

# CARE IS FUNDAMENTAL

How Funders Can Accelerate Vital Progress on Caregiving



# **FOREWORD**

The need for care spans our entire lives. Caregiving is a longstanding priority for Grantmakers In Aging (GIA), part of our mission of mobilizing money and ideas to strengthen policies, programs, and resources for all of us as we age.

GIA members fund a variety of efforts to support caregivers, and the GIA <u>Family Caregiving Funders Community</u>, active since 2016, continues to create important collaborative learning and co-funding opportunities and champion caregiving to other funders. Financial support for the Funders Community is provided by the Ralph C. Wilson,

Jr. Foundation, Archstone Foundation, and The John A. Hartford Foundation.

This guide, funded by the Ralph C. Wilson, Jr. Foundation, draws on interviews with 17 leaders in philanthropy to elevate caregiving as an essential and emerging public health issue. Alongside funders, policymakers, advocates, and those in other sectors (including technology and entertainment) are stepping up to promote the development and execution of caregiving strategies that improve quality of life for millions of Americans who need help to meet their health and social needs.

Caregiving is a vitally important national issue with a great many cross-cutting touchpoints. With this report, we want to encourage funders, particularly those who may not consider themselves focused on caregiving, to become more involved.

For a more in-depth inventory and analysis of care-related grantmaking, particularly directly related to aging, please consult GIA's <u>National Strategy to Support Family Caregivers: Action Guide for Philanthropy</u>.

We need a revolution for every person in this country to have a shared recognition of the importance of family caregiving and for that recognition to come with increased investment, increased attention, and a widespread demand for change."

SERENA WORTHINGTON, RRF FOUNDATION FOR AGING

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**GRANTMAKERS IN AGING** 

# CARE IS FUNDAMENTAL, AND COMPLICATED

Like food or water, care is a fundamental human need across the lifespan. Sooner or later, all of us will require care, or need to provide care for someone else. Good care allows people to live with as much dignity and comfort as possible, while allowing parents, grandparents, spouses, friends, and extended families to live and work, with the support they need and the knowledge that their loved ones are in good hands.

That is the goal. The reality is quite different. Caregivers can be family members, close friends, "chosen family," or paid professionals, and our system relies on all of them doing their utmost

to provide care, while often being stretched to their limits in the process.

Caregiving can be rewarding but can also take a personal, health, and financial toll that reverberates across society. An estimated 53 million family members – or one in five adults – regularly provide unpaid care without training or support. That number is expected to double by 2040, according to the advocacy group Caring Across Generations.

About one in three family caregivers are "sandwich generation caregivers" for both children and older family members or friends, according to <u>analysis</u> by AARP.

Estimates of time spent on family caregiving range from 23 hours to as much as 45 hours per week. The Rosalynn Carter Institute for Caregivers estimates that 60 percent of working family caregivers miss an average of 3.2 days of work a month. All told, AARP estimates the economic value of family caregivers' unpaid contributions was approximately \$600 billion in 2021.

Caregiving is having a particular breakthrough moment. This is different from when we came into this work.

We're seeing more traction."

CATHERINE COLLEN, METTA FUND

"When I was first approached to participate in Tight Knit and tell my story about caring for my mom, I was hesitant. But then I thought to myself, 'Will it help somebody?' After all, caregiving is all about helping someone else. I hope that sharing our story will help other families like ours find peace and joy amid this journey."

Roger Young, in the documentary <u>Today Was</u>
<u>A Good Day</u>, part of the Tight Knit series
(Read more here.)



## CARE IS FUNDAMENTAL, AND COMPLICATED

Millions of Americans also rely on the help of the direct care workforce — approximately 4.8 million people. Direct care work, which includes paid services delivered by home health aides, personal care and nursing assistants, and others, is life-sustaining. It is also demanding, under-recognized, and underpaid. As a result, there is a massive shortage of workers to fill this growing need.

This workforce includes a disproportionate number of women, people of color, and immigrants, fueling a powerful equity argument for greater investment in caregiving.

