 1987 (P.L. 100-175). However, there was no funding until 1992, after the program was reauthorized and expanded by the Home Health Care and Alzheimer's Disease Amendments of 1990 (P.L. 101-557). The Health Professions Education Partnerships Act of 1998 (P.L. 105-392) re-authorized funding for ADDGS for FY1998 through FY2002. While the program is currently unauthorized, Congress continues to appropriate funding. For FY2008, funding for ADDGS is \$11.5 million.<sup>66</sup>

## **Senior Companion Program (SCP)**

Title II-C of the Domestic Volunteer Service Act (DVSA, P.L. 93-113), as amended, establishes the Senior Companion Program (SCP). Administered by the Corporation for National and Community Service, SCP provides older adults with the opportunity to assist homebound, frail elderly, and other adults with disabilities. SCP volunteers offer companionship to care recipients,

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<sup>64</sup> Administration on Aging, *Fiscal Year 2008: Justification of Estimates of Appropriations Committees*, Department of Health and Human Services, 2008.

<sup>65</sup> Ibid.

<sup>66</sup> Ibid.

as well as help with transportation and a variety of in-home tasks, so that older individuals can remain independent in their homes. Volunteers can directly assist family caregivers by providing respite care. Other services, such as transportation to medical appointments, can indirectly benefit family caregivers. For FY2008, funding for SCP is \$46,144.<sup>67</sup>

## **Social Services Block Grant (SSBG)**

Title XX of the Social Security Act authorizes the SSBG block grant. SSBG directs funds to states for a broad array of social services. Direct services that states may make available to caregivers through SSBG include information and referral and respite care. Although respite services are not specifically mentioned in statute, they fall within the allowable social services that states may provide.<sup>68</sup> Services provided to persons with long-term care needs, including adult day care, home-delivered and congregate meals, and home-based services, such as homemaker, chore, home maintenance, and house management services, may also provide indirect benefits to caregivers.

The SSBG program is administered by the Administration for Children and Families (ACF). The ACF allocates funds to the states and territories, who then in turn determine whether services will be provided by state or local agency staff or through grants or contracts with private organizations. States have broad discretion in determining the use of SSBG funds. There are no federal eligibility requirements for SSBG activities. States may set their own criteria (with the exception of any SSBG funding that comes via a transfer from the Temporary Assistance for Needy Families [TANF] block grant; individuals served with TANF funds must be below 200% of the Federal Poverty Level).<sup>69</sup>

In 2006, SSBG fund allocations were \$1.70 billion and TANF transfers to SSBG were about \$944 million, for a total of \$2.77 billion in SSBG expenditures.<sup>70</sup> However, the services that provide direct and indirect support to caregivers are small, relative to total SSBG program expenditures. Furthermore, SSBG services are not exclusively targeted at caregivers or older adults and vary by state. For example, 2006 SSBG expenditures for home-based services, information and referral, and adult day care combined were less than 8% of total SSBG expenditures (see **Table 7**).

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<sup>67</sup> See CRS Report RL33931, *The Corporation for National and Community Service: Overview of Programs and FY2009 Funding*, by (name redacted) and Abigail B. Rudman.

<sup>68</sup> SSBG regulations include a list of 29 uniform definitions of service categories for which SSBG funds may be used, including “prevention and intervention services” and “special services for the disabled,” which include respite care.

<sup>69</sup> For further information, see CRS Report 94-953, *Social Services Block Grant (Title XX of the Social Security Act)*, by (name redacted).

<sup>70</sup> U.S. Department of Health and Human Services, Administration for Children and Families, Office of Community Services, *Social Services Block Grant Program: 2006*, at <http://www.acf.dhhs.gov/programs/ocs/ssbg/annrpt/2006/index.html>. (Hereinafter referred to as DHHS, *Social Services Block Grant Program: 2006*.)

**Table 7. Selected SSBG Expenditures, by Service, 2006**

SSBG Service Category	2006 Total SSBG Expenditures (millions)	Percentage of Total SSBG Expenditures	Number of States
Information and Referral	\$18.0	0.7%	22
Home-Based Services	\$182.1	6.6%	46
Adult Day Care	\$15.8	0.6%	24

**Source:** Adapted by CRS from DHHS, Social Services Block Grant Program: 2006, accessed at <http://www.acf.dhhs.gov/programs/ocs/ssbg/annrpt/2006/index.html>.

