



## CRS Report for Congress

# Family Caregiving to the Older Population: Recent and Proposed Legislation

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### Summary

It is estimated that about 5.5 million adults aged 65 and older, or 16% of the U.S. population 65 and older, receive long-term care services and supports.<sup>1</sup> Of those older Americans who receive long-term care, most receive some form of informal, or unpaid, care primarily provided by spouses and adult children.<sup>2</sup> Many believe that the demand for family caregiving is likely to increase with further increases in life expectancy and the aging of the baby-boom generation. At the same time, demographic trends such as reduced fertility, increased divorce rates, and greater labor force participation among women lead some to believe that the number of available caregivers, as well as the capacity for caregivers to provide needed care to older individuals may be declining. Although the federal government has established some programs and services to support family caregivers, policy makers have identified the need for additional federal benefits. This report briefly describes legislation enacted in the 109<sup>th</sup> Congress and proposals introduced in the 110<sup>th</sup> Congress that directly assist family caregivers (H.R. 1032, H.R. 1161, H.R. 1369, H.R. 1542, H.R. 1560, H.R. 1807, H.R. 1871, H.R. 1911, H.R. 2244, H.R. 2392, H.R. 2792, H.R. 6029, H.R. 6390, H.R. 6448, H.R. 6665, H.R. 7233, S. 614, S. 897, S. 898, S.910, S. 1340, S. 1681, S. 2121, and S. 2267).

Family caregiving to older individuals in need of long-term care encompasses a wide range of activities including assistance with personal care needs, such as bathing, dressing, or eating, as well as other activities that are necessary for independent living, such as shopping, medication management, and meal preparation. In addition, family caregivers may support older family members in accessing the health care and social

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<sup>1</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 CRS calculations based on unpublished tabulations from the 1999 National Long Term Care Survey by Brenda C. Spillman, the Urban Institute, 2003.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 Carol O'Shaughnessy, Julie Stone, Laura B. Shrestha, and Thomas Gabe.

<sup>2</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 analysis of the National Long Term Care Survey, 1999.

services systems, communicate with providers and insurers, and advocate for the care recipient. Family caregivers may also arrange, supervise, or pay for formal care to be provided to the care recipient.<sup>3</sup>

Recognizing family caregivers as an important part of the nation's long-term care delivery system, the federal government established the National Family Caregiver Support Program (NFCSP) in 2000, under Title III of the Older Americans Act (OAA, P.L. 106-501). The NFCSP provides services that are directly targeted to family caregivers, including information and referral services; counseling, support groups, and caregiver training; respite care services; and supplemental services on a limited basis (e.g., adult day care, home care, home modifications).<sup>4</sup> For FY2008, NFCSP funding accounts for \$153.4 million, or 8% of total OAA expenditures.<sup>5</sup>

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 assistance to family caregivers. Some policy makers favor enhancing services that provide direct support or expanding the availability and amount of federal income tax relief to caregivers, while others believe the federal government has a limited responsibility in assisting families who provide unpaid assistance, many by choice, to older individuals. The following describes legislation enacted in the 109<sup>th</sup> Congress and proposals in the 110<sup>th</sup> Congress that would provide new benefits or enhance and expand existing federal benefits and services to assist family caregivers.

## Recently Enacted Legislation

The following summarizes legislation enacted in the 109<sup>th</sup> Congress to directly assist family caregivers to older adults. Recently enacted legislation includes the Lifespan Respite Care Act (P.L. 109-442) and new provisions under Title III, Part E of the OAA pertaining to the NFCSP that were included in the reauthorization of the OAA (P.L. 109-365).

**Lifespan Respite Care Act.** In an effort to expand federal support of respite services for family caregivers caring for individuals of all ages, the 109<sup>th</sup> Congress passed the Lifespan Respite Care Act of 2006. The law defines "respite care" to mean planned or emergency care provided to a child or adult of any age with a special need in order to give temporary relief to the family caregiver. The Lifespan Respite Care Act authorizes appropriations totaling \$289 million for FY2007 through FY2011. However, Congress did not fund these activities for FY2007 or FY2008. Thus, implementation of the law is contingent on future appropriations.

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<sup>3</sup> CRS Report RL34123, *Family Caregiving to the Older Population: Background, Federal Programs, and Issues for Congress*, by Kirsten Colello.

<sup>4</sup> For additional information on NFCSP, see CRS Report RL34123.

<sup>5</sup> See CRS Report RL33880, *Older Americans Act: FY2008 Funding and FY2009 Funding Proposals*, by Angela Napili.

The Lifespan Respite Care Act authorizes the Secretary of the Department of Health and Human Services (HHS) to award matching grants to eligible state agencies to: (1) develop or enhance lifespan respite care activities at the state and local levels, (2) improve the statewide dissemination and coordination of respite care, and (3) provide, supplement, or improve access and quality of respite care services to family caregivers caring for children and adults.

The law also instructs the Secretary of HHS to ensure coordination of respite care services for family caregivers by working with the NFCSP and other respite care programs within HHS. P.L. 109-442 authorized a National Resource Center on Lifespan Respite Care, which, among other responsibilities, would provide training and technical assistance to state, community, and nonprofit respite care programs, and offer public information, referral, and educational programs on lifespan respite care.