Funders and their nonprofit partners play a valuable role in developing and delivering solutions, and recently caregiving has been receiving more attention from other sectors as well. Policymakers are creating new funding streams and standards; advocates are lifting up the cause of the direct care workforce and the role of caregiving as a critical part of the nation's infrastructure; grassroots groups and entertainers are tapping storytelling and lived experience to shift societal attitudes; and private industry is getting involved, creating important public-private partnerships.

This powerful intersection of interests opens the door to an exciting chapter for all of us who will ever need or receive care.

# BUILDING MOMENTUM: COMMITMENT, INTERSECTIONS, AND TIMING

Caregiving is having a long-awaited season of prominence, for several reasons.

First, its challenges are universal and intersect with many other issues. Caregiving is a huge issue in its own right, but it is also an aging issue, an economic issue, a social justice issue, a public policy issue, a health and wellness issue, a workplace and workforce issue, a women's issue, an immigration issue, a children's issue, and a disability issue.

"If a funder is focused on democracy, if a funder is focused on racial justice, if a funder is focused on women's rights, if a funder is focused on aging, ... caregiving should be a prominent part of what they work on," says Anna Wadia of the CARE Fund.

For funders of all types and sizes, there is an array of opportunities to contribute to this momentum. As Carol Zernial of WellMed Charitable Foundation says, "Caregiving has something for everyone."

Some funders, including many in the aging space, have long made support for family caregivers a priority. Among these initiatives are:

- Respite programs, such as <u>Exhale</u>, supported by the Ralph C. Wilson, Jr. Foundation, the Health Foundation for Western and Central New York, the Ann Arbor Area Community Foundation, and the Michigan Health Endowment Fund; or the <u>registry</u> of respite options for military family caregivers curated by the Elizabeth Dole Foundation.
- Efforts to involve caregivers fully in their loved one's healthcare, such as Archstone Foundation's work to <u>prioritize</u> interdisciplinary care teams that engage the caregiver. "The family caregiver is very much central to that work, making sure that they are the ones that are directing the care that they prefer," says Jasmine Lacsamana of Archstone Foundation.
- Focus on the caregiver's own health, such as the <u>Caring for Caregivers</u> initiative at Rush University Medical Center. This was funded in 2019 by RRF Foundation for Aging, then <u>disseminated</u> as part of the Age-Friendly Health Systems movement with funding from The John A. Hartford Foundation (JAHF).

#### **BUILDING MOMENTUM**

- Dissemination and action on the National Strategy to Support Family
   Caregivers (read more <a href="here">here</a>). A <a href="grant">grant</a> to the National Academy for State Health
   Policy (NASHP), which includes leveraging the lived experience of caregivers,
   comes from JAHF through its priority area on family caregiving.
- Recognizing the critical role of caregivers in times of natural disaster, the Rosalynn Carter Institute for Caregivers has <u>partnered</u> with the Federal Emergency Management Agency (FEMA) on a new first-of-its-kind guide to help caregivers protect their loved ones, called <u>Take Control in 1, 2, 3</u>: <u>Disaster Preparedness Guide for Caregivers</u>.
- Projects like <u>Best Programs for Caregiving</u>, a free online database to help caregivers and professionals find evidence-based dementia care programs, funded by JAHF, RRF Foundation for Aging, and Archstone Foundation.
- Helping both family and paid caregivers provide culturally and linguistically appropriate services, receive training and access resources, and educate the public and decision-makers about the value and rights of low-income and immigrant caregivers through advocacy and storytelling. From Metta Fund, through its Caregiving portfolio.

This foundational investment was much needed, says Serena Worthington of RRF Foundation for Aging, because, "people were just starting to understand the caregiver burden and the huge societal benefit that family caregivers provide."

# Other funders come to caregiving when and/or where it intersects their existing priorities.

- Stupski Foundation includes caregiver support in its <u>program</u> for serious illness and end-of-life care, noting that one in five caregivers reported that their seriously ill family member received "too little care," particularly pain and symptom management, during their last month of life.
- New York State Health Foundation, along with the Ralph C. Wilson, Jr.
   Foundation, JAHF, Cambia Foundation, and others, <u>supports</u> the Open
   Notes movement, which seeks to transform primary care while empowering caregivers through easier access to electronic medical records.