**Note:** Total SSBG expenditures includes SSBG expenditures and any expenditures made from TANF transfers; Number of states include states reporting SSBG expenditures and states reporting TANF transfers.

## Medicaid

The Medicaid program gives states the ability to cover services that can directly and indirectly assist family members who provide long-term care to an eligible beneficiary. Jointly funded by federal and state governments, Medicaid is a state-administered entitlement program that operates within broad federal guidelines. The program covers long-term care services in both institutional and home and community-based settings for eligible persons with disabilities of all ages and is intended to serve as a safety net for those who cannot afford the cost of care.

The majority of Medicaid home and community-based services are designed to help the beneficiary live and function independently in the community. One optional service under Medicaid that directly assists family caregivers is respite care. Respite care can provide direct assistance to caregivers who need a short break from caregiving responsibilities. States that choose to offer respite care may target this service to specific beneficiaries and limit the benefit amount available.

Another Medicaid program feature that states have experimented with is consumer-directed service delivery models. These programs often allow the consumer (i.e., the beneficiary) to hire family members to provide certain long-term care services. Thus, in some circumstances, family caregivers may be paid with Medicaid dollars to provide personal care services. Self-directed program models can assist family caregivers by providing some monetary compensation. Cash assistance to caregivers may help caregivers replace lost wages from unpaid time off work or continue to provide care in the care recipient's home rather than transferring the care recipient into an institution. Hiring family caregivers may increase the supply of direct care workers, particularly in rural and hard-to-service areas.<sup>71</sup>

Other Medicaid home and community-based services may indirectly benefit family caregivers by supplementing informal care provided to beneficiaries in the home or substituting some informal care for formal care. These services may have an indirect effect on family caregivers by relieving the strain and physical burden often associated with hands-on care to a disabled older family member while allowing the care recipient to remain in the home. Home and community-based

<sup>71</sup> For further information on consumer-directed care, see CRS Report RL32219, *Long-Term Care: Consumer-Directed Services Under Medicaid*, by (name redacted).

services may include personal care services, case management, homemaker/home health aide services, and adult day health, among other services.

## **Employment Policy**

To assist workers in balancing work and caregiving-related activities, Congress passed the Family and Medical Leave Act of 1993 (FMLA, P.L. 103-3). The FMLA makes it possible for workers who take time off to care for a parent, spouse, or child with a serious health condition to do so without fear of jeopardizing their jobs. The FMLA requires private employers with at least 50 employees employed within 75 miles, and public employers, regardless of size, to extend job-protected, unpaid leave to employees who meet length-of-service and hours-of-work eligibility requirements. Covered, eligible employees are entitled to 12 weeks of unpaid leave per year. Employees can also invoke FMLA to attend to their own serious health condition and to care for a newborn, newly adopted, or newly placed foster child.<sup>72</sup>

According to a U.S. Department of Labor survey conducted in the late 1990s, most employees reported attending to their own health as the predominant reason for taking leave under the act (48.7%). Only 10.6% of workers reported using the FMLA to care for a seriously ill parent.<sup>73</sup>

As of 2008, 45 states and the District of Columbia had enacted family and medical leave laws. Generally, the FMLA and state family and medical leave laws are similar with regard to the availability of leave, but can differ in terms of coverage and scope (e.g., cover small firms and other reasons for leave). In addition, some employers offer paid family and medical leave benefits. Because FMLA was intended to guarantee the minimum benefit, employees are entitled to the more favorable leave benefits offered under state law or by an employer.<sup>74</sup>

## **Tax Policy**

Tax provisions in current law provide benefits to some caregivers of older family members. Two tax provisions that provide direct benefits to employed family caregivers include the dependent care tax credit (DCTC) and the exclusion from income for employer-provided dependent care assistance programs (DCAP). Three provisions that provide indirect assistance to family caregivers, regardless of employment status, include (1) the dependancy exemption, (2) the head of household filing status, and (3) deductions for unreimbursed medical expenses. Rules regarding eligibility and other limitations sometimes restrict the use of these benefits.

