



**RRF** | Foundation  
for Aging

# INVESTING IN CAREGIVERS

## AN ESSENTIAL RESOURCE FOR OUR NATION

ISSUE BRIEF #2: MAY 2021

### About RRF Foundation for Aging

The mission of RRF Foundation for Aging (RRF) is to improve the quality of life for older people. RRF is one of the few private foundations in the United States devoted exclusively to aging issues. Our vision is that ALL older people will continue to be valued and respected as participants in and contributors to our communities. In addition to caregiving, RRF's grantmaking focuses on three other priorities areas—economic security in later life, housing, and social and intergenerational connectedness.

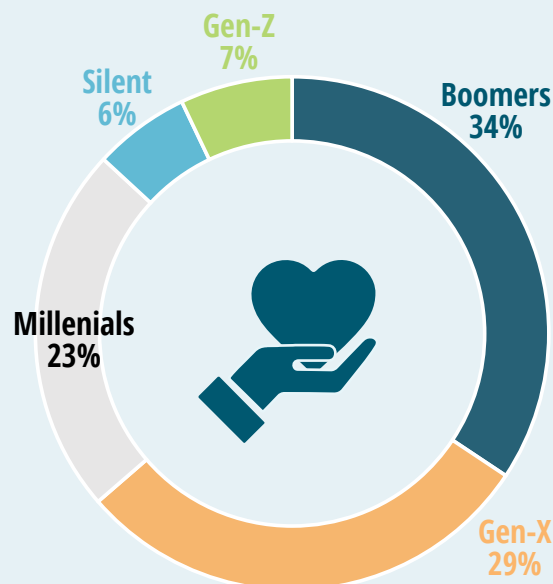
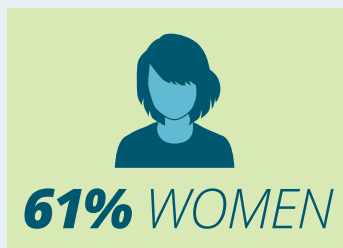
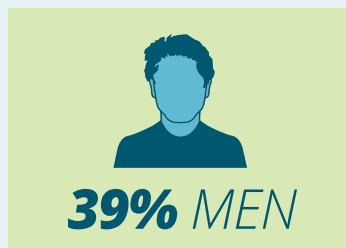
We are pleased to introduce RRF's Issue Brief on Caregiving. This is the second in a series that, together, will describe our approach to funding and working to improve the quality of life for older people.

More than 53 million people—one in five of us in the U.S.—are family caregivers<sup>1</sup> who provide essential support to older adults who can no longer live independently. Estimates suggest that the care they provide is worth nearly half a trillion dollars, an economic contribution significantly greater than all government outlays for institutional and community-based long-term services and support (LTSS) combined.<sup>2</sup> This makes caregivers the nation's largest healthcare workforce, an indispensable part of the health and social service delivery system for older adults and a vital resource for the nation.

To be sure, most of us find caregiving to be a deeply meaningful role that gives us a true sense of purpose.<sup>3</sup> At the same time, we often need help to manage the increasingly challenging, often multi-year nature of this role, which significantly impedes our own ability to age successfully after caregiving.

More and more of us, in caring for older loved ones, are stressed by trying to master highly technical, traditionally medical-nursing tasks for which we have not been trained -- such as maintaining feeding tubes, dressing wounds, and managing medical equipment. Increasing numbers of us also care for more than one older adult and must juggle caregiving with employment and meeting the needs of children or grandchildren — leaving little time to care for our own well-being. Caregiving is also costly. Many caregivers must give up paid employment or go part-time, a threat to our future financial security. Moreover, we spend, on average, nearly \$7,500 a year of our own funds to meet the needs of the older adults in our care.

## Who are today's family caregivers?



Source: <https://www.caregiving.org/caregiving-in-the-us-2020/>

While the challenges are significant, there does exist a strong foundation of work done by researchers, advocates, and practitioners during the last several decades. We have strong data describing the scope, dimensions, financial contributions, and impact of unpaid caregiving in the U.S. Federal and state policy makers recently have begun to pay more serious attention to the issue. And there are also many evidence-based interventions that have been shown to have at least some benefit for caregivers, although more research is needed.

Progress to date, however, is not adequate to meet the needs of today's caregivers and **two demographic trends will only magnify the scope of the challenge, underscoring the need for public action and investments in this caregiving infrastructure.** First, there is the large, rapidly increasing population of aging baby boomers who, within a decade, will increasingly need LTSS themselves. Second, these older boomers had fewer children than their parents and were also more likely to divorce and remarry.<sup>5</sup> Clearly, then, the post-WWII baby boom will have fewer offspring to care for them while their offspring will have more older relatives for whom they will have to provide care.