#### **BUILDING MOMENTUM**

- Bader Philanthropies makes Alzheimer's disease one of its special focus areas, with several programs that include socialization and support for dementia caregivers and care partners. One of these is SPARK! which offers facilitated sessions for artmaking, drama, music, poetry, and storytelling, and welcomes extended families and grandchildren.
- Margaret A. Cargill Philanthropies' grantmaking includes a focus on quality of life. Through that initiative, support to Lutheran Services in America powers the Rural Aging Action Network, which seeks innovative, community-led options for both older adults and their caregivers in rural Minnesota, Montana, North Dakota, and South Dakota.
- Cambia Health Foundation has a strong focus on palliative care and includes caregivers in several ways. The foundation supports <u>Sojourns</u>

Scholars (emerging leaders in the field) working on many aspects of caregiving, such as research on surrogate decision-making, meaning-centered psychotherapy for family caregivers, and training for multidisciplinary oncology healthcare providers to improve communication with LGBTQ+ patients' families of choice.

# THE PANDEMIC AS WAKE-UP CALL

A second driver of heightened interest was the COVID-19 pandemic, which laid bare the realities of caregiving while creating new ones and served as a harsh wake-up call about the fragility of our system. "The whole system fell apart, and it hasn't recovered," says Julia Stoumbos of the Henry and Marilyn Taub Foundation.

According to the financial firm <u>Genworth</u>, one out of every three Americans became an instant caregiver at the start of COVID. Even people who didn't become full-time caregivers

The pandemic pulled the invisibility cloak off of the caregiving realities that families had always experienced, especially low-income families, especially families of color."

ANNA WADIA, THE CARE FUND

#### **BUILDING MOMENTUM**

overnight witnessed, via Zoom, the struggles of others. "It's not just childcare, it's eldercare, it's persons with disabilities," says Carol Zernial. "COVID made caregiving more concrete to people."

"It was an experience everyone was having at once, and suddenly people were able to talk about it," recalls Tim Niyonsenga of the Michigan Health Endowment Fund. "Everyone was like, 'I didn't realize that is what people have been doing for all these years.' But they weren't calling it caregiving. It had another name, like 'taking care of my kids' or 'taking care of my aging relative.'"

Advocates seized the moment. The CARE (Care for All with Respect and Equity) Fund <a href="launched">launched</a> with an ambitious vision of "the care economy" in 2021. The CARE Fund seeks to raise and distribute \$50 million over five years to build a movement for a universal publicly supported care infrastructure that will fuel economies, improve the wellbeing of kids and families, create millions of good jobs, promote equity, and enable people with disabilities and older adults to live independently with safety and dignity.

"The pandemic pulled the invisibility cloak off of the caregiving realities that families had always experienced, especially low-income families, especially families of color," says the CARE Fund's Anna Wadia.

A first-of-its kind pooled fund with shared decision-making, CARE Fund recruited a diverse coalition, including The Ford Foundation, a GIA member. "Many of us have been talking about and trying to do something for a long time, but it was the urgency of the moment that got foundations to come around the table," Wadia adds.

Finally, in today's highly polarized political landscape, caregiving is an anomaly: a bi-partisan issue.

"When it comes to caregiving, everyone has a story," says Rani Snyder, Vice President, Program, at The John A. Hartford Foundation, and one of the original members of the Family Caregiving Funders Community at GIA. "You could probably go to any elected official on either side of the aisle, and they're going to have a caregiving story."

# A COMPREHENSIVE STRATEGY, AT LAST

One of the clearest indications of the new momentum is emergence of the first-ever <u>national strategy</u> for caregiving. A critical step was passage in 2018 of the <u>RAISE Family Caregivers Act</u> (Recognize, Assist, Include, Support and Engage), which directed the Secretary of Health and Human Services (HHS) to develop the strategy.

"Looking back, RAISE was a signal moment," says Rani Snyder of The John A. Hartford Foundation. "Prior to it, there had been no national approach to recognize and support family caregivers."

If RAISE is the blueprint, the National Strategy to Support Family Caregivers implementation, developed in 2022, is the <u>roadmap</u>. HHS Secretary Xavier Becerra <u>called</u> support for family caregivers "an urgent public health issue, exacerbated by the long-term effects of the COVID-19 pandemic."

