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CRS Report for Congress

Family Caregiving to the Older Population: Legislation Enacted in the 109th Congress and Proposals in the 110th Congress

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Summary

Family caregivers fulfill the majority of the need for long-term care provided to older persons with chronic disabilities in the United States. Among those older Americans receiving long-term care, the overwhelming majority receive some form of informal, or unpaid, care primarily provided by spouses and adult children. Family caregiving encompasses a wide range of activities, including assistance with personal care needs, medication management, and coordination with other health care professionals. For many, caregiving is a rewarding experience; however, for some, caregiving can lead to emotional and physical strain, as well as financial hardship. As demand for caregiving to the older population is likely to increase, certain demographic factors may limit the number of family caregivers and their capacity to provide care. Although the federal government has established programs and services for family caregivers, policy makers have identified the need for additional federal benefits. This report briefly describes legislation enacted in the 109th Congress and proposals introduced in the 110th 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, S. 614, S. 897, S. 898, S.910, S. 1340, S. 1681, and S. 2267). This report will be updated upon significant legislative activity.

Background

Family caregivers fulfill the majority of the need for long-term care provided to older persons with chronic disabilities in the United States. 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.[1] The overwhelming majority (90%) receive

[1] CRS calculations based on unpublished tabulations from the 1999 National Long Term Care Survey by Brenda C. Spillman, the Urban Institute, 2003.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 (continued...)

informal, or unpaid, care — primarily provided by spouses and adult children — either alone or in combination with formal, or paid, care.[2]

Family caregiving to older individuals in need of long-term care encompasses a wide range of activities, services, and supports. Caregiving activities can include 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 assist older family members with accessing the health care and social 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.[3]

While 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, or 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. Moreover, 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.[4]

Many believe that the demand for family caregiving to the older population is likely to increase with further increases in life expectancy and the aging of the baby-boom generation. However, others caution that 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.

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, including respite care, education and training, tax

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[1] (...continued)
Report RL33919, *Long-Term Care: Consumers, Providers, Payers, and Programs*, by Carol O'Shaughnessy, Julie Stone, Laura B. Shrestha, and Thomas Gabe.

[2] 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.

[3] CRS Report RL34123, *Family Caregiving to the Older Population: Background, Federal Programs, and Issues for Congress*, by Kirsten Colello (hereinafter referred to as CRS Report RL34123).

[4] 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 (hereinafter referred to as Spillman and Long, *Does High Caregiver Stress Lead to Nursing Home Entry?* 2007).

credits, and cash assistance.[5] 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 favor enhancing services and supports that provide either direct assistance or 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 past few Congresses have enacted legislation and introduced several bills that would provide new benefits or enhance and expand existing federal benefits and services to assist family caregivers.

Legislation in the 109th and 110th Congresses

The following summarizes legislation enacted in the 109th Congress to directly assist family caregivers to older adults and identifies bills in the 110th 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:

- enhancing and expanding caregiver services and supports,
- assisting employed caregivers through flexible workplace accommodations and income security policies, 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 or assistance as caregiving demands change over time. Research provides support for services to family caregivers that 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.[6]

In an effort to expand and enhance respite services to family caregivers at the federal level, the 109th Congress passed the Lifespan Respite Care of Act of 2006. Signed by President Bush on December 21, 2006 (P.L. 109-442), 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 provide temporary relief to the family caregiver. The Lifespan Respite Care Act authorizes appropriations totaling $289 million for FY2007 through FY2011. However, Congress did not provide any funds for FY2007 or FY2008. Thus, implementation of the law is contingent on future appropriations.

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

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[5] CRS Report RL34123.

[6] Spillman and Long, *Does High Caregiver Stress Lead to Nursing Home Entry?* 2007.

- develop or enhance lifespan respite care activities at the state and local levels,
- improve the statewide dissemination and coordination of respite care, and
- 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 National Family Caregiver Support Program (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 information, referral, and educational programs on lifespan respite care to the public.

Legislation enacted in the 109th Congress and family caregiver legislation proposals in the 110th Congress have sought to target services and supports to those caring for an individual with physical disabilities, Alzheimer's disease, or other chronic conditions. 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 109th Congress amended the OAA (P.L. 109-365) 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.[7]

Introduced in the 110th Congress, S. 898/H.R. 1560 (Mikulski/Markey) would, among other things, 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.[8] It also would 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. 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.