Recognizing these current and developing challenges associated with caregiving in the United States, RRF Foundation for Aging wants to ensure that these vital care partners are informed, well-trained, and supported while they care for older people in community settings. RRF's grantmaking to support caregiving now focuses on:

### Four Caregiving Strategies

1

Advocating to advance national and state policies that benefit caregivers

2

Promoting replication of evidence-based caregiver programs and developing culturally and linguistically appropriate versions for people of color and minorities

3

Promoting identification and assessment of caregivers at all health and social service points to enable access to training, information and services

4

Supporting research that advances needed policy and practice improvements

# Inter-related Strategies to Address Inter-related Challenges

As we've seen, there are multiple, inter-related challenges facing caregivers and those for whom they provide care. An infusion of public funding, coupled with Medicare and Medicaid payment reforms, are needed to significantly expand needed services and ensure they are reimbursed. We have to be able to identify which

specific programs are most effective and deserving of replication, and we need to make sure those programs work across diverse caregiver populations. We need further research to identify the most cost-effective programs that deliver the best outcomes. RRF's grantmaking is centered around four, inter-related strategies to address these challenges. We look forward to building on and broadening the collaborations needed, as together we seek the best possible solutions.

**ONE in FIVE** Americans



An estimated  
**53 MILLION**  
people

**Are  
Caregivers**



Source: <https://www.aarp.org/caregiving/basics/info-2020unpaid-family-caregivers-report.html>



## *Advocating for better national and state policies and funding*

Attention to the plight of caregivers has grown at all levels of government, although funding has not been sufficient to meet the need. Many states have obtained Medicaid waivers to support the lowest income caregivers, but this leaves those who are near-poor or have moderate incomes without the same support. Most states also have enacted the CARE Act, requiring hospitals to identify patients' caregivers and prepare them to perform the medical nursing tasks their care partners need done. Yet few, if any, of these states have put regulatory requirements on health systems to follow the Act's mandate or instituted financial incentives for doing so. At the federal level, funds for the National Family Caregiver Support Program have been expanded through the period of the COVID pandemic. In 2018, the federal RAISE Act was signed into law, requiring the Department of Health and Human Services to develop a caregiving strategy for all levels of government and the business sector as well, although it is unclear how much of the cost of implementing those strategies will be funded by government.

To move caregiving policy to the level needed, RRF is promoting advocacy to educate elected officials about the scope and nature of the caregiving crisis and the critical need to invest more public funds to broaden the safety net for us as caregivers. One thing Congress can do is to make permanent and expand support for the Money Follows the Person (MFP) demonstration program. MFP allows for paying informal caregivers to provide care, an option that simultaneously addresses financial challenges families face when caregiving as well as the inadequacy of the paid caregiving workforce. This has been particularly important during the pandemic, but should be an ongoing investment. Caregiver Tax Credits and Paid Family Leave are related policies that should be expanded.

Payment reforms also have a major role to play. For example, Medicare and Medicaid reimbursement rates could be adjusted to incentivize health care systems to identify, educate, and support caregivers of older patients discharged to the community.<sup>6</sup> Similarly, payment reform could be used to foster growth in the availability and affordability of adult day care, which is an essential resource for working caregivers but is often too expensive.

### *Key Projects Funded by RRF Foundation for Aging*



- **National Academy for State Health Policy (NASHP)**  
RRF is supporting NASHP's efforts to create a State Policy Roadmap on Caregiving, identifying which states are leading the way in state-level caregiving policy and programs. The Roadmap, along with NASHP consultation for select states, should make it easier for interested states to move forward more efficiently as the RAISE Family Caregiver Act strategies are promulgated in 2022.
- **University of Iowa**  
With RRF support, Iowa researchers are evaluating the impact of state paid family leave (PFL) policies on informal caregiving and workforce participation. Researchers are exploring whether and how time spent working and time spent caregiving change with the passage of PFL legislation, while also exploring gender differences in outcomes.



