

# National Strategy to Support Family Caregivers

## Action Guide For Philanthropy



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At Grantmakers In Aging (GIA), caregiving has been a longstanding priority. Most of us are, or will one day be, providers and recipients of care.

Since 2016, GIA has had the privilege of convening and facilitating the Family Caregiving Funders Community (FCFC), which represents more than 30 funders investing in initiatives to advance caregiver-friendly programs and policies.

## An Unprecedented Opportunity

In September 2022, the Administration for Community Living released the first [National Strategy to Support Family Caregivers](#) (hereinafter referred to as “Strategy”). The Strategy was developed jointly by the advisory councils created by the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiving Act and the Supporting Grandparents Raising Grandchildren Act, with extensive input from the public, including family caregivers and the people they support.

*Members of the FCFC made more than 370 grants totaling \$100mil that were directly aligned with the goals of the National Strategy in 2021 and 2022.*

GIA members, both individually and collectively through the FCFC, have deployed significant intellectual and financial capital to support the national strategy. GIA collected data from members of the FCFC and found that more than 370 grants totaling over \$100 million made in 2021 and 2022 directly aligned with each of the goals of the Strategy (**see Exhibit 1**). GIA conducted an analysis of the number of projects funded that support the Strategy which provides insights into best practices as well as gaps in funding. **Exhibit 2** demonstrates the scope of initiatives funded by the FCFC relative to the five goals of the Strategy.

## Uniquely Positioned

Philanthropy played an important role in the development of the Strategy. Two GIA members, Carol Zernial of **WellMed Charitable Foundation** and Deborah Stone-Walls of **USAging** served on the RAISE Advisory Council; **The John A. Hartford Foundation** funded resources, technical assistance, and policy analysis to support the Council; and RRF Foundation for Aging and The John A. Hartford Foundation funded [Supporting Family Caregivers: A Roadmap for States](#).

## Philanthropy Action Guide

Moving forward, philanthropy will play a critical role in the implementation of the Strategy. While the Strategy itself was monumental, Congress has appropriated nominal additional funding for the Strategy. Support to advance the recommendations will need to come from many different stakeholders and sectors, including philanthropy.

There are five overarching goals that provide the framework for the Strategy.

1. Increase awareness of and outreach
2. Advance partnership and engagement
3. Strengthen services and supports
4. Ensure financial and workplace security
5. Expand data, research, and evidence-based practices.

This guide provides examples of initiatives being funded in each goal area, and actionable ideas for where philanthropy can support efforts to advance the recommendations.

# Goal 1 Public Awareness and Outreach

Philanthropy can *increase awareness of and outreach to* family caregivers by funding:

- » Media coverage in print, TV, film, and social media.
- » Caregiver coalitions that amplify voices of caregivers in advocacy work.
- » Advocacy efforts for publicly-funded caregiving infrastructure.
- » Outreach campaigns to connect caregivers with support and resources.

## SELECT PUBLIC OUTREACH INITIATIVES

» **The Care for All with Respect and Equity (CARE) Fund** strives to bolster paid leave, quality jobs for care workers, and access to long-term services and supports and is supported by 11 funders, including **Ford Foundation** and **Robert Wood Johnson Foundation**, investing \$50 million over 5 years.

» **Connecting with Elusive Caregivers** supports the New York and Michigan Solutions Journalism Collaborative to reach caregivers, tell their stories in the media and operate the Caregiving Coverage Data Center across both regions with funding from the **Ralph C. Wilson, Jr. Foundation**.

» **Changing the Care Conversation** is a national learning and action-oriented initiative to improve support for family caregivers of older adults and

people with disabilities, especially those with low and moderate incomes and caregivers of color, through technical assistance and small grants to coalitions in 10 states. GIA serves as the fiscal agent for the initiative which is funded by **Archstone Foundation, Bader Philanthropies, Health Foundation for Western and Central New York, Ralph C. Wilson, Jr. Foundation, RRF Foundation for Aging, and St. David's Foundation.**

» **The Caregiving Project** is a four-part WETA (PBS affiliate) documentary focused on caregiving, which will also include a national engagement campaign and educational content with support from the **Ralph C Wilson, Jr. Foundation** and other private and corporate funders including **Care.com**.