### **Dependent Care Tax Credit (DCTC)<sup>75</sup>**

Caregivers may be eligible for a tax credit to offset some costs of formal care for a qualifying child or a disabled spouse or dependent. The qualifying child must be the taxpayer's dependent

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<sup>72</sup> For further information, see CRS Report RL31760, *The Family and Medical Leave Act: Current Legislative and Regulatory Activity*, by (name redacted).

<sup>73</sup> For further information, see CRS Report RL31755, *Family Caregiving to the Elderly by Employed Persons: The Effects on Working Caregivers, Employers, and Federal Policy*, by (name redacted).

<sup>74</sup> For further information, see CRS Report RL33710, *State Family and Medical Leave Laws*, by (name redacted) and (name redacted).

<sup>75</sup> Sec. 21 of the Internal Revenue Code.

and under age 13 when care was provided; the qualifying spouse or dependent of the taxpayer must be physically or mentally incapable of providing self-care and live with the taxpayer for more than half the tax year.<sup>76</sup> A special rule permits the disabled person to be classified as a dependent even if they have gross income of \$3,500 (i.e., the exemption amount in 2008) or more. The credit is limited to circumstances in which the child or dependent care is necessary for the taxpayer's employment. Dependent care may be provided by either a private individual (e.g., personal care, home health) or a dependent care center that meets state and local laws and regulations (e.g., adult day health center).

The DCTC is calculated as a percentage of qualified employment-related expenses. These expenses are limited to \$3,000 for one qualifying individual and to \$6,000 for two or more qualifying individuals. In addition, qualified expenses cannot exceed the earned income of the taxpayer. For married taxpayers, qualified expenses are limited to the earned income of the lesser earning spouse.<sup>77</sup> The credit rate is 35% for taxpayers whose adjusted gross income (AGI) does not exceed \$15,000, and is gradually reduced to 20% for taxpayers whose AGI is over \$43,000. For example, a married couple with a dependent frail parent living in their household, having an AGI of \$50,000 and \$3,000 in qualifying expenses, would be eligible for a credit of \$600 (i.e., \$3,000 x 20%).<sup>78</sup>

The DCTC is a nonrefundable tax credit, which means that the credit is limited by the taxpayer's regular income tax liability. A taxpayer whose tax liability is completely offset by his or her standard deduction and personal and dependent exemptions does not benefit from the credit. As a consequence, many lower income taxpayers cannot claim the credit. For example, in 2008, a married couple with one dependent does not benefit from the credit until their AGI exceeds \$21,400. They could not claim the full credit based on \$3,000 of qualifying expenses until their AGI reaches \$29,500. Depending on the couples' other deductions and exemptions, the income threshold could be even higher.

### **The Dependent Care Assistance Program (DCAP)<sup>79</sup>**

Caregivers who work for employers with a DCAP may exclude up to \$5,000 of earnings used for qualified dependent care expenses. The exclusion applies to income taxes and employment taxes. The definitions for qualified dependent care expenses and qualifying person are the same as the DCTC. The employer DCAP must be a written plan that meets certain rules for nondiscrimination among employees. Employers can provide day care themselves, provide direct payments to other providers, or reimburse employees for care they have arranged. Usually, DCAPs are funded under salary reduction agreements through a "cafeteria plan."<sup>80</sup> Like the DCTC, the amount of the

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<sup>76</sup> Persons who cannot dress, clean, or feed themselves because of physical or mental problems or who must have constant attention to prevent them from injuring themselves or others are considered not able to care for themselves. For further information, see Department of the Treasury, *Publication 503 Child and Dependent Care Expenses: For use in preparing 2007 Returns*, Internal Revenue Service, 2007.

<sup>77</sup> Exceptions are for a student spouse or disabled spouse.

<sup>78</sup> For further information, see CRS Report RS21466, *Dependent Care: Current Tax Benefits and Legislative Issues*, by (name redacted).

<sup>79</sup> Sec. 129 of the Internal Revenue Code.

<sup>80</sup> Cafeteria plans are employer-established benefit plans under which employees may choose between receiving cash (typically additional take-home pay) and certain normally nontaxable benefits (such as employer-paid health insurance) without being taxed on the value of the benefits if they select the latter. For further information, see CRS Report RL33505, *Tax Benefits for Health Insurance and Expenses: Overview of Current Law and Legislation*, by (name redacted) (continued...)

DCAP exclusion cannot exceed the earned income of the taxpayer or, in the case of a married couple, the earned income of the lower-paid spouse.