## *Enabling replication of evidence-based caregiver programs and developing culturally and linguistically appropriate versions for people of color and minorities*

Given a plethora of existing programs to support caregivers, RRF is focusing its efforts on seeing as many of these proven models as possible broadly replicated. (See [Best Practice Caregiving](#), a free online database of proven dementia programs for family caregivers.) Of course, this will require substantial new investments. At the same time, though, caregivers are a highly diverse group representing all ethnicities and races. For this reason, we have also prioritized efforts to see existing programs modified to meet the cultural and linguistic characteristics of diverse caregiver populations and ensure they are effective for people in a wide variety of communities.



### ***Key Projects Funded by RRF Foundation for Aging***

- **Diverse Elders Coalition**

RRF funding supports efforts by the Diverse Elders Coalition, in partnership with member organizations serving Latinx, Black, Native American, LGBT+, and Asian communities, to implement a training program that will raise awareness about the unique needs of diverse caregivers.

- **Emory University**

Emory University received funding to develop and test an online version of The Great Village, a dementia caregiver support program anchored in the values and culture of African Americans. The program will address caregiving during a pandemic; navigating a health care system that is shaped by health disparities and implicit biases; guiding and managing daily life; and self-care.

## *Promoting identification and assessment of caregivers at all health and social service touch points to enable access to training, information, and resources*

Many caregivers see themselves simply as spouses, daughters, or sons, fulfilling a natural family obligation. This complicates caregiving programs as many people don't see themselves as caregivers and view caregiving programs for others, not themselves. However, health and social service providers are positioned to identify caregivers, help them to accept assistance, and connect them with knowledge and other supports. The CARE Act, which has been passed in more than 40 states, seeks to address this issue by requiring health systems to identify, assess, and train caregivers of older patients before they are discharged back to home.

### *Key Projects Funded by RRF Foundation for Aging*

- **Rush University Medical Center**

In response to the CARE Act, Rush received funding from RRF and The John A. Hartford Foundation to standardize processes to identify family caregivers, assess their needs, and provide relevant services and resources throughout the Rush University Medical System. Lessons learned will be shared nationally to help health systems develop their own processes.

