

Family Caregivers: The Backbone of Our Eldercare System

“The need to recognize and support family caregivers is among the most significantly overlooked challenges facing the aging US population, their families, and society.” – National Academies

The State of Family Caregivers in the US

Family caregivers are the backbone of our long-term care system for older Americans. Due to demographic changes, the demand for family caregivers of adults over the age of 65 is increasing significantly but we do not have an eldercare system properly equipped to support them. Family caregivers need more recognition, training, and support in order to provide high-quality care to their loved ones and maintain their own health and well-being. At the same time, the health care workforce needs enhanced training to identify, assess, and engage family caregivers.

A family-centered health care delivery system that addresses the needs of family caregivers and integrates their role in the health care team is vital to supporting family caregivers.

Scope of the CHALLENGE:

Family caregivers typically provide health care at home, navigate complicated and fragmented health care and long-term services and support systems, and serve as surrogate decision makers.

Although family caregivers play an integral role in the care of older adults with disabilities and complex health needs, they are often marginalized or ignored in the delivery of health care and long-term services and supports.

They may be excluded from treatment decisions and care planning, even though providers assume caregivers’ availability to perform the wide range of tasks reflected in the older adult’s care plan.

Many family caregivers are provided little, if any, information and training to carry out the personal care, care coordination, and medical/nursing tasks they are expected to deliver.

To find the full National Academies of Sciences, Engineering, and Medicine *Families Caring for an Aging America* report, please visit: nationalacademies.org/caregiving.

Family Caregiving by the Numbers

- 17.7 million:** Number of people who serve as a caregiver to an older loved one.
- 5:** The median number of years of caring for someone with high need.
- 32:** Percent of caregivers who are themselves older adults.
- 41:** Percent increase in the size of the over 65 population between 2012 and 2030.
- 30 million:** Number of Americans over the age of 80 by 2050.
- 50:** Percent of caregivers who are employed.
- \$234 Billion:** CBO estimate of economic value of unpaid family caregiving in 2011
- 1 in 3:** Number of caregivers who reported a health professional asked what support they need to care for their loved one.

Figures from NASEM *Families Caring for an Aging America* (2016)



Source: National Academies of Sciences, Engineering, and Medicine

The PATH FORWARD:

➤ National Family Caregiver Strategy:

The National Academies of Sciences, Engineering, and Medicine (NASEM), in the 2016 *Families Caring for an Aging America* report, calls for the creation of a National Family Caregiver Strategy to address the health, economic, and social issues facing family caregivers.

Policy Recommendation: Support Passage of the RAISE Family Caregivers Act.

The *RAISE Family Caregivers Act* directs the Department of Health and Human Services (HHS) to develop and sustain a **national strategy to support family caregivers**. The bill would create a Family Caregiving Advisory Council composed of family caregivers, older adults with long-term care needs, individuals with disabilities, employers, health care and social service providers, state and local officials, experts in family caregiving, and other stakeholders, as well as relevant federal agencies to make recommendations regarding the strategy. The strategy would identify specific actions private and public stakeholders can take to support family caregivers.

➤ Training the Eldercare Workforce:

The National Academies' *Families Caring for an Aging America* report calls for action to strengthen the training and capacity of health care and social services providers to recognize and engage family caregivers and to provide them evidence-based supports and services in the community.

Policy Recommendation: Support funding for the Geriatrics Workforce Enhancement Program

The Geriatrics Workforce Enhancement Program (GWEP) supports development of a better healthcare workforce for older adults by integrating geriatrics with primary care, maximizing older adult and family caregiver, and transforming the health care system. There are only 44 GWEPs in 29 states and additional funding is required to meet the increasing demand from our aging society.

“With current funding, the GWEP caregiver curriculum...reaches only a small fraction of the relevant providers. Work to date falls far short of a systemic and comprehensive effort.” –
Families Caring for an Aging America report

➤ Increasing Family Caregiver Support:

To meet the growing need, we must strengthen programs that provide explicit supportive services for family caregivers.

Policy Recommendation: Increase funding for federal family caregiver support programs.

Administered by the Administration for Community Living, the federal government funds several programs that provide direct support to family caregivers:

- National Family Caregiver Support Program
- Native American Caregiver Support Program
- Alzheimer's Disease Supportive Services Program
- Lifespan Respite Care Program

These programs, along with caregiver support programs run by the Department of Veterans Affairs, must be bolstered to meet the growing demand for services.

“If the needs of caregivers are not addressed, we as a society are compromising the well-being of elders. Supporting family caregivers should be an integral part of the nation’s collective responsibility for caring for its older adult population.”

– Richard Schulz, NASEM Committee Chair

Website: www.eldercareworkforce.org

Facebook: /eldercarealliance

Twitter: @eldercareteam

Blog: eldercareworkforce.wordpress.com

The Eldercare Workforce Alliance is a project of The Advocacy Fund

The positions of the Eldercare Workforce Alliance reflect a consensus of 75 percent or more of its members. Statements reflect the consensus of the Alliance and do not necessarily represent the position of individual Alliance member organizations.