The DCAP limit of \$5,000 in qualifying expenses applies regardless of the number of qualifying individuals. For families with only one qualifying person, the DCAP can be more advantageous than the DCTC, for which the limit on qualifying expenses is \$3,000. Taxpayers can use both the DCTC and the DCAP in the same year, but not for the same expenses. Qualifying DCTC expenses must be reduced by the DCAP exclusion. Thus, if the married couple with the frail older parent also had a child under 13 living in their household and spent \$6,000 on care, they could use the DCAP for \$5,000 of the expenses and the DCTC for \$1,000 of the expenses (i.e., the \$6,000 maximum expenses for the DCTC minus \$5,000 excluded under the DCAP).<sup>81</sup>

Income tax savings from the DCAP depend on the taxpayer's marginal tax rate. For example, a taxpayer in the 10% tax bracket would save \$500 from a \$5,000 DCAP exclusion (i.e., \$5,000 x 10%), whereas a taxpayer in the 25% bracket would save \$1,250 (i.e., \$5,000 x 25%). In addition, they both would save \$383 in employment taxes (\$5,000 x 7.65%).

### **Exemptions for Dependents<sup>82</sup>**

Caregivers may be allowed a tax exemption for an older adult if they can claim him or her as a dependent. In general, to be a dependent, a person must be a qualifying child or a qualifying relative. The definition of a qualifying relative is defined broadly to include both relatives and non-relative household members. A qualifying relative could be a

- father, mother, or an ancestor or sibling of a father or mother (e.g., grandmother, grandfather, aunt, or uncle);
- brother, sister, or a son or daughter;
- child, stepchild, foster child, or a descendant of the child (e.g., grandchild);
- stepbrother, stepsister, stepfather, stepmother, son-in-law, daughter-in-law, father-in-law, mother-in-law, brother-in-law, or sister-in-law; or
- any other person (other than a spouse) who lived with the taxpayer all year as a household member, as long as the relationship did not violate local law.

To claim a qualifying relative as a dependent, the taxpayer must provide more than half of the person's support during the calendar year. Multiple support agreements permit one taxpayer to claim the dependent when several taxpayers together provide more than half of support. The qualifying relative must also have a gross annual income that is less than the exemption amount (i.e., \$3,500 in 2008).<sup>83</sup>

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(...continued)

and (name redacted).

<sup>81</sup> Ibid. For further information, see CRS Report RL31755, *Family Caregiving to the Elderly by Employed Persons: The Effects on Working Caregivers, Employers, and Federal Policy*, by (name redacted).

<sup>82</sup> Secs. 151 and 152 of the Internal Revenue Code.

<sup>83</sup> Department of the Treasury, *Exemption, Standard Deduction, and Filing Information*, Internal Revenue Service, Publication 501, 2007.

Tax savings from the dependent exemption depend on the taxpayer's marginal tax rate. A taxpayer in the 10% bracket would save \$350 (i.e., \$3,500 x 10%) by claiming a single dependent exemption. A taxpayer in the 25% bracket would save \$875 (i.e., \$3,500 x 25%).

### **Head of Household Status** <sup>84</sup>

Unmarried caregivers in some caregiving situations may be eligible for a more advantageous tax filing status. Generally, taxpayers who are unmarried must file as single taxpayers. However, unmarried taxpayers can claim the more favorable head of household filing status if they paid more than half the cost of keeping up a home and a qualifying person lived with them for more than half the year. A special rule permits an unmarried taxpayer who has a dependent parent to claim the head of household filing status even if the parent lives in a different household. The taxpayer must also pay more than half the cost of keeping up the home that was the parent's main home for the entire year; this includes paying more than half the cost of a rest home, or home for the elderly.

The head of household filing status is more advantageous than the single filing status. The standard deduction for a single taxpayer in 2008 is \$6,800, and for a head of household, \$9,350. In addition, the tax brackets are more favorable. For example, in 2008, for a single taxpayer, the 25% tax rate starts with a taxable income of \$32,550, but for the head of household, the tax rate starts with a taxable income of \$43,650.