# Goal 2 Partnership with and Engagement of Family Caregivers in Health Care Services and Systems

Philanthropy can *increase engagement of family caregivers in health care services and systems* by funding:

- » Efforts to identify caregiver needs and connect them to support in health care settings.
- » Initiatives aimed at providing family caregiver access to electronic health records.
- » Studies of return on investment in integrating family caregivers into the care team. (Also supports Goal 5)
- » Promotion of culturally appropriate training on ways to partner with caregivers and development of training for caregivers. (Also supports Goal 3)
- » Promotion of evidence-based tools for assessment and support. (Supports all goals)

## SELECT PARTNERSHIP WITH CAREGIVERS INITIATIVES

- » [OpenNotes](#) is a movement to facilitate greater transparency in health care where patients can read the notes health care providers write in the medical chart.
  - » [OurNotes](#), a component of OpenNotes, identifies family caregiver needs and connects caregivers to resources as part of standard clinical visits, processes and interactions, funded by the **Ralph C. Wilson, Jr. Foundation**.
  - » The [Coalition for Care Partners](#), a collaboration between OpenNotes and the Roger C. Lipitz Center for Integrated Health Care at the Johns Hopkins Bloomberg School of Public Health, is building knowledge, and tools knowledge and tools directed at strengthening health system capacity to systematically identify, engage, and support care partners in care delivery, funded by **The John A. Hartford Foundation, Ralph C. Wilson, Jr. Foundation, and Cambia Health Foundation**.
  - » [Engaging Family Caregivers through Shared Access to the Electronic Health Record: A Multi-Site Demonstration](#) funds research in three health systems – Providence, University of Utah Health, and University of Rochester Medical Center, funded by **The John A. Hartford Foundation and Cambia Health Foundation**.
- » [Caring4Caregivers \(C4C\) program](#), developed with support from the **RRF Foundation for Aging**, at the RUSH Center for Excellence in Aging has documented evidence of success addressing serious gaps in care provision related to a lack of identification of family caregivers within health systems. The model assesses and supports caregivers' readiness, willingness, and ability to provide care. **The John A. Hartford Foundation** and RUSH are working to spread the model to other health systems and Area Agencies on Aging nationwide through USAging's Aging and Disability Business Institute. In collaboration with the Institute for Healthcare Improvement, the project will also integrate the essential elements of caregiver inclusion into the Age-Friendly Health Systems movement.
- » The [Caregiver Navigation Toolkit](#) provides guidance on how to identify and integrate family caregivers as part of the healthcare team. The **Ventura County Community Foundation** and the Hospital Association of Southern California (HASC) have partnered to advance this program.

- » [Caregiver Journey Map](#) visually illustrates key points where the right people, organizations, and service providers can step in and support family caregivers as they adapt to new roles and challenges, funded by **The Elizabeth Dole Foundation** and several other partners (Philips, RAND Corporation).
- » The [Campaign for Inclusive Care](#) includes a four-module training program for Veterans Administration hospitals on how to partner with caregivers, funded by **The Elizabeth Dole Foundation**, the Department of Veterans Affairs and USAA.
- » [Caring for Those Who Care](#) is a training program for professionals offered by the Diverse Elders Coalition that addresses the needs of six racially and ethnically diverse caregiver groups, fueled by support from **The John A. Hartford Foundation, RRF Foundation for Aging, and the May and Stanley Smith Charitable Trust**.
- » [Family Caregiving How-To Video Series](#), produced by AARP, provides demonstrations of common caregiving tasks such as pain management, preparation for hospital stays, specialized medical equipment, diet, and wound care, etc. funded by the **Ralph C. Wilson, Jr. Foundation, The John A. Hartford Foundation, RRF Foundation for Aging and Centene Foundation for Quality Healthcare**.



## Goal 3: Services and Supports for Family Caregivers

Philanthropy can amplify **services and supports for family caregivers** by funding:

- » Navigation programs to help caregivers access services.
- » Awareness about the importance of respite care and projects that support its expansion and availability.
- » Support of innovative caregiver services including the use of technology to enhance training, mitigate social isolation, etc.
- » Initiatives that support the development and sustainability of the direct services workforce.

### Select Services and Supports Initiatives

[EXHALE](#), the Family Caregiver Initiative, funds innovative collaborative projects that are reimagining and increasing respite opportunities for family caregivers of older adults, funded by **The Ann Arbor Area Community Foundation, Ralph C. Wilson, Jr. Foundation, and the Health Foundation for Western and Central New York** and managed by **The Philanthropic Initiative**.