**National Family Caregiver Support Program.** The Older Americans Act (OAA) gives priority for NFCSP services to caregivers who are older individuals (i.e., those aged 60 and older) with greatest economic or social need, and with particular attention to low-income older individuals. The 109<sup>th</sup> Congress amended the OAA to clarify that priority for NFCSP services is also given to older individuals who are providing care to persons with severe disabilities (including children with severe disabilities). P.L. 109-365 also required the state to give priority to those caregivers providing assistance to persons aged 60 and over with Alzheimer's disease and related neurological disorders.

## Proposed Legislation

The following identifies bills in the 110<sup>th</sup> Congress that would expand or enhance the federal government's role in providing direct assistance to family caregivers. These laws and proposals are organized into the following sections: (1) enhancing and expanding caregiver services and supports, (2) assisting employed caregivers through flexible workplace accommodations and income security policies, and (3) providing caregivers with opportunities for additional tax credits.

**Caregiver Services.** Many family caregivers identify the need for enhanced services that can help them with their current caregiving responsibilities and provide further information or assistance as caregiving demands change over time. Research suggests that providing support for services to family caregivers can reduce caregiver stress, avoid burnout, and allow family members to continue providing informal care to an older relative, thus potentially avoiding or delaying unnecessary institutionalization.<sup>6</sup> As previously mentioned, one federal program, the NFSCP, provides services that directly assist family caregivers to older individuals. Other federal programs, may provide benefits to assist family caregivers, however, they may have eligibility restrictions, or limitations on the amount and duration of covered services. Proposals to expand services to caregivers include, but are not limited to, increased funding to the NFCSP, national

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<sup>6</sup> Brenda C. Spillman and Sharon K. Long, "Does High Caregiver Stress Lead to Nursing Home Entry?" Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, January 26, 2007.

resource centers or call centers for caregivers, targeted services to assist those caring for individuals with Alzheimer's disease.

Two bills (S. 2121/Senator Robert Menendez, S. 2267/Senator Amy Klobuchar) would amend the OAA to increase funding for the NFCSP to \$250 million for each of FY's 2008 through 2011. In addition, S.2267 would also establish a National Resource Center on Family Caregiving to provide information, education, and support to family caregivers. S. 898/H.R. 1560 (Senator Barbara Mikulski/Representative Edward J. Markey) would, among other things, authorize the Alzheimer's 24/7 Call Center, which provides caregivers with crisis assistance and decision-making support, as well as referrals to local community programs and services.<sup>7</sup> The bill would also increase funding authorization for the Alzheimer's Disease Demonstration Grants to States (ADDGS) program from \$12 million in FY2007 to \$20 million in each of FY's 2008 through 2012.<sup>8</sup> States may use ADDGS funds to deliver respite care or other services that can directly support caregivers (i.e., personal care, day care, and companion services) that can indirectly benefit caregivers.

Other bills would provide funding for caregiver training and education. Reintroduced in the 110<sup>th</sup> Congress, H.R. 1032 (Representative Maxine Waters), would make grants to public and private health care providers, including senior centers and area agencies on aging, to provide training and support services for families and caregivers of Alzheimer's patients, among other things. S. 1340/H.R. 2244 (Senator Blanche L. Lincoln/Representative Gene Green) would offer family caregiver education and counseling as part of a proposed chronic care assessment and coordination benefit under Medicare. The bill would also include family caregivers in the process of planning and implementing beneficiaries' care plans.

**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. Some proposals have suggested different approaches that would broaden the Family Medical Leave Act (FMLA, P.L. 103-3) to make the law's requirements an option for more employees. Examples of these approaches, described below, include expanding FMLA eligibility, broadening the care recipient group, and expanding the type of activities for which FMLA can be taken.

Under current law, 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 invoke FMLA to attend to their own serious health condition and to care for a newborn, newly adopted, or newly placed foster child. The

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<sup>7</sup> On August 3, 2007, S. 898 was reported by the Senate Committee on Health, Education, Labor, and Pensions with an amendment in the nature of a substitute and placed on the Senate calendar.

<sup>8</sup> For FY2008, the ADDGS program was funded at \$11.5 million.

FMLA also makes it possible for covered 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.

Two proposals would broaden FMLA eligibility by lowering the threshold for coverage of private sector employers from 50 to 25 or 15 employees (H.R. 1369/Representative Carolyn Maloney and H.R. 2392/Representative Lynne Woolsey, respectively).<sup>9</sup> Another proposal would eliminate the hours-of-work eligibility requirement (H.R. 6029/Representative Tammy Baldwin), which states that an employee must have at least 1,250 hours of employment during the 12-month period prior to the leave request, replacing it with an employment requirement of at least 12 months by a covered employer prior to the leave request.

One proposal (H.R. 2792/Representative Carolyn Maloney) would assist family caregivers by broadening the care recipient groups under the FMLA statute beyond the employee's own parent, spouse, or child to include elderly relatives such as a parent-in-law or grandparent, in addition to other individuals (e.g., domestic partner, non-disabled children aged 18 or older). Another bill, H.R. 7233 (Representative Carolyn Maloney) would assist family caregivers by expanding the type of activities for which FMLA can be taken, such as allowing leave for transporting older relatives to medical and dental appointments and for visiting them in nursing or group homes.