### **Unreimbursed Medical Expenses** <sup>85</sup>

Caregivers may claim a tax deduction for unreimbursed medical expenses provided to a care recipient. Specifically, taxpayers who itemize their deductions may deduct unreimbursed medical expenses to the extent they exceed 7.5% of AGI. These expenses can be for the taxpayer, the taxpayer's spouse, or dependents. A special rule permits deductions for unreimbursed medical expenses for a qualifying dependent who has gross annual income of \$3,500 or more (in 2008).

Medical expenses must be primarily to alleviate or prevent a mental or physical illness, and do not include expenses for the benefit of general health. The former expenses include costs for equipment, supplies, and diagnostic devices needed for these purposes, in addition to dental expenses. Expenses also include health insurance premiums paid by the taxpayer and, in some cases, transportation to medical care, qualified long-term care costs, and long-term care insurance premiums that do not exceed certain limitations.

This deduction is not widely used. For most taxpayers, the standard deduction is larger than the sum of their itemized deductions; moreover, most do not have unreimbursed medical expenses that exceed 7.5% of AGI. In 2003, about one-third (34%) of all individual income tax returns had itemized deductions. Of these returns, less than 20% (about 6.7% of all returns) claimed a medical expense deduction.<sup>86</sup>

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<sup>84</sup> Sec. 2(b) of the Internal Revenue Code.

<sup>85</sup> Sec. 213 of the Internal Revenue Code.

<sup>86</sup> For further information, see CRS Report RL33505, *Tax Benefits for Health Insurance and Expenses: Overview of Current Law and Legislation*, by (name redacted) and (name redacted).

## Issues for Congress

As the nation prepares for the growing older population and likely increase in demand for long-term care services among the frail elderly, Congress will face a decision whether to expand the role of the federal government in providing direct support to family caregivers. Some policy makers may favor enhancing services and supports that provide either direct assistance or federal income tax relief to caregivers. In doing so, the federal government would devote additional funding to new or existing programs or reduce federal revenues, implying increasingly difficult tradeoffs between support to caregivers and federal programs that benefit other populations.

Alternatively, other policy makers may feel that greater state assistance to family caregivers is warranted, and that the federal government can best serve family caregivers by providing technical assistance to states in service planning and delivery. Still others may believe the federal government has a limited responsibility in assisting families who provide unpaid assistance, many by choice, to older individuals. Thus, Congress may decide that no additional federal assistance can be made available to help family caregivers. In this case, federal policy makers may want to evaluate how best to spend existing funds.

This section briefly describes three sets of policies that would expand or enhance the federal government's role in providing direct assistance to family caregivers to older adults. These policy issues, which have either received recent congressional attention or otherwise been the subject of discussion among federal policy makers and other interested stakeholders, are organized into the following topics: enhancing and expanding caregiver services and supports, assisting employed caregivers through flexible workplace accommodations and income security, and providing caregivers with opportunities for additional tax credits.

## Caregiver Services and Supports

Many family caregivers identify the need for enhanced services and supports that can help them with their current caregiving responsibilities and provide further information assistance as caregiving demands change over time. Policy makers indicate that services such as respite care can improve care quality, avoid burnout, and allow caregivers to continue providing informal care to an older relative, thus potentially avoiding or delaying unnecessary institutionalization. Proponents of increased federal funding for services and supports to caregivers have indicated the need for enhanced education and training for caregivers so that they can develop the skills necessary to provide quality care to a frail elderly population. Others have suggested targeting services and supports to those caring for individuals with specific illnesses or disease, such as Alzheimer's.

Advocates have also suggested adding an assessment of the caregiver's needs to the existing eligibility determination and assessment processes for public benefits.<sup>87</sup> The caregiver assessment process would identify and link appropriate services and support for family caregivers. These services could provide back-up support, in cases of emergency, counseling, or respite care. Caregiver assessments would also elicit information about the caregiver's health, willingness to

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<sup>87</sup> Lynn Friss Feinberg et al., "Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support," AARP Public Policy Institute (Washington, DC, March 2006).



provide care, and training and support needs. Through the assessment process family caregivers could learn about the resources available to them in their communities.

## **Workplace Accommodations and Income Security**

Employed family caregivers often face disruptions in their work patterns as a result of elder care responsibilities. These disruptions may include arriving to work late or leaving early, taking time off during the day, reducing the number of hours worked from full-time to part-time status, or taking a leave of absence. Major changes to employee work schedules and work disruptions can affect income and job security. Those who do leave the workforce to care for an older disabled family member have less opportunity to save or accrue benefits over their lifetime, which may leave them economically vulnerable in retirement.