# The strategy lays out five high-level, multisector goals:

- 1. Increasing awareness and outreach
- 2. Advancing partnership and engagement
- 3. Strengthening services and supports
- 4. Ensuring the financial and workplace security
- 5. Expanding data, research, and evidencedbased practices

Funders have helped move the strategy forward.
Two GIA members, Carol Zernial of WellMed
Charitable Foundation and Deborah Stone-Walls
of USAging, served on the RAISE Advisory Council.

RAISE was a signal moment. Prior to it, there had been no national approach to recognize and support family caregivers."

RANI SNYDER, THE JOHN A. HARTFORD FOUNDATION

The John A. Hartford Foundation (JAHF) <u>funded</u> resources, technical assistance, and policy analysis to support the Council. RRF Foundation for Aging and JAHF funded the National Academy for State Health Policy (NASHP) to create

### A COMPREHENSIVE STRATEGY, AT LAST

<u>Supporting Family Caregivers: A Roadmap for States</u>. JAHF also supported a website, <u>supportcaregiving.org</u>, with resources for caregivers of all ages, funders, employers, managed care plans, and elected officials, and funded the National Alliance for Caregiving to lead the <u>#ActOnRAISE</u> campaign, which is working with stakeholders to drive implementation of the national strategy.

And, as GIA's <u>Action Guide for Philanthropy</u> (also funded by JAHF) details, GIA members made more than 370 grants totaling more than \$100 million in 2021 and 2022 that were directly aligned with the RAISE goals. The Action Guide also outlines ongoing opportunities for funders.

## THE CAREGIVER-IN-CHIEF

Adding to the momentum, the Biden administration laid out many ways to support caregiving in the <u>proposed</u> 2021 Build Back Better agenda. Then, in April 2023, President Biden <u>signed</u> an <u>Executive Order</u> calling on Congress to "make significant new investments" and directing executive departments and agencies to use their authority to increase availability of child care and education, long-term care, home-based care for veterans, and support for family caregivers.

President Biden cited the importance of caregiving support in his own life after his wife and daughter died in a car accident and he became the sole parent to his two young sons. Then he framed the issue in the strongest possible policy terms, as "critical to our Nation's economic growth and economic security ... [and] to our national security, because it helps ensure the recruitment, readiness, and retention of our military service members."

Funding began to flow. Since September 2023, the Administration for Community Living (ACL) has announced two rounds of <u>awards</u> totaling \$6.6 million (of a planned total of \$20 million) for new approaches supporting family caregivers and generating best practices.

## **CARING ACROSS STATES**

Critical progress is happening at the state level as well.

<u>Changing the Care Conversation</u>, launched in 2022, convenes 10 state-based family caregiving coalitions, each of which recruited family caregivers and worked with them to tell their personal stories as a means of advocating for change in their communities. The coalitions developed policy priorities,

## A COMPREHENSIVE STRATEGY, AT LAST

met with state legislators and administrators, led statewide summits, and formed statewide advisory committees, all focused on boosting recognition, support, and inclusion of family caregivers. Support comes from Archstone Foundation, Bader Philanthropies, Health Foundation for Western and Central New York, the Ralph C. Wilson, Jr. Foundation, RRF Foundation for Aging, and St. David's Foundation and is led by the National Alliance for Caregiving (NAC). GIA serves as the fiscal agent.

Coalition leaders attended NAC's <u>Caregiver Nation Summit</u> in the fall of 2023, where they held more than 60 meetings with members of Congress.

Other state initiatives are focusing on direct care workers' rights, narrative change, and paid family and medical leave policies. Caring Across Generations' <u>Care Can't Wait in the States program</u> is building power through grassroots organizing in California, Illinois, Michigan, Georgia, and New York. Funders include CARE Fund, Metta Fund, the Ralph C. Wilson, Jr. Foundation, RRF Foundation for Aging, and the Robert Wood Johnson Foundation.

## PROGRESS ON PAID FAMILY LEAVE

Americans frequently incur major financial stress when taking care of family members. In fact, AARP estimates that family caregivers <u>spend</u> an average of 26 percent of their income on caregiving activities (averaging \$7,242 annually.)

In addition, people (most often women) who take time out of the workforce to provide care lose not just salary and benefits, but promotions, pensions, retirement savings, and Social Security credits. Some end up having to leave the workforce entirely.

