

## **Congressional Research Service: Long Term Family Care Giving**

*This report describes the role of family caregivers in providing long-term care to older individuals; federal programs and initiative that directly and indirectly assist family caregivers; and, selected policy issues that would provide direct assistance to family caregivers.*

### **Lead Agency:**

Congressional Research Service

### **Agency Mission:**

The Congressional Research Service provides, exclusively to the United States Congress, objective, non-partisan assessments of legislative options for addressing the public policy problems facing the nation.

### **Principal Investigator:**

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### **General Description:**

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

This report describes the role of family caregivers in providing long-term care to older individuals; federal programs and initiatives that directly and indirectly assist family caregivers; and, selected policy issues that would provide direct assistance to family caregivers. 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.

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 among 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.

***Excellence:*** What makes this project exceptional?

This report assists Congress in identifying and describing the various federal programs and initiatives that provide both direct and indirect assistance to family caregivers. 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. This report summarizes federal programs and initiatives that provide both direct and indirect support to family caregivers. Benefits that are targeted directly at family caregivers help 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. This report assists federal policymakers by describing these federal programs and initiatives. The report also summarizes key policy issues for family caregivers to the older population that have been the subject of discussion among federal policymakers and other interested stakeholders.

***Significance:*** How is this research relevant to older persons, populations and/or an aging society?

The need for long-term care increases with advancing age. Family caregivers fulfill the majority of the need for long-term care among 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 as well as the capacity for caregivers to provide needed care to older individuals. Given these competing factors, it is likely that family caregiving to the older population will remain an important topic for consideration among policymakers.

***Effectiveness:*** What is the impact and/or application of this research to older persons?

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. It is estimated that between 7 and 54 million Americans provide assistance with personal care and other activities necessary for

individuals to function independently in their own homes and communities. The majority of these individuals providing care to older relatives are family members, such as a spouse or adult child. Many do so willingly out of a sense of responsibility or personal obligation to their family member. As a result, some do not identify themselves as caregivers. However, researchers have increasingly paid more attention to the issue of family members providing unpaid care to older relatives, many of whom provide assistance with long-term care needs for extended periods of time. It is estimated that family caregivers provide on average, 46 hours of care per week for over 4 years. Family caregivers seeking information on available public and private long-term care services and supports for their older relative may be overwhelmed with what is often described as a fragmented and confusing system.

***Innovativeness:*** Why is this research exciting or newsworthy?

Family caregivers will continue to play an important role in the delivery of long-term care services and support to the older population. Researchers are continuing to examine ways in which education, training, and other services and supports can best assist family caregivers. Policymakers will continue to debate ways in which the federal government can further assist family caregivers providing long-term care to older individuals