Workplace accommodations that allow employees to take unpaid leave for the purposes of assisting with the long-term care needs of older relatives can directly assist caregivers. Requiring employers to provide paid time off to their employees to care for the medical needs of certain family members may assist in alleviating some of the financial burden associated with caring for an older family member. Federal policies that support flexible workplace accommodations may prevent individuals from leaving the workforce altogether. Publicly funded programs that allow payment of family caregivers through consumer-directed service delivery models may provide caregivers with some income security.

## **Tax Credits**

As previously mentioned, for many family caregivers, providing assistance to a frail older individual can impose a substantial financial burden. Targeted tax relief to caregivers could offset some of the direct expenses associated with caregiving, including transportation for long-distance caregivers, purchase of assistive devices and technology (i.e., grab bars, bed rails, emergency response systems) or home modifications (i.e., wheel chair ramps, shower stalls) that can assist with the delivery of personal care, dietary supplements for the care recipient, adult day health care, and other medical or health-related services and products.

Additional tax relief measures that would directly assist families caring for a disabled older individual include a targeted tax credit to caregivers. Other tax policies that would directly assist family caregivers would expand on current tax relief measures by broadening the taxpayer population eligible for these benefits. For example, expanding the dependent definition under the DCTC to include disabled older relatives who do not live with the taxpayer may include additional eligible taxpayers. Other policy proposals have included expanding the definition of dependent care expenses to include eldercare-related expenses and services.

## Appendix. Summary of Federal Programs and Initiatives Offering Direct and Indirect Benefits to Caregivers

**Table A-1. Federal Programs and Initiatives Offering Direct and Indirect Benefits to Caregivers: Eligibility, Services, and Scope of Benefit**

Program/Initiative	Eligibility	Service(s)/Benefit(s) and Scope
<b>Older Americans Act</b>		
National Eldercare Locator Service	Persons aged 60 and older, and caregivers of any age.	Information and referral services. (D)
Aging and Disability Resource Centers (ADRCs)	Initially grantee states must target resource services to the elderly with disabilities and at least one additional population with disabilities (i.e., adults with physical disabilities, mentally ill, and/or persons with mental retardation/developmental disabilities), and caregivers of any age.  The goal is to serve all individuals with long-term care needs regardless of their age or disability, and their caregivers.	Information and referral services. (D)  Resource services offered vary by state and may be made available on a less-than-statewide basis.
Home and Community-Based Supportive Services	Persons aged 60 and older. No means test, but services are to be targeted to those with greatest social or economic need, with particular attention to those with low-income, minority older persons, those residing in rural areas, those at-risk of institutionalization, and those with limited English-speaking proficiency.  States may establish service guidelines, such as functional eligibility criteria for personal care, homemaker, and chore services. However, guidelines must be consistent with federal statutes and regulations.	Personal care services, homemaker and chore services. (I)  Services offered vary by state.

Program/Initiative	Eligibility	Service(s)/Benefit(s) and Scope
National Family Caregiver Support Program (NFCSP)	<p>Priority given to: caregivers aged 60 and older; caregivers to those with severe disabilities (including children with severe disabilities); and, caregivers providing assistance to older persons with Alzheimer's disease and related neurological disorders.</p> <p>No means test, but services are to be targeted to those with greatest social or economic need, with particular attention to those with low-income, minority older persons, those residing in rural areas, those at-risk of institutionalization, and those with limited English-speaking proficiency.</p>	<p>Information and referral; access assistance; counseling, support groups, caregiver training; respite care services, supplemental services. (D)</p> <p>Services offered vary by state.</p>
<b>Alzheimer's Disease Demonstration Grants to States</b>		
ADDGS	<p>No federal eligibility criteria; State grantees have discretion to develop demonstration programs that are specific to their needs and resources.</p> <p>Program funds are intended to target persons with Alzheimer's disease and related disorders (i.e., dementia), with a focus on hard-to-reach and underserved persons with the disease</p>	<p>May include respite care. (D)</p> <p>May include home health, personal care, day care, and companion services, among other services. (I)</p> <p>Services, if offered, vary by grantee states.</p>
<b>Domestic Volunteer Service Act</b>		
Senior Companion Program (SCP)	<p>Senior volunteers must be aged 60 or older and meet income eligibility requirements. Volunteers must be able to serve at least 15 hours a week. Participants receive a stipend of \$2.65 an hour.</p> <p>Care recipients are frail older adults, adults with disabilities, and those with terminal illnesses who are homebound.</p>	<p>Respite care. (D)</p> <p>Homemaker services, chore services, transportation, and companionship. (I)</p>
<b>Title XX of the Social Security Act</b>		
Social Services Block Grant (SSBG)	<p>No federal eligibility criteria; states have discretion to set their own criteria.</p> <p>No means test, but services are intended to be distributed to individuals with greatest economic or social need; particular attention is given to low-income older individuals.</p>	<p>Information and referral, respite care. (D)</p> <p>Personal care services, homemaker services, chore services, home maintenance services, and household management services, adult day care, home-delivered and congregate meals. (I)</p> <p>Services offered vary by state.</p>
<b>Title XIX of the Social Security Act</b>		