While the US Family and Medical Leave Act (FMLA) offers workplace protections to those who take time off to care for a family member, it does not provide financial compensation. But in recent years, 14 states have stepped in to <a href="mailto:mandate">mandate</a> paid benefits, and four more have voluntary payment programs.

Stories are how human beings connect with one another and make sense of the world. In fact, MRI studies reveal that listening to a story activates the brain in such a way that it begins to mirror the activity of the storyteller's brain.

The power of stories to help achieve narrative change has attracted many advocates and funders. (A useful <u>definition</u> of narrative change is "changing the collective story we tell ourselves in order to support policymaking.")

# **NEW PARTNERS, NEW NARRATIVES**

In 2021, six philanthropy membership organizations, supported by the CARE Fund, joined forces to explore using narrative change to deepen funders' understanding of the intersectional and intergenerational nature of caregiving and the care economy. The organizations are the Asset Funders Network, the Disability & Philanthropy Forum, the Early Childhood Funders Collaborative, Economic Opportunity Funders, Grantmakers In Health, and GIA.

The report they commissioned, <u>The Story of Care: A Snapshot of the Care Narrative</u> Change Landscape, framed the challenge and the solution this way:

"Care and caregiving are undervalued and chronically underfunded due to systemic racism, sexism, ageism, ableism, and other intersecting oppressions...

... Addressing care as a systemic, societal, and communal responsibility using narrative-change strategies will pave the way for seismic cultural, political, and economic shifts in the United States."

The report also held out a goal of shifting public beliefs and values about care. Here are a few examples:

CURRENT REALITY	THE VISION
Care is the responsibility of individuals, families, and women.	Care is a collective responsibility and is supported by public dollars.
Care work is underpaid.	Care work is valued. Care jobs are well-paid, safe, family-supporting jobs.
Care is a niche issue.	Care is essential to health; early childhood; youth development; education; aging; and racial, economic, gender, immigrant, and disability justice.

## **FUNDING NARRATIVE CHANGE**

Funders have embraced this strategy, supporting journalism, podcasts, documentaries, and entertainment vehicles that portray caregiving in vivid and realistic ways.

# In journalism:

 The <u>Age Boom Academy</u>, offered through Columbia Journalism School, is a media training intensive focused on aging, funded by RRF Foundation for Aging, with prior funding from the Alfred P. Sloan Foundation, Atlantic Philanthropies, and AARP Foundation.

Alumni have written <u>stories</u> for high-profile outlets. <u>The Quiet Cost of Family Caregiving</u>, by The New York Times' Paula Span, tells the story of Dana Guthrie. "We were a close-knit family, and I would do it again," Guthrie recalled. "But I took a beating, emotionally and financially, and I haven't really been able to recover."

The Ralph C. Wilson, Jr. Foundation (RCWJRF) made multiple grants to the <u>New York & Michigan Solutions Journalism Collaborative</u> to support the Connecting with Elusive Caregivers program and operate the Caregiving Coverage Data Center. The network has also been funded by the Knight Foundation, the Health Foundation for Western and Central New York, and the Greater Rochester Health Foundation.

"Our investments in narrative and storytelling are predicated on the belief that you need to change hearts as much as minds to make societal progress with issues like caregiving," says RCWJRF's Amber Slichta.

 The Family Caregiving Funders Community of Grantmakers In Aging produces a podcast, <u>Investing in Caregiving</u>, featuring interviews with a range of advocates and innovators.

# In documentary:

- Caregiving, a two-hour documentary from WETA, co-executive produced by Bradley Cooper (a caregiver for his father) and his production company, Lea Pictures, will premiere in Spring 2025 with support from various corporate, non-profit, and philanthropic sponsors and partners.
- <u>Tight Knit</u> is a series of intimate portraits of caregivers in Southeast Michigan and Western New York. Funded by RCWJRF, it includes eight podcast episodes (on <u>Apple Podcasts</u> and <u>Spotify</u>) and two documentaries (on the foundation's <u>YouTube channel</u>.)
- Portraits of Care is a photography and video interview <u>series</u> commissioned from artist Paola Mendoza for the Care Can't Wait campaign, from Caring Across Generations.

