Supporting Family Caregivers

June 2025

Shirley Ryan Abilitylab
Center for Rehabilitation Outcomes Research

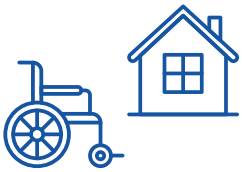
Overview

A family caregiver is a person who has a relationship with and provides unpaid assistance to another person with a chronic condition, disability, or functional limitations. The family caregiver may be related (e.g., parent, child) or unrelated (e.g., friend, neighbor).

Family caregivers, through the assistance they provide, enable many people with disabilities to live in their own homes and communities. However, caregiving may create physical, emotional, and financial strain for family caregivers. Action is needed to support family caregivers and acknowledge their significant contributions to community living for people with disabilities in the United States.

Background

About 53 million, or 1 in 5 Americans, are identified as family caregivers.



Family caregiving is the most common source of care for people receiving care services and support at home.

Family caregivers assist with activities of daily living and health and medication management.

Many caregivers perform complex caregiving tasks, frequently with limited access to training and assistance.

Contributions of Family Caregivers

The estimated value of care provided by family caregivers in the United States is $600 billion.

Family caregiving enables people with disabilities to live in their own homes and communities.

Family caregiving empowers people with disabilities to choose trusted caregivers, supporting person-centered care.

Family involvement in care at home may improve recipient outcomes (like reduced emergency department use).

Caregiving May Create Physical, Emotional and Financial Strain

While many family caregivers report a sense of purpose and meaning in caregiving, they may also experience physical, emotional and financial strain due to their caregiving role.

Physical Strain

Family caregiving is associated with reports of physical difficulty by caregivers, lower levels of subjective well-being, and increased risk of heart disease among women.

Emotional Strain

Family caregivers may experience negative mental health outcomes, such as depression and psychological distress, depression or anxiety.

Financial Strain

Family caregivers may face a higher likelihood of financial difficulty, difficulty paying bills, and food insecurity.

Furthermore, studies have shown that poor caregiver outcomes may also increase nursing home placement of care recipients.

Beyond improving the life and wellbeing of family caregivers who provide valuable assistance to friends and family living at home, improving family caregiver outcomes may also delay institutionalization and extend community living for people with disabilities.

Ways to Support Family Caregivers

One of the most prominent recent initiatives to support family caregivers is the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act and the resulting 2022 National Strategy to Support Family Caregivers created under the Act.

Recommendations from the National Strategy include:

- Increase awareness and outreach
- Advance partnerships and engagement with family caregivers
- Strengthen services and supports
- Ensure financial and workplace security
- Expand data, research and evidence-based practice

As detailed in the National Strategy, there are many avenues to support family caregivers and improve their wellbeing. The following list—although not exhaustive—details a few practical ways that policymakers, advocates, and other stakeholders can improve outcomes for caregivers:

Explore Payment/Tax Incentives for Family Caregiving

Programs and policies that support caregivers financially—for example, tax incentives for caregivers, hiring of caregivers through self-direction, structured family caregiving programs, and waiver modification options (e.g., Appendix K), may help alleviate financial challenges faced by family caregivers

Increase Access to Respite Care

Respite care is frequently requested by caregivers. Expanding funding of respite programs and strengthening of respite care workforces (e.g., respite volunteers, direct care workers) helps ensure that family caregivers have access to the respite supports they need.

Address the Direct Care Workforce Shortage

A strong direct care workforce ensures accessibility of respite care services. Improving the supply of direct care workers also improves the accessibility and affordability of paid support, when needed by family caregivers and/or care recipients.

Support and Fund Family Caregiver Support Programs

The National Family Caregiver Support Program (NFCSP) assists caregivers through information sharing, counseling, and respite care, linking caregivers to resources and providing them with support needed to care for their loved ones at home.

This document is based on a policy brief titled "Supporting America's 53 Million Family Caregivers. You can find the policy brief at https://www.sralab.org/research/labs/cror/news/policy-brief-supporting-americas-53-million-family-caregivers/

This document was written by Supakorn (Mint) Kueakomoldej, PhD, with funding from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) to the Rehabilitation Research and Training Center on Home and Community-Based Services in the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab (grant 90RTGE0004). NIDILRR is a Center within the Department of Health and Human Services (HHS). The contents of this publication do not necessarily represent the policy of NIDILRR or HHS.