[Lori's Hands](#) is a college student-based service learning program that provides practical home-based services to support older adults and caregivers. **Michigan Health Endowment Fund** funded Eastern Michigan University (EMU) and Lori's Hands to partner to address the existing home-based service gaps by prioritizing older adults who are waitlisted for services with the local Area Agency on Aging in Wayne and Washtenaw counties in Michigan, with the goal of eventual statewide implementation.

[Expanding the direct care workforce](#) is a policy priority of **Lutheran Services in America**. They advocate for policy changes that support the expansion of a more sustainable workforce such as immigration reform, expanded reimbursement and training mechanisms, and reduction of burdensome regulations, like unfunded staffing minimums.

[Care Integration Senior Aide \(CISA\)](#), is a PHI initiative to launch an advanced position, specially trained on social determinants of health, to make home visits and then report

back to an interdisciplinary team, funded by New York City Workforce Funders, National Fund for Workforce Solutions, and JPMorgan Chase Foundation.

[“Crisis on the Frontline”](#) is a PHI report on the challenges and opportunities facing New Jersey's direct care workforce. PHI continues the work through a statewide coalition advocating for improved direct care wages and reimbursement rates, training innovations, and data collection, with support from the **Henry and Marilyn Taub Foundation**.

[Caregiving Project at Kimochi](#) provides culturally relevant support to paid direct service workers working with Japanese older adults and their caregivers, with support from **Metta Fund**.

[Strengthening Policy to Support Older Adults and Their Caregivers](#) supports PHI's work to better integrate support for both direct care workers and family caregivers who form the frontline of support for older adults who reside in their homes. Funding will enable PHI and the National Alliance for Caregiving to identify and map the health and social service regulations, training, health systems technology needs and funding mechanisms that affect the interconnected relationship between family caregivers and direct care workers with funding from **The John A. Hartford Foundation**.

## Goal 4: Financial and Workplace Security

Philanthropy can advance **financial and workforce security** by funding:

- » Employment initiatives within the public and private sectors.
- » Readiness for retirement initiatives.
- » Financial planning initiatives.

### SELECT FINANCIAL AND WORKPLACE SECURITY INITIATIVES

- » The [Rosalynn Carter Institute for Caregivers \(RCI\)](#) launched an initiative exploring the effects of employment policies on family caregivers who work full-time, funded by the **Cambia Health Foundation and Ralph C. Wilson, Jr. Foundation**.
- » [WISER's Financial Caregiver Project](#) promotes education, tools, and resources around financial wellness and retirement readiness so that caregivers can effectively plan for their own future economic security and that of their care recipient, with support from the **RRF Foundation for Aging**.
- » [ARCHANGELS Any Care Counts Campaign](#) in New York is part of a larger effort the **New York State Office for the Aging (NYSOFA)** launched to support working caregivers. The **Ralph C Wilson, Jr. Foundation, NYSOFA, ARCHANGELS**, and the Association on Aging in New York collaborate on the campaign.





## Goal 5: Data, Research, and Evidence-Based Practices

To promote *data and research* on family caregiving needed to inform policies and *evidence-based practices*, philanthropy can

- » Support research on caregiving by expanding on evidence-based program pilots.
- » Fund evaluations of caregiver programs.
- » Advance research in caregiver policy.

The Strategy calls out an important need for consistent data on caregivers, an area in which philanthropy can be supportive. These strategies include:

- » Establish a set of standards for data collection to enable researchers and other key stakeholders to better evaluate research results.
- » Improve quality of long-term services and supports by funding or otherwise encouraging coordinated and consistent measurement development for home and community-based services and family experiences of care.
- » Create a caregiver data repository that caregivers can opt into to share data with researchers.
- » Encourage widespread adoption of a core minimum data set with standardized data
- » Educate stakeholders about the value of a coordinated approach to data collection about caregiving.
- » Include adequate funding for administrative costs to provide incentives for community-based organizations to include data collection and research learning as a part of their programs and services.
- » Gather consistent data that builds the business case for workplace supports and encourages more businesses to adopt such supports.

