

The Power of Caregivers for a Healthy America

Every day, more than 70 million unpaid and paid caregivers help make independent living possible for older adults and people with disabilities. Caregivers are the bedrock of America's long-term care system, yet they often face physical, emotional, and financial strain that threatens their ability to provide care to others and themselves. Family caregivers are increasingly being called upon to fill critical gaps left by the high turnover and persistent staffing shortages within the direct care workforce, which are expected to intensify in the years ahead.

Family caregiving

- 63 million Americans 1 in 4 adults —provide ongoing care for older adults and people with disabilities, up 24% from five years ago.¹
- Family caregivers, on average, provide care for 27 hours per week, and 24% of caregivers provide more than 40 hours of care every week. While 55% of caregivers often perform complex medical and nursing tasks, only 22% receive training for these activities.
- Family caregivers experience higher rates of depression than non-caregivers of the same age and have a mortality rate 63% higher than non-caregivers. iv
- Informal caregivers lose an estimated \$522 billion in wages each year due to caregiving, and employers lose an estimated \$33 billion per year due to employees' caregiving responsibilities.
- 61% of people with intellectual and developmental disabilities (I/DD) receiving long-term services
 and supports live with a family member. Approximately 24% of those individuals live with an aging
 caregiver a number expected to increase as the I/DD population continues to live longer.
- 1.3 million adults with I/DD do not receive formal services from state agencies and are supported by their families, with parents being the primary caregivers.

Direct care workforce

- The direct care workforce includes professionals identified by a range of different job titles including personal care attendants, home health aides, direct support professionals, job coaches, residential workers, and others who provide similar support.
- More than 5.4 million direct care workers are currently supporting older adults and people with disabilities in the U.S.^{vi}
- Low wages, poor quality jobs, and limited career growth impacts workforce recruitment and retention, and in 2024, the turnover rate in home care was nearly 75%.
- In 2025, 88% of provider organizations reported moderate or severe staffing challenges, and 62% reported turning away new referrals due to inadequate staffing.^{viii}
- Changing demographics impact the availability of family caregivers, and in the coming decades, a
 greater share of people will age with disability when it's less likely a spouse or children will be
 available to provide care.
- By 2032, an additional 800,0000 direct care workers will be needed, higher than for any other occupation in the U.S.^x



ACL efforts to advance caregiving

ACL is tackling the caregiving crisis in America to ensure that older adults and people with disabilities have access to the full range of support needed to live independently in their homes and communities. By addressing diverse forms of care — from direct care workers to family, friends, and neighbors — ACL seeks to develop and scale community solutions that honor individual choice, promote health and safety, avoid costly institutional care, and strengthen the caregiving infrastructure across the country.

ACL's strategy reflects a multifaceted approach: combining 1) a leadership role on the issue of caregiving, 2) financial investment in direct services and supports, and 3) research and innovation.

- 1) ACL provides strategic leadership and coordination on caregiving by bringing together federal and non-federal partners to develop and align national strategies and federal efforts to strengthen caregiver support systems. The <u>RAISE Family CAREGIVING Advisory Council</u> and the <u>Advisory Council to Support Grandparents Raising Grandchildren</u> co-lead the development and implementation of the <u>National Strategy to Support Family Caregivers</u>, in partnership with more than 15 federal agencies, fulfilling nearly 350 commitments for near-term actions to support family caregivers.
- 2) ACL funds a diverse portfolio of programs that support caregivers across the lifespan.
 - The <u>National Family Caregiver Support Program</u> funds a variety of supports that help family and informal caregivers care for older adults in their homes for as long as possible.
 - The <u>Native American Caregiver Support Services Program</u> provides grants to tribal organizations to support family and informal caregivers of American Indian, Alaskan Native, and Native Hawaiian elders.
 - The <u>Lifespan Respite Care Program</u> increases the availability and quality of respite services for caregivers of older adults and people with disabilities.
 - <u>University Centers for Excellence in Developmental Disabilities (UCEDDs)</u> offer a variety of resources for families and caregivers including guides, videos, webinars, and trainings.
 - The <u>Grandfamilies and Kinship Support Network</u> offers technical assistance to government agencies and nonprofit organizations to help them collaborate to improve supports and services to grandfamilies and kinship families.
 - The <u>National Caregiver Support Collaborative</u> (NCSC) increases the recognition and support of family, kin, and tribal caregivers, resulting in measurable improvements to assess caregiver needs, provide supportive services, collect data, and support well-being.
 - <u>Community Care Corps</u> supports communities to develop volunteer programs to provide nonmedical support to older adults and adults with disabilities.
 - The <u>Alzheimer's Disease Programs Initiative</u> brings dementia-capable home and community-based services (HCBS) and supports to individuals living with Alzheimer's disease and their caregivers.
 - The <u>Direct Care Workforce Strategies Center</u> provides technical assistance to states to improve the recruitment, retention, and training of the direct care workforce.
 - <u>Person-Centered, Trauma-informed Service</u> provides person-centered, trauma-informed services to Holocaust survivors, older adults with a history of trauma, and their family caregivers.



- The Community of Practice (CoP) for Supporting Families of Individuals with I/DD is a network of 22 state teams seeded through a 5-year Project of National Significance grant driving sustainable change to support better lives for people with disabilities and their families.
- The Bridging the Aging and Disabilities Networks grant is a Project of National Significance that is building the capacity of states' aging and disability networks to support individuals with I/DD and their families.

3) ACL funds applied research and rapid innovation that supports caregivers.

Research portfolio:

- The National Rehabilitation Research and Training Center on Family Support partners with government, academia, and the broad family support stakeholder community to translate state-ofthe-art research and training into services and support programs to improve the care, health, and quality of life of all persons with disabilities and the families who support them.
- The RESILIENCE Rehabilitation Research and Training Center improves the health and function of people with disabilities and their caregivers by adapting and scaling two evidence-based programs for children and older adults with disabilities and designing new approaches.

Rapid Innovation:

- The Caregiver Al Prize Competition will incentivize and reward innovators who develop, test, and scale Al-enabled tools that support family caregivers and the direct care workforce in providing safe, person-centered care at home.
- Small Business Innovation Research funding provides opportunities to advance applications of technology, robotics, and AI to extend the caregiving workforce, support independent living, and enable a pathway for broad adoption of affordable tools.



Caregiving in the US Research Report 2025.

iii Ibid.

iv Schulz R, Beach SR. Caregiving as a risk factor for mortality. The Caregiver Health Effects study. JAMA December 15, 1999;282:2215-9.

The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business, Page 17.

vi Direct Care Workers in the United States: Key Facts 2025.

Understanding the Direct Care Workforce. PHI.

The State of America's Direct Support Workforce Crisis 2025.

Euture Change in Caregiving Networks: How Family Caregivers and Direct Care Workers Support Older Adults Now and in the Future (2023)

^x Direct Care Workers in the United States: Key Facts 2025.