Federal and State Family Caregiving Legislation:  
A Summary of Bills from 2004-2006

As the U.S. population ages, the challenges and pressures of family caregiving are an increasing reality of daily life for America’s families. Family and informal (i.e., friends and neighbors) caregivers are the primary source of help to older people and adults with chronic, disabling conditions. Although unpaid family caregivers are the backbone of our long-term care system in the U.S., the significance of their role – and their own care-related stress, financial strain and compromised health – is often overlooked. In recent years, lawmakers have begun to recognize family caregiving as a growing public issue. If family and informal caregivers are going to be able to provide good care, keep their loved ones living at home or in the community rather than institutions, and take good care of their own health and maintain quality of life, they need assistance. Caregivers may need specialized information about diseases/disorders and care strategies, education and training, respite care, emotional support, family leave in the workplace, and/or financial assistance.

In response, many states have become innovators in designing and financing diverse strategies to support family caregivers. States are also moving toward rebalancing their long-term care systems away from institutional care and toward strengthening home and community-based services which intensifies reliance on family care. The federal government has also provided some assistance to family caregivers, largely through the Older Americans Act’s National Family Caregiver Support Program (NFCSP) that was created in 2000, the Family and Medical Leave Act (FMLA) of 1993, and through Medicaid Home and Community-Based Services (HCBS) waiver programs that include respite care for family caregivers.

The Last Three Years. This review of family caregiving legislation covers bills introduced in the states between 2004 and 2006 and those introduced at the federal level between 2005 and 2006 (109th Congress). During that time, over 100 bills to assist family caregivers were introduced in 32 states and at the federal level. Twenty-one of those bills passed – one in four states (13) passed a total of 16 family caregiving-related bills, and the 109th Congress was responsible for passing the other five enacted bills. For more information, visit FCA’s website, http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1848.

KEY FACTS

- Twenty-five federal bills with provisions to help family caregivers were introduced in the 109th Congress. ¹
- Five federal bills related to family caregiving were enacted in the 109th Congress.
- At least 78 caregiving bills in 32 states were introduced between 2004 and 2006.

¹ In instances where a set of companion bills in both legislative chambers or multiple, nearly identical bills were introduced, they are counted as just one bill for the purposes of this fact sheet.
• Thirteen states passed a total of 16 bills with caregiver-related provisions between 2004 and 2006.
• Hawaii introduced nine caregiver-related bills – the most of any state; Illinois and Minnesota followed by introducing six bills each.
• Illinois, Michigan and Virginia each passed two caregiving-related bills from 2005 to 2006.
• Most of the bills introduced from 2004 to 2006 were related to tax incentives for caregivers – 18 bills were introduced in twelve states and four bills were introduced at the federal level.
• Twenty bills related to family and medical leave for workers providing care to a family member were introduced in eleven state legislatures and Congress, and 16 bills related to respite services and grants were introduced in eight states and in Congress between 2004 and 2006.

DIVERSE STRATEGIES & INNOVATIVE IDEAS

Caregiver legislation introduced between 2004 and 2006 fell under a variety of public policy strategies – ranging from health policy to tax laws to labor policies. The three most common strategies were:
• Caregiver tax incentives
• Family and medical leave policies
• Respite care provisions.

In addition, there were bills related to:
• Care Coordination
• Caregiver Assessment
• Training and Education
• Consumer Direction
• Medicaid Benefits
• Medicare Provisions
• Private Long-Term Care Insurance and Tax Credits
• Research and Policy Recommendations
• Alert Systems for Adults with Dementia
• General Caregiver Support

Among the 21 bills that became law, lawmakers employed a variety of policy strategies for helping family caregivers. At the federal level, they enacted bills focused on the National Family Caregiver Support Program, revised Medicaid provisions affecting long-term care, and provided respite assistance and training for family caregivers. At the state level, the new laws range from establishing a Medicaid benefit for family caregivers and requiring the state to use established measures to assess the well-being of caregivers (Idaho), to establishing legislative committees to research and recommend family caregiver support services (Hawaii), to creating an adult day health care benefit under Medicaid (Louisiana).

Tax Incentives. The emotional and physical strain of caregiving is often exacerbated by worries over paying for care. Tax deductions and tax credits are two strategies utilized by policymakers to provide some financial relief to families. In fact, tax incentives for family caregivers was the most popular type of caregiver legislation introduced – but not passed – in the last three years.
Twelve states, as well as federal lawmakers, introduced a total of 22 caregiver tax incentive bills. Many of those bills included income tax credits ranging from $500 (CA, HI) to $5,000 a year (MA). Other bills specified that a tax deduction could be claimed in order to offset between 20% and 50% of the costs of various home care services, specialized equipment, or home modifications purchased by the caregiver (AZ, AL, NJ, VA).

**Family and Medical Leave Policies.** The financial impact of caregiving is most apparent for family caregivers when it affects their ability to engage in and perform effectively at work. Twenty bills to support working families and broaden the scope of family and medical leave laws were introduced in eleven states and at the federal level, making it the second most common type of caregiving legislation introduced between 2004 and 2006. Different state bills would have provided workers anywhere from four weeks (IL) to twelve weeks (NJ, MA, PA) of paid leave at 67% of their wages in order to care for a family member. Other bills proposed family temporary care insurance programs for paid time off (PA, WA); wage replacement savings plans (NE); and tax incentives for small businesses that offer paid leave to their employees (PA). Washington passed a law to bring the state in line with the federal Family and Medical Leave Act.

**Respite Assistance.** Respite care addresses one of the most pressing needs identified by families, namely to provide temporary relief from day in and day out caregiving responsibilities. That is why legislators in eight states and Congress introduced 17 respite care bills in the last two years, making it the third most common legislative strategy. The most significant bill to pass was the federal Lifespan Respite Care Act, signed into law in December 2006. The new law authorized $289 million over five years for grants to state agencies and organizations to develop state and local respite care programs, to provide family caregivers of children and adults with increased access to respite care services, and to train and recruit respite care workers and volunteers. The new law will not be implemented until Congress appropriates the funds. In addition, both Maryland and Virginia passed laws to provide grants of up to $500 per year to qualified family caregivers to pay for respite care, various medical services, home repair or modification, and other goods and services.

**CONCLUSION**

As evidenced by the bills introduced in the last three years, family caregiving issues are now on the policy agenda at both the federal and state levels. However, less than 25% of those family caregiving bills that were introduced were enacted, and the programs and laws that currently exist only skim the surface of what is needed. In caring for their loved ones, family caregivers save taxpayers an estimated $306 billion in long-term care costs a year.² As new legislative sessions get underway in states across the country and in Congress and as the public becomes more aware of caregivers' stories – their contributions to society and the harmful effects they often suffer as a result of caregiving, we expect lawmakers to continue to promote policy initiatives and innovations to support the nation’s family caregivers.

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NOTE ON METHODOLOGY

The bills included in this database were gathered by FCA’s National Center on Caregiving staff using web-based services designed to conduct federal and state legislation searches in specific issue areas from year to year. Key words such as "caregiver," "consumer direction," "paid family leave," "respite," and various disease names were used to identify, track and categorize relevant legislation affecting family caregivers of older people and adults with disabilities. While every effort was made to compile specific caregiving legislation, this database is not meant to represent an exhaustive list of all legislation relating to family caregiving.

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