



PRIORITY AREA

Caregiving

*Ensuring that caregivers are informed, well-trained, and supported,
while providing care to older people in community settings*

Long-Term Vision

In selecting Caregiving as a Priority Area, RRF envisions that caregivers¹ will be better prepared and supported in assisting their family and friends, and providers will be more prepared to identify, assess, train, and support caregivers. As a result, the physical, emotional, and economic burden placed on caregivers will be reduced, enabling them to provide better care, while simultaneously improving the quality of life and well-being of the care recipients they serve.

Background on Topic

Providing care comes with a great economic, physical, and emotional toll. Caregivers of older people assume responsibility for a wide variety of tasks, from instrumental chores (e.g., driving and paying bills) to more intense medical and nursing tasks (e.g., assisting with bathing/dressing, coordinating healthcare, maintaining feeding tubes, dressing wounds, and managing medical equipment). Many are responsible for these tasks without training or guidance from healthcare professionals. Many find the role burdensome and experience stress due to fears of making mistakes.² The demands of the caregiving role typically follow a trajectory of increasing complexity and intensity as care recipient health and function diminish over time. Data driving the decision to prioritize projects addressing caregiving include:

- Nearly 44 million Americans serve as caregivers.
- The average caregiver spends more than 24 hours weekly in this role, with 25% providing more than 40 hours of care each week.
- On average, caregivers serve in this role for at least four years; one in four caregivers serves from five to nine years. Fifteen percent of caregivers provide care for a decade or longer.³
- Many caregivers feel the need to reduce hours of paid work or leave the workforce entirely.
- As a group, caregivers spend an average of \$6,954 annually on caregiving-related purchases.
- The estimated value of their combined services is \$470 billion per year, exceeding the entire annual cost of the Medicaid program and four times what Medicaid spends on long-term services and supports.⁴

¹ RRF is focusing on care partners that include family members, friends, or neighbors, whether paid or unpaid.

² Reinhard, S. C., Young, H. M., Levine, C., Kelly, K., Choula, R. B., & Accius, J. C. (2019). Home alone revisited: Family caregivers providing complex chronic care.

³ National Academies of Sciences, Engineering, and Medicine. (2016). *Families caring for an aging America*. National Academies Press.

Attention to the plight of caregivers has grown at the local, state, and federal levels. In 2018, the Federal RAISE Act⁵ was signed into law to fund the development of a national caregiver policy. A few states have begun using Medicaid waiver dollars to fund family caregiver services; more than 200 local communities have passed tax levies to raise local dollars offering services for older adults that can lessen the load on caregivers. Many states also have passed the CARE Act,⁶ requiring hospitals caring for older adults to identify patients' caregivers and prepare them to perform the medical nursing tasks their care partners will require after discharge. However, strategies and resources for implementing the CARE Act are lacking.

Funding Opportunities

Addressing the needs of informal care partners will be challenging. Caregivers are often unaware of services and training available to them and frequently refuse assistance. While there are many evidence-based programs from which caregivers can benefit, inadequate funding limits their uptake and sustainability; there also is a lack of data about the cost-effectiveness of these programs. Despite these challenges, there remain opportunities to improve the well-being of caregivers and, in doing so, enable dependent older adults to remain living where they prefer. There are several activities RRF might fund to prepare and support caregivers of diverse populations.

Examples of possible funding opportunities for this Priority Area include (but are not limited to):

- study the capacity of Area Agencies on Aging, and the community-based organizations with which they partner to adopt family-centered assessment, training, and services;
- promote translation of evidence-based programs for caregivers from diverse cultures;
- enable replication of proven caregiver interventions through web-based training and technical assistance, and modify them, where needed, for appropriateness in supporting care partners from diverse cultures;
- leverage technology to promote systematic identification and assessment of caregivers across all health and home- and community-based service "touch points" to enable family-centered care coordination and service delivery;
- advocate for local, state, and federal investment to support caregiver services, most notably training, adult day, respite, and home-based primary care;
- advocate for paid family leave for working care partners of older adults; and
- study the unique challenges of care partners who are themselves facing chronic illness, and develop methods for targeting these caregivers with services.

⁴ Reinhard, S. C., Feinberg, L. F., Choula, R., & Houser, A. (2015). Valuing the invaluable: 2015 update. Undeniable progress, but big gaps remain. Washington, DC: AARP Public Policy Institute.

⁵ Recognize, Assist, Include, Support, and Engage

⁶ Caregiver Advise, Record, Enable