Reintroduced in the 110th Congress, H.R. 1032 (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

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[7] The NFCSP provides direct services for caregivers, including information and assistance accessing available long-term care services; individual counseling, support groups, and caregiver training; respite care services to provide families temporary relief from caregiving responsibilities; and supplemental services on a limited basis (e.g., adult day health care, home care, home modifications, incontinence supplies, nutritional supplies, assistive devices). For further information on the NFCSP, see [http://www.aoa.gov/prof/aoaprog/caregiver/overview/overview_caregiver.asp].

[8] For FY2008, the ADDGS program was funded at $11.5 million.

patients, among other things. Another bill, S. 2267 (Klobuchar), would amend the OAA to increase funding for the NFCSP to $250 million for each of FY's 2008 through 2011.[9] The bill would also establish a National Resource Center on Family Caregiving to provide information, education, and support to family caregivers. S. 1340/H.R. 2244 (Lincoln/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. The following proposals can directly assist family caregivers by allowing for workplace accommodations or providing income security to current employees and retirees.

Several proposals have suggested broadening the Family Medical Leave Act (FMLA, P.L. 103-3) to make the law's requirements an option for more employees. 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 also invoke FMLA to care for a newborn, newly adopted, or newly placed foster child and to attend to their own serious health condition. The FMLA 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 introduced in the 110th Congress would broaden FMLA eligibility by lowering the threshold for coverage of private sector employers from 50 to 25 or 15 employees (H.R. 1369/Maloney and H.R. 2392/Woolsey, respectively).[10] Other proposals would directly assist family caregivers. Reintroduced in the 110th Congress, H.R. 2792/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). Introduced in the 108th Congress, H.R. 956 (Maloney) would have assisted 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.

Other legislative 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

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[9] For FY2008, the NFCSP was funded at $153.4 million.

[10] For further information, see CRS Report RL31760, *The Family and Medical Leave Act: Recent Legislative and Regulatory Activity*, by Linda Levine.

members. Reintroduced in the 110th Congress, S. 910/H.R. 1542 (Kennedy/De Lauro) would require certain employers to provide minimum paid sick leave benefits to eligible workers. S. 1681 (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.

Those who leave the workforce to care for an older disabled family member 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 (Lowey), reintroduced in the 110th Congress, 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 measures that would directly assist families caring for a disabled older individual. Tax provisions include targeted tax relief to family caregivers and broadening the dependent definition under the Dependent Care Tax Credit (DCTC).[11] In the past three Congresses, several bills have been introduced that would provide a tax credit to directly assist family caregivers. In the 110th Congress, S. 897/H.R. 1807 (Mikulski/Johnson) would allow a phased-in income tax credit for family caregivers of spouses and dependents who have long-term care needs, among other things. The tax credit would amount to $1,000 in 2007, increasing to a maximum of $3,000 in 2011. S. 2267 (Klobuchar) would allow caregivers a tax credit of up to $6,000 for eldercare expenses for their parents.

Other proposals have suggested changes to the DCTC. These changes would expand either the tax credit amount or the eligible dependent population. Two bills in the 110th Congress, H.R. 1911 (Donnelly) and S. 614 (Schumer), include provisions to expand the DCTC to taxpayers with caregiving expenses for a physically or mentally incapacitated parent or grandparent who does not live with the taxpayer. Another bill, H.R. 1871 (Gillibrand), would increase the tax credit to 40% of qualified employment-related expenses for taxpayers with adjusted gross incomes (AGIs) of $100,000 or less. Past proposals have included expanding the definition of dependent care expenses to include eldercare-related expenses and services (109th Congress, S. 1826/Kohl).

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[11] The DCTC provides eligible taxpayers a tax credit to offset some costs of formal care for a qualifying child or a disabled spouse or dependent. The DCTC is limited to circumstances in which the child or dependent care is necessary for the taxpayer's employment (Sec. 21 of the Internal Revenue Code). For further information on the DCTC, see CRS Report RS21466, *Dependent Care: Current Tax Benefits and Legislative Issues*, by Christine Scott; for information on the DCTC as it applies to family caregivers, see CRS Report RL34123.