

Supporting the Critical Role of Family Caregivers: State Opportunities

An estimated 34 million Americans provide care to an older family member.¹ They provide emotional support and assist with daily activities like eating and bathing, as well as housework and providing transportation to medical appointments. Some family caregivers also manage complex care and perform a range of medical/nursing tasks, including managing medications, performing wound care, and preparing food for special diets, among many other activities — often with little to no training.^{2,3}

The Value of Family Caregivers

The help family caregivers provide is worth, by some estimates, nearly \$470 billion annually,⁴ providing savings to the health care system. By helping patients live at home for longer, family caregivers may also delay the need for costly home health services or long-term care facility stays.⁵ Perhaps more importantly, family caregivers can potentially improve the quality of health care and outcomes by reinforcing provider care instructions at home, administering medications, and providing emotional support. In a recent AARP study, 88 percent of primary care physicians said they believed family caregivers improved patient health outcomes.⁶



The Personal Toll of Caregiving

While family caregivers report much joy and satisfaction in their critical role,⁷ caring for a family member can also come at a cost. In many communities, there is a shortage of skilled home caregivers and families need to perform duties that they may be unprepared to undertake. From managing complex medical procedures and equipment, to assisting with shopping and transportation to medical appointments, **family caregiving is work — and largely uncompensated, without adequate training.** Without proper supports, family caregivers are often overwhelmed and may have difficulty managing other responsibilities at work and at home. As many as six in 10 family caregivers reported cutting work hours, taking a leave of absence, or receiving a warning from their employer about performance or attendance.⁸ For family caregivers who choose to leave the workforce to care for a family member or friend, early retirement has a lifetime associated cost of approximately \$300,000 in lost wages and retirement benefits.⁹

How States Can Support Family Caregivers

States increasingly recognize the value of supporting family caregivers' challenges, yet limited comprehensive state and federal programs exist to support the full range of family caregiver needs. [Helping States Support Families Caring for an Aging America](#), a national initiative led by the Center for Health Care Strategies through support from The John A. Hartford Foundation, Milbank Memorial Fund, the May & Stanley Smith Charitable Trust, and the Gordon and Betty Moore Foundation, is working with six states — **Alabama, Idaho, Iowa, New Hampshire, South Carolina, and Virginia** — that are committed to increasing the effectiveness and reach of family caregiver supports.

Following are examples of activities that states can consider to enhance family caregiver supports:

State Options to Support Family Caregivers	
TACTIC	EXAMPLE
 <p>Create uniform policies across family caregiver organizations, and health and social service agencies to streamline caregiver communications and access.</p>	<ul style="list-style-type: none"> ■ Idaho is strengthening public/private partnerships between payers and family caregiver support agencies to enhance access to information and services. ■ Iowa is streamlining the services and supports for family caregivers currently offered through its network of Area Agencies on Aging.
 <p>Inventory available community services and identify mechanisms to make resources available for caregivers.</p>	<ul style="list-style-type: none"> ■ New Hampshire is developing a more streamlined and consistent process for assessing family caregiver capacity. ■ South Carolina is inventorying and assessing its current family caregiver resources, and developing a set of statewide recommendations to support family caregivers.
 <p>Establish data sources to consistently identify and track family caregivers, and properly assess their needs.</p>	<ul style="list-style-type: none"> ■ Virginia aims to modify their health risk assessment to include family caregiving-related questions in an effort to more accurately identify family caregivers, determine their needs, and offer education and resources.
 <p>Provide training opportunities to family caregivers on critical topics such as managing chronic diseases, coordinating medication regimens, and accessing community resources.</p>	<ul style="list-style-type: none"> ■ Virginia is partnering with community-based organizations and health plans to offer training and resources to health plan care coordinators to ensure that they have the tools to support family caregivers.
 <p>Expand access to respite and adult day care services providing caregivers a much-needed break from the 24/7 care routine, thereby reducing caregiver stress and preventing burnout.</p>	<ul style="list-style-type: none"> ■ Alabama, with support from the state's speaker of the house, is developing recommendations for draft legislation to support respite care services and developing standards and trainings for respite care workers.

Learn More

This fact sheet is a product of the Center for Health Care Strategies' (CHCS) [Helping States Support Families Caring for an Aging America](#) initiative. With support from The John A. Hartford Foundation, Millbank Memorial Fund, the May & Stanley Smith Charitable Trust, and the Gordon and Betty Moore Foundation, CHCS is working with six states committed to developing policies or programs to support family caregivers and address the challenges of an aging population.

¹ AARP Public Policy Institute and the National Alliance for Caregiving. [Caregiving in the U.S. 2015](#). June 2015.

² AARP Public Policy Institute. [Home Alone Revisited: Family Caregivers Providing Complex Care](#). April 2019.

³ Ibid.

⁴ AARP Public Policy Institute. [Valuing the Invaluable 2015 Update: Undeniable Progress, but Big Gaps Remain](#). July 2015.

⁵ "Embracing the Role of Family Caregivers in the U.S. Health System," *Health Affairs Blog*, September 8, 2016.

⁶ AARP Research. [Primary Care Providers' Experiences with Family Caregivers](#). February 2019.

⁷ L. Skufca. [AARP Family Caregiving Survey](#). AARP. November 2017.

⁸ National Alliance for Caregiving (NAC) and AARP Public Policy Institute. [Caregiving in the U.S.](#) June 2015.

⁹ The MetLife Mature Market Institute. [The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents](#). June 2011.