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Supporting Family Caregivers

By Joshua Ewing

Generally, the longer people live, the more health-related services they require. The implications for states and the health care system are significant, because about 8,000 U.S. baby boomers reach age 65 per day. In addition, nearly 70 percent of people over age 65 will need some form of long-term services and supports. The bulk of that care is provided by unpaid family caregivers.

Long-term services and supports include meeting the personal and health needs of people living with disabilities, chronic diseases, complex medical needs, impaired mobility or impaired cognitive function. Support can range from providing home health and personal care (such as bathing and dressing), which helps people live successfully and independently at home, to providing care in institutional settings, such as nursing homes. About half the people who require long-term services and supports are older than 65, and half are people with disabilities who are under age 65. As the population ages, the number of people who need these types of services will grow.

AARP estimates the value of unpaid care provided by family caregivers today to be in excess of \$450 billion annually. To put this figure in perspective, total federal and state spending for Medicaid was \$413.7 billion in FY 2013. As states continue to move toward more home and community-based services for older citizens and those with disabilities, it is clear that family caregivers will continue to play a significant role.

Of interest to policymakers is that, in addition to helping more seniors remain independent, family caregivers also help reduce unnecessary hospitalization and costly Medicaid-funded institutionalization. Policymakers are examining how they can best support family caregivers and those who count on them to live independently at home.

Serving as a family caregiver can be difficult, however. Some issues caregivers face include the following.

- Many caregivers provide care during their peak earning years, meaning that stress and time away can have a negative economic impact on them and their families.
- Family caregivers are assuming greater responsibilities, including performing complex medical or nursing tasks, such as managing medications, caring for wounds and operating special medical equipment. These are tasks for which they have little or no training.
- Caregiving can be emotionally and physically challenging, and can take a toll on the caregiver's own health and well-being.

Did You Know?

- About 8,000 baby boomers reach age 65 every day.
- Nearly 70 percent of people over age 65 will need some form of long-term services and supports in their lives.
- AARP estimates the value of uncompensated care provided by family caregivers to be more than \$450 billion annually.

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Executive Director
William T. Pound

Denver
7700 East First Place
Denver, Colorado 80230
Phone (303) 364-7700
www.ncsl.org

Washington, D.C.
444 North Capitol Street, NW, Suite 515
Washington, D.C. 20001
Phone (202) 624-5400

State Action

Family Caregiver Legislation. In 2014, state legislatures enacted laws that addressed workplace flexibility, allowing family caregivers to care for a loved one without the fear of losing their jobs; uniform guardianship and power of attorney so caregivers can make crucial medical decisions on behalf of an ill relative; and expanded authority for nurses who support family caregivers and their loved ones to practice more independently and prescribe certain medications.

CARE Act. Lawmakers in New Jersey and Oklahoma enacted versions of what is known as the Caregiver Advise, Record and Enable, or CARE Act, in 2014. When a patient is admitted, and with his or her consent, the law requires hospitals to record the caregiver's name; to notify that caregiver before the patient is discharged; and to help instruct the caregiver about the medical or nursing tasks he or she is being asked to perform for the patient at home. The CARE Act has been introduced in 15 state legislatures in 2015.

Legislative Committees. Legislatures in Delaware, Hawaii, Mississippi and New Mexico formed committees or task forces in 2014 to study how the state currently provides support for family caregivers and what changes need to be put in place. Recommendations from these committees are framing the agenda for legislation in the 2015 session.

Federal Action

Caregiver Support. The National Family Caregiver Support Program was established in 2000 to provide grants to states and territories with the goal of assisting family caregivers. Under the program, states provide five types of services:

- Informing caregivers about available services
- Helping caregivers gain access to the services
- Providing individual counseling, organizing support groups and offering caregiver training
- Offering respite care
- Providing limited supplemental services

Federal funding for the program has remained level, at roughly \$150 million or less annually.

Lifespan Respite Care. Congress passed the Lifespan Respite Care Act in 2006 to help improve the quality of and access to respite care for family caregivers of children or adults with special needs, but the program has received only limited funding. The act is pending congressional reauthorization.

Services for Family Caregivers of Post-9/11 Veterans. Congress passed the Caregivers and Veterans Omnibus Health Services Act in 2010 to provide training and support for family members who care for post-9/11 military veterans. This law provides a range of services for a targeted caregiver population, including, but not limited to, training, counseling and respite services.

NCSL Contact

Joshua Ewing
NCSL—Denver
(303) 856-1459

Additional Resources

Home Alone: Family Caregivers Providing Complex Chronic Care

Valuing the Invaluable: 2011 Update—The Growing Contributions and Costs of Family Caregiving