Yet other workforce related proposals would require employers to provide paid time off to their employees for their own medical needs or to care for the medical needs of certain family members. Two bills (S. 910/Senator Edward M. Kennedy, H.R. 1542/Representative Rosa L. De Lauro) would require certain employers to provide minimum paid sick leave benefits to eligible workers. S. 1681 (Senator Chris Dodd) uses employer and employee contributions to create a trust fund that would partially compensate eligible workers on job-protected leave for FMLA reasons. Other proposals, H.R. 1369 and H.R. 2392, mentioned above, would also authorize grants to state and local governments for wage replacement for eligible individuals who take leave from employment to respond to family caregiving needs.

Another type of proposal is directed at assisting those who leave the workforce to care for an older disabled family member. These individuals may have less opportunity to save or accrue benefits over their lifetimes, which may leave them economically vulnerable in retirement. One proposal designed to alleviate the long-term financial affects for caregivers would amend the Social Security Act with respect to determining entitlement for Old Age, Survivors and Disability Insurance (OASDI). H.R. 1161 (Representative Nita M. Lowey) would deem an individual to have been paid a wage (according to a specified formula) for each month during which the individual provided care to a dependent relative, of any age, for at least 80 hours without monetary compensation, for a maximum of five years.

**Tax Credits.** Policy makers have also suggested additional tax relief that would directly assist families caring for an older individual in need of long-term care. Several

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<sup>9</sup> For further information, see CRS Report RL31760, *The Family and Medical Leave Act: Recent Legislative and Regulatory Activity*, by Linda Levine.

bills would provide a tax credit to directly assist family caregivers. These proposals vary in terms of the size of the tax credit, any income limitations in determining the amount of the credit, whether the credit is phased-in over time, the amount of applicable individuals, and whether the tax credit is refundable or non-refundable (i.e., limited to the taxpayer's liability).

For example, S. 897 (Senator Barbara Mikulski) and H.R. 1807 (Representative Eddie Bernice Johnson), would allow for a phased-in non-refundable tax credit for family caregivers, among other things. The tax credit would amount to \$1,000 in 2007, increasing to a maximum of \$3,000 in 2011. S. 2267 would allow caregivers a non-refundable tax credit of up to \$6,000 for eldercare expenses for their parents. Yet another bill, H.R. 6665 (Representative J. Gresham Barrett) would provide caregivers a \$3,000 non-refundable tax credit for up to two qualifying family members. Other proposals would provide refundable tax credits. S. 2121 would allow a phased-in refundable tax credit for family caregivers, among other things. The tax credit would amount to \$2,500 in 2008, increasing to a maximum of \$3,000 in 2010. H.R. 6448 (Representative Christopher P. Carney) would provide a refundable tax credit of \$2,500 to family caregivers for each applicable family member, while H.R. 6390 (Representative Corrine Brown) would provide caregivers with a \$3,000 refundable tax credit for up to two family members with long-term care needs.

Policymakers have also suggested changes to the Dependent Care Tax Credit (DCTC) and the Dependent Care Assistance Program (DCAP) which would expand either the tax credit amount or the eligible dependent population.<sup>10</sup> The DCTC provides eligible taxpayers a credit to offset some costs of formal care for a qualifying child or a disabled spouse or other dependent. The DCTC is limited to circumstances in which the care is necessary for the taxpayer's employment. The Dependent Care Assistance Program (DCAP) which allows caregivers who work for employers with a DCAP to exclude up to \$5,000 of earnings used for qualified dependent care expenses. The DCAP limit of \$5,000 in qualifying expenses applies regardless of the number of qualifying individuals.

Three bills, H.R. 1911 (Representative Joe Donnelly), H.R. 6390 (Representative Corrine Brown), and S. 614 (Senator Charles E. Schumer), include provisions to expand the DCTC to taxpayers with caregiving expenses for a parent or grandparent who does not live with the taxpayer. Another bill, H.R. 1871 (Kirsten E. Gillibrand), would increase the tax credit rate to 40% of qualified employment-related expenses for taxpayers with adjusted gross incomes (AGIs) of \$100,000 or less. H.R. 5655 (Representative Anthony D. Weiner) would increase the dollar limitation on employment-related expenses that qualify for the tax credit for the DCTC from \$3,000 to \$6,000 as well as make the tax credit refundable. The bill would also expand eligibility by repealing the requirement that the taxpayer and dependent share the same residence and requiring that qualifying retirees be eligible for such credit. One proposal, (H.R. 6448) would increase the DCAP tax credit by applying the \$5,000 limit to each qualifying individual, up to a maximum of 4 individuals.

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<sup>10</sup> For further information on the DCTC and DCAP, see CRS Report RS21466, *Dependent Care: Current Tax Benefits and Legislative Issues*, by Christine Scott; for information on the DCTC and DCAP as it applies to family caregivers, see CRS Report RL34123.