Program/Initiative	Eligibility	Service(s)/Benefit(s) and Scope
Medicaid Home and Community-Based Services	These criteria vary by state.  States may limit the number of individuals who can receive these services.	Respite care. (D)  Includes case management, homemaker/home health aide services, personal care, adult day health, habilitation, and respite care, among others. (I)  Services offered vary by state. Service package may vary by beneficiary population. Services may be made available on a less-than-statewide basis.
<b>Family and Medical Leave Act</b>		
FMLA	Employees working for a private employer with at least 50 employees employed within 75 miles, or for a public employer, regardless of size, who worked for at least 12 months (not necessarily consecutive), and a minimum of 1,250 hours (excluding paid or unpaid leave time) in the 12 months preceding the start of their FMLA leave.	Up to 12 weeks of job-protected, unpaid leave per year to take care of a serious personal health condition, to care for a spouse, child, or parent with a serious health condition, or to care for a newborn, newly adopted, or newly placed foster child. (D)  FMLA guarantees a minimum benefit. Employees are entitled to more favorable leave benefits offered under state law, by an employer, or through a collective bargaining agreement.
<b>Tax Provisions</b>		
Dependent Care Tax Credit (DCTC), Sec. 21	Employed taxpayers with qualifying child or a disabled spouse or dependent.	Tax credit calculated as a percentage of qualified employment-related expenses, limited to \$3,000 for one qualifying individual, and \$6,000 for two or more qualifying individuals. (D)  Federal tax provision.
Dependent Care Assistance Program (DCAP), Sec. 129	Employed taxpayers with qualifying child or a disabled spouse or dependent.	Excludes up to \$5,000 of earnings used for qualified dependent care expenses (exclusion applies to income taxes and employment taxes). (D)  Federal tax provision.
Exemptions for Dependents, Secs. 151 and 152.	Taxpayers can claim a qualifying relative as a dependent if the taxpayer provided more than half of the person's support during the calendar year, and the qualifying relative must have a gross annual income that is less than \$3,500 in 2008.	Tax savings depend on the taxpayer's marginal tax rate. (I)  Federal tax provision.

Program/Initiative	Eligibility	Service(s)/Benefit(s) and Scope
Head of Household Status, Sec. 2(b)	<p>Taxpayers who are unmarried can claim the more favorable head of household filing status if they paid more than half the cost of keeping up a home;</p> <p>AND</p> <p>a qualifying person lived with them for more than half the year.</p> <p>A special rule permits an unmarried taxpayer who has a dependent parent to claim the head of household filing status even if the parent lives in a different household.</p>	<p>More advantageous than the single filing status and more favorable tax brackets. (I)</p> <p>Federal tax provision.</p>
Unreimbursed Medical Expenses, Sec. 213	Taxpayers who itemize their deductions.	<p>Deductions for unreimbursed medical expenses for the taxpayer, the taxpayer's spouse, or dependents to the extent they exceed 7.5% of Adjusted Gross Income (AGI). (I)</p> <p>Federal tax provision.</p>

**Source:** Table compiled by CRS.

**Note:** (D) = Services that may directly benefit caregivers; (I) = Services that may indirectly benefit caregivers; (D/I) = Services that may directly and indirectly benefit caregivers.

This report will be updated as warranted.

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