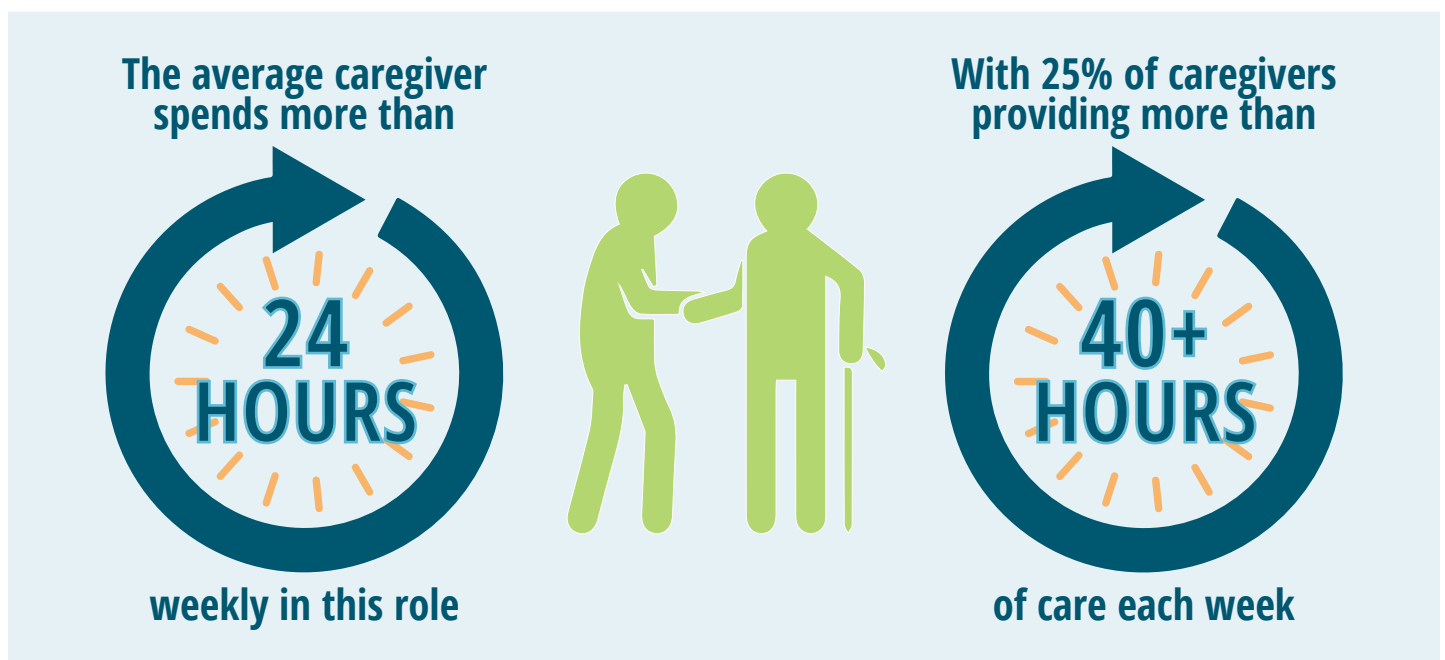


- **AARP Public Policy Institute Home Alone Alliance**

AARP received funding to develop how-to videos for training caregivers on the use of medical equipment commonly needed to support loved ones after hospital discharge. The videos include content developed by the University of California Davis Nursing School's Caregiving Institute addressing oxygen equipment, mechanical lifts, home infusion, and home dialysis, and are accompanied by resource guides that caregivers can download. The videos can be found here: <https://www.aarp.org/ppi/initiatives/home-alone-alliance/family-caregiving-videos/>

## Advancing caregiving research

There remain research needs in the caregiving space.<sup>7</sup> One area where research is urgently needed is documenting the impact/cost-effectiveness of policies that intend to benefit caregivers. Similarly, studies on the cost-effectiveness of existing caregiver programs are required. For example, research could compare outcomes for caregivers and care recipients when caregivers are identified and trained by health systems and when they are not. Finally, there is a demand for research that tests how combinations of programs can be used to magnify the assistance caregivers receive.



Source: 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.

### Key Projects Funded by RRF Foundation for Aging

- **Benjamin Rose Institute on Aging**

Benjamin Rose Institute on Aging received funding to create, launch, and evaluate an online, comprehensive, searchable database called Best Practice Caregiving. It features information to compare and contrast evidence-based programs that service providers can adopt to assist family caregivers of persons with dementia. The goal is to help potential adopters identify programs worthy of replication.

- **Miami University Scripps Gerontology Institute**

Miami University Scripps Gerontology Institute received funding for research to estimate how many local tax levy-funded older adult service programs there are in the U.S. and to examine if and how they are also supporting family caregivers of those served. Findings reveal that 15 states have tax levy-funded older adult services, with a total of 377 distinct local levy-funded programs. Of these, nearly 200 reported that some services they fund provide benefits for caregivers.



# Looking Ahead

There are many ways we can work together to ensure that caregivers are informed, well-trained, and supported while they care for older people in community settings. Good solutions require diverse, integrated strategies that include direct service, research, advocacy, and education, and training. There is much to do and much to learn from an ever-broadening network of partners.

At RRF Foundation for Aging, we look forward to collaborating with new organizations and individuals who are developing and fueling promising approaches, while we continue to build on the work of existing partners and trailblazers across the country. We hope you will join us in developing the next generation of collective solutions to this increasingly important issue.



## Contact Us

We would like to hear from you. Please contact us at [info@rrf.org](mailto:info@rrf.org). And follow us on Twitter [@RRFAging](https://twitter.com/RRFAging) and on LinkedIn at [linkedin/company/rrf-aging](https://www.linkedin.com/company/rrf-aging).

## NOTES AND SOURCES

<sup>1</sup>RRF focuses on care partners that include family members, friends, or neighbors, whether paid or unpaid.  
<https://www.aarp.org/caregiving/basics/info-2020/unpaid-family-caregivers-report.html>

<sup>2</sup><https://rrf.issuelab.org/resource/caregiving-in-the-u-s-2020.html>

<sup>3</sup>Caregiving in the U.S. - 2020

<sup>4</sup><https://rrf.issuelab.org/resource/caregiver-statistics-work-and-caregiving.html>

<sup>5</sup>Children per capita: <https://www.statista.com/statistics/718084/average-number-of-own-children-per-family/#:~:text=The%20typical%20American%20picture%20of,18%20per%20family%20in%201960>

Divorce rate: <https://www.nationalaffairs.com/publications/detail/the-evolution-of-divorce#:~:text=This%20legal%20transformation%20was%20only,divorces%20per%201%2C000%20married%20women>

<sup>6</sup>Projected 5-Year Age Groups and Sex Composition: Main Projections Series for the United States, 2017-2060. U.S. Census Bureau, Population Division: Washington, DC.

<sup>7</sup>Richard Schulz, Sara J. Czaja, Family Caregiving: A Vision for the Future, *The American Journal of Geriatric Psychiatry*, Volume 26, Issue 3, 2018, Pages 358-363.



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