### SELECT SUPPORT FOR DATA, RESEARCH AND EVIDENCE-BASED PRACTICES INITIATIVES

- » [Moving Hospital at Home into the Mainstream of Health Care Delivery, Addressing Health Equity and Supporting Family](#) funds research on the mainstreaming of Hospital at Home programs as a strategy to advance health equity and elevate the role of family caregivers. The grant will continue to support expansion of a Hospital at Home Users Group for adopting health systems and continue to promote permanent Medicare payment, funded by **The John A. Hartford Foundation**.
- » Cambia Health Foundation supports research on [surrogate decision-making](#) about care and palliative care goals, [meaning-centered psychotherapy](#) for family caregivers, and

[stakeholder-informed communication](#) skills training program for multidisciplinary oncology healthcare providers to improve palliative care communication quality with LGBTQ+ patients' families of choice are all research projects supported by the **Cambia Health Foundation**.

- » [Best Practice Caregiving \(BPC\)](#) Phase III is a partnership between **Benjamin Rose Institute on Aging** and Family Caregiver Alliance that will allow family and friend caregivers and persons living with dementia to enter their zip code and find support programs near them. This is supported by **Archstone Foundation, The John A. Hartford Foundation and RRF Foundation for Aging**.

# CALL TO ACTION

It is a critical time for philanthropy and policymakers to prioritize and invest in projects to support family caregivers. The momentum from the [National Strategy to Support Family Caregivers](#) and the [Biden administration's sweeping executive actions](#) to improve the lives of families, caregivers, and care workers provide a strong framework for where additional support is needed.

To ensure accountability, National Alliance for Caregiving (NAC) recently launched the [Act on RAISE National Campaign](#). Funded with a cornerstone investment from **The John A. Hartford Foundation**, the campaign calls on policymakers, state, and federal agencies to realize the promise of the RAISE Family Caregivers Act by implementing the actions outlined in the National Strategy. The campaign will accelerate implementation efforts by:

- » Systematically working with federal policymakers, agency leadership, and administration officials to ensure the timely implementation of the National Strategy, ensuring transparency and accountability.
- » Creating a space for information sharing and coordination among caregiving, healthcare, patient advocacy, and aging and disability networks around the National Strategy.

Funders and Organizations can engage in these efforts by signing up [here](#).

## **The Family Caregiving Funders Community**

To learn more about the work of the Family Caregiving Funders Community, a network of more than 30 funders (Exhibit 3), please reach out to Emily Hinsey, Director of Programs at Grantmakers In Aging, at [ehinsey@giaging.org](mailto:ehinsey@giaging.org).

## Acknowledgements

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## About The John A. Hartford Foundation

The John A. Hartford Foundation, based in New York City, is a private, nonpartisan philanthropy dedicated to improving the care of older adults. Established in 1929, the Foundation has three priority areas: creating age-friendly health systems, supporting family caregiving, and improving serious illness and end-of-life care. For more information, visit [www.johnahartford.org](http://www.johnahartford.org) and follow @johnahartford.

## About the Administration for Community Living

The Administration for Community Living (ACL) was created around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities.

By funding services and supports provided primarily by networks of community-based organizations, and with investments in research, education, and innovation, ACL helps make this principle a reality for millions of Americans. Learn more at [acl.gov](http://acl.gov)

## About the National Academy for State Health Policy

For over 35 years, the National Academy for State Health Policy (NASHP) has been a nonpartisan organization committed to developing and advancing state health policy innovations and solutions. We

are a nonprofit organization, predominantly funded by grants, that supports state leaders by providing technical assistance, publishing and disseminating research and analyses, sharing best practices, and bringing new health policy ideas across executive and legislative branches of state government. Learn more at [nashp.org](http://nashp.org)

## About Grantmakers In Aging

Grantmakers In Aging (GIA) is the only global membership organization focused on aging and philanthropy. GIA serves as a network and resource for funders and a champion for aging-related issues and investments. GIA mobilizes social, financial, and intellectual capital to catalyze change and improve the experience of aging, now and in the future. As the hub of the aging philanthropy ecosystem, GIA creates opportunities for funders to connect, collaborate, and learn from one another. Our vision is a just and inclusive world where all people are fully valued, recognized, and engaged at all ages.

GIA brings funders together from across sectors and geographies to share promising practices and to apply an aging lens to intersecting priority areas such as financial security, physical and mental health, workforce development, mobility, housing, livable communities, and the arts. To learn more, please visit [www.GIAging.org](http://www.GIAging.org) and follow @giaging.

