

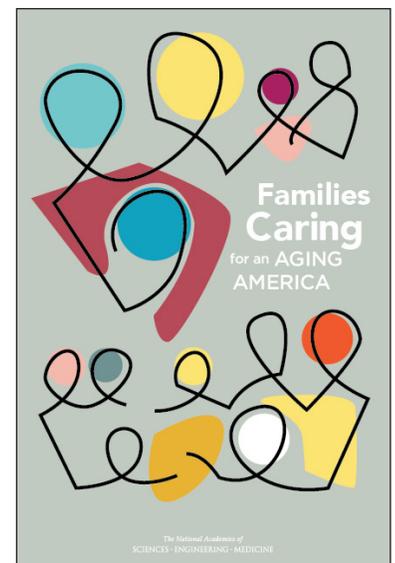
September 2016

## Families Caring for an Aging America

Millions of Americans are providing care and support to an older adult—a parent, spouse, friend, or neighbor—who needs help because of a limitation in their physical, mental, or cognitive functioning. For decades, demographers, gerontologists, health researchers and providers, economists, and other experts have raised concerns about the rapid aging of our population and its implications for the health care system; Social Security; and local, state, and federal resources. Far less attention has been given to family caregivers who provide the lion's share of long-term services and supports (LTSS) to our older adult population. Many are unaware that today, some family caregivers are expected to provide complex health care services once only delivered by licensed health care personnel in a hospital or other setting.

At least 17.7 million individuals in the United States are family caregivers of someone age 65 and older who has a significant impairment. The circumstances of individual caregivers are extremely varied. They may live with, nearby, or far away from the person receiving care. The care they provide may be episodic, daily, occasional, or of short or long duration. The caregiver may help with household tasks or self-care activities, such as getting in and out of bed, bathing, dressing, eating, or toileting, or may provide complex medical care tasks, such as managing medications and giving injections. The older adult may have dementia and require a caregiver's constant supervision. Or, the caregiver may be responsible for all of these activities.

With support from 15 sponsors, the National Academies of Sciences, Engineering, and Medicine convened an expert committee to examine what is known about the nation's family caregivers of older adults and to recommend policies to address their needs and help to minimize the barriers they encounter in acting on behalf of an older adult. The resulting report, *Families Caring for an Aging America*, provides an overview of the prevalence and nature of family caregiving of older adults as well as its personal impact on caregivers' health, economic security, and overall well-being. The report also examines the available evidence on the effectiveness of programs and interventions designed to support family caregivers. It concludes with recommendations for developing a national strategy to effectively engage and support them.



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## **RAPIDLY INCREASING NUMBERS OF OLDER ADULTS, SHRINKING FAMILIES**

A number of factors underscore the urgency of addressing the needs of family caregivers. There is a growing gap between the demand for and supply of family caregivers for older adults. The demand for caregivers is increasing significantly not only because of the dramatic increase in numbers of older adults but also because the fastest growing cohort of older adults are those age 80 and older—the age when people are most likely to have a significant physical or cognitive impairment or both. At the same time, the size of American families is shrinking and the makeup of families is changing as more people do not have children, never marry, divorce, or blend families through remarriage. Moreover, half of family caregivers are employed.

## **THE PERSONAL IMPACT OF FAMILY CAREGIVING**

American families are more diverse—ethnically, racially, economically, religiously, and in many other ways—than ever. Their experiences and the older adults they care for are as varied as the nation's population. For some people, caregiving can instill confidence, provide meaning and purpose, enhance skills, and bring the caregiver closer to the older adult. For others, caregiving takes a significant toll. An extensive literature indicates that compared to non-caregivers, family caregivers of older adults are more likely to experience emotional distress, depression, anxiety, or social isolation. Some caregivers also report being in poor physical health, and some have elevated levels of stress hormones or higher rates of chronic disease.

The intensity and duration of caregiving and the older adult's level of impairment are consistent predictors of negative health effects for the caregiver. Family members who spend long hours caring for older relatives with advanced dementia, for example, are especially at risk. Other risk factors include low socioeconomic status, high levels of perceived suffering of the care recipient, living with

the care recipient, lack of choice in taking on the caregiving role, poor physical health of the caregiver, lack of social support, and a physical home environment that makes care tasks difficult.

Family caregivers of significantly impaired older adults are also vulnerable to financial harm. Caregivers may lose income, Social Security and other retirement benefits, and career opportunities if they have to cut back on work hours or leave the workforce. They may also incur substantial out-of-pocket expenses that may undermine their own future financial security.

## **SYSTEMIC BARRIERS**

In order to fulfill the roles that they play, family caregivers must interact with a wide range of providers and navigate within a variety of systems. They interact with physicians, physician assistants, nurses, nurse practitioners, social workers, psychologists, pharmacists, physical and occupational therapists, direct care workers, and others. They serve as key information sources about older adults' health histories, their medications, previous treatments and surgeries, and adverse reactions to any drugs. They represent older adults in dealings with home health care agencies, physicians' and other providers' offices, hospitals, pharmacies, assisted living facilities, and nursing homes.

Yet, family caregivers are often marginalized in the delivery of health care and LTSS. Paradoxically, some providers exclude them from older adults' treatment decisions and care planning while also assuming they are able, have the knowledge, and are willing to perform essential tasks. Caregivers describe learning by trial and error and report fear of making a mistake.

## **EFFECTIVE INTERVENTIONS ARE AVAILABLE**

A growing body of research provides important insights into how to effectively support family caregivers. The

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most effective interventions begin with an assessment of caregivers' risks, needs, strengths, and preferences. Education and skills training can improve caregiver confidence and ability to manage daily care challenges. Counseling, self-care, relaxation training, and respite programs can improve both the caregiver's and care recipient's quality of life. Some research also suggests that providing services, such as personal counseling and care management, may delay older adults' institutionalization and reduce re-hospitalization. Nevertheless, few caregivers have access to such services.

### **AN URGENT NEED FOR ACTION**

The committee calls for a transformation in the policies and practices affecting the role of families in the support and care of older adults, stating that today's emphasis on person-centered care needs to evolve into a focus on person- and family-centered care. The committee urges that the Secretary of Health and Human Services, in collaboration with the Secretaries of Labor and Veterans Affairs, and others, create and implement a National Family Caregiver Strategy that includes the following

- effective mechanisms to ensure that family caregivers are routinely identified in delivery of services to older adults with impairments;
- Medicare and Medicaid payment reform to motivate providers to engage family caregivers effectively;
- training of health care and LTSS providers to engage caregivers;
- dissemination and funding for evidence-based caregiver services;
- evaluation and adoption of federal policies that provide economic support to working caregivers; and
- expansion of the national data collection infrastructure to create a knowledge base about caregivers.

States also have an important role to play, as does the private sector. State agencies can learn from the states that have

enacted job protections and expanded access to family leave for caregivers. Also, a public-private innovation fund could leverage private funding to accelerate research and development of assistive technologies, remote monitoring and sensing systems, telehealth applications, and other tools to assist family caregivers.

Because the future of caregiving for older Americans will be shaped not only by the growing numbers of older adults needing care but also by the increasing diversity of older people and their families, all of the above actions should address the needs and values of diverse family caregivers.

To read the full text of the committee's recommendations, please refer to the recommendations insert.

### **CONCLUSION**

This report raises serious concerns about the current state of family caregiving of older adults in the United States. The impact of caregiving on families should not be ignored. If the needs of caregivers are not addressed, we risk compromising the well-being of our elders and their families. Taking on these challenges means seizing an opportunity to discover the potential societal benefits of effectively engaging and supporting family caregivers in the care of older adults—both economic and otherwise.

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