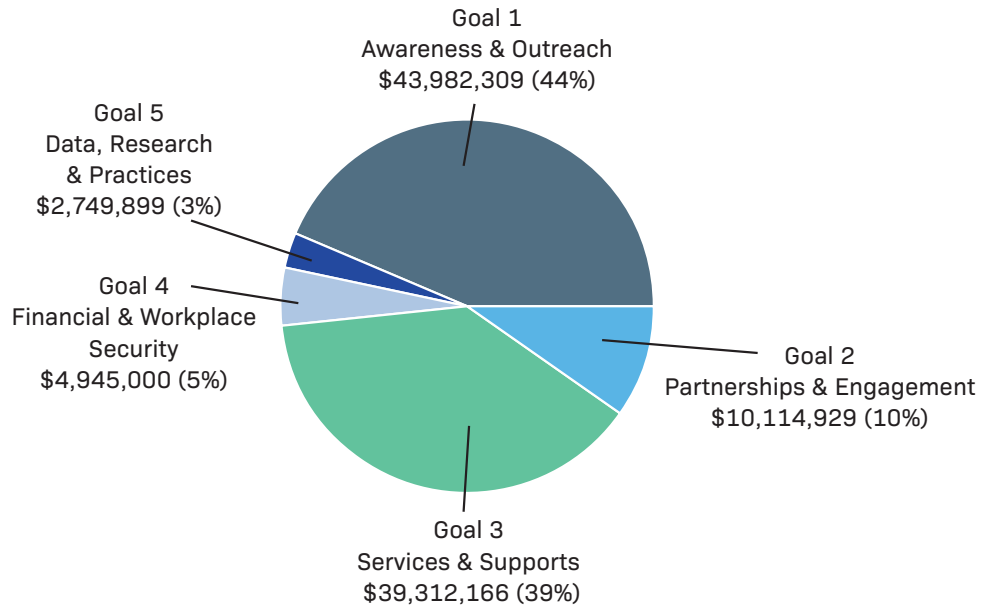
## Editorial and Design Services

Written by Christina Neill Bowen, of Christina Neill Bowen Consulting, LLC, and Erika Robbins, of Coryell-Robbins, LLC, both subject matter experts to the Family Caregiving Funders Community. Graphic design by MarcCardwell.com



**Exhibit 1: Family Caregiving Funders Community Grants in alignment with the National Strategy Goals — a \$100M Investment**

**Caregiving Funders Community Support of RAISE Act Goals (n=29)**  
 Reflecting Unduplicated Data categorized by Best Fit for grants awarded 2021-2022



**Exhibit 2: Initiatives Funded by the Family Caregiving Funders Community by Goals Outlined in the National Strategy**



Source: FCFC data collection 2022/2023 about the types of activities funded through philanthropy investment (n=36; duplicated counts).

**Exhibit 3: Family Caregiving Funders Community Members (as of 2023)**

*Altman Foundation*

*Ann Arbor Area Community Foundation*

*Archstone Foundation*

*CARE Fund*

*Carl C. Anderson Sr. and Marie Jo. Anderson Foundation*

*Csomay Center for Gerontological Excellence*

*Florence and Laurence Spungeon Family Foundation*

*Fremont Area Community Health Foundation*

*Health Foundation of Western & Central New York*

*Hearst Foundations*

*Henry and Marilyn Taub Foundation*

*Grotta Fund at Jewish Federation of Greater Metro-West New Jersey*

*Lutheran Services in America*

*May and Stanley Smith Charitable Trust*

*Metta Fund*

*McKnight Brain Research Foundation*

*Michigan Health Endowment Fund*

*National Council on Aging*

*New York State Office for the Aging*

*NYS Health Foundation*

*Presbyterian Villages of Michigan Foundation*

*Point32Health Foundation*

*Ralph C. Wilson, Jr. Foundation*

*Rita and Alex Hillman Foundation*

*RRF Foundation for Aging*

*Sahm Family Foundation*

*St. David's Foundation*

*Stupski Foundation*

*The John A. Hartford Foundation*

*The Oasis Institute*

*The Rosalinde and Arthur Gilbert Foundation*

*The Sephardic Foundation on Aging*

*The West End Home Foundation*

*Ventura County Community Foundation*

*Virginia G. Piper Charitable Trust*

*Williamsburg Health Foundation*