## In entertainment:

 Comedian Seth Rogen brought a younger, edgier tone to caregiving when he launched <u>Hilarity for Charity</u> with his wife, Lauren, after her mother received a diagnosis of Alzheimer's disease. We were a close-knit
family, and I would do
it again. But I took a
beating, emotionally
and financially, and I
haven't really been able
to recover."

FAMILY CAREGIVER
DANA GUTHRIE

"Like most people, I didn't think about caregiving until my father was diagnosed with cancer. That was a wake-up call for me, certainly – one that really opened my eyes to the world of caregiving."

Bradley Cooper, from a preview of the documentary he co-executive produced



The Caregiving Project | Coming 2025

#### SHIFTING THE NARRATIVE

The organization also funds the <u>HFC In-Home Care Grant Program</u>, which provides respite care grants to dementia caregivers for three to six months of free, professional in-home care, delivered with partner Home Instead.

The hit show "This Is Us" wrote dementia caregiving into its plotline. Then the
cast and executive producer teamed up with the Rogens and Ai-Jen Poo of
Caring Across Generations for a webinar on scripting nuanced realities
of caregiving.

An <u>evaluation</u> in the *Journal of Health Communication* found the episode resonated with viewers who said it helped reduce stigma surrounding dementia and encouraged families to discuss caregiving plans for aging relatives.

# Others in Hollywood are also working to use their art to talk about caregiving.

- AARP recently <u>partnered</u> with <u>The Creative Coalition</u> (a group of writers, actors, producers, directors, agents, designers, and entertainment lawyers) to launch the <u>Entertainment Industry Commission</u> on <u>Caregiving</u>.
- The <u>Creative Care Council</u> a project of Caring Across Generations aims to influence elected leaders to pass affordable childcare programs, paid leave for all, and accessible in-home care.

# **RESOURCES FOR FUNDING NARRATIVE CHANGE**

<u>Hollywood</u>, <u>Health & Society</u>, a program of the USC Annenberg Norman Lear Center, provides the entertainment industry with information for storylines on health, including aging and caregiving.

A 2023 report, <u>Narrative Change and Impact</u>, funded by the California Health Care Foundation, identified some key considerations, including:

- The need to align expectations, particularly around the long time horizons for results, which may not fit well with philanthropic funding cycles.
- Ensuring that funders understand the creative process and the timeline for approving projects, which are unpredictable and often out of their control.
- The difficulty, and importance, of achieving message saturation in today's fractured media landscape.
- The need for cross-sector and organizational collaboration.
- The role of flexible, experimental, and iterative work that could include message testing and learning opportunities.

# "THE WORK THAT MAKES ALL OTHER WORK POSSIBLE"

Caregiving is personal, as is our perception of who is a caregiver. Many caregivers are not family members. Some are close friends (sometimes called "chosen family"); others are paid professionals in the direct care workforce. All need to be included in any new policies and progress.

"At some point, you're going to need a caregiver, whether it's a loved one or somebody who is paid in that position," says Maria Gonzalez of the Fremont Area Community Foundation. "Both have equal value, and both should absolutely be supported."

The direct care workforce is composed of approximately 4.8 million people who work in private homes, in group homes and assisted living facilities, and in nursing homes and hospitals, according to the research and advocacy organization PHI.

Advocates like Caring Across Generations stress the importance of including early care and education workers, long-term care providers, and home- and-community-based service providers in the universe of caregivers.

These diverse roles have something important in common, writes Sarita Gupta of the Ford Foundation who is also cofounder of Caring Across Generations. Gupta calls caregiving "the work that makes all other work possible," adding that, "in all permutations, in the United States, it's work that's both undervalued and unseen."



At some point, you're going to need a caregiver, whether it's a loved one or somebody who is paid in that position. Both have equal value, and both should absolutely be supported."

MARIA GONZALEZ, FREMONT AREA COMMUNITY FOUNDATION

## "THE WORK THAT MAKES ALL OTHER WORK POSSIBLE"

Being undervalued is not difficult to quantify. The median wage for direct care workers in 2022 was just \$15.43 per hour and nearly four out of ten (39%) live in or near poverty, according to PHI.

More than 85 percent of the direct care workforce are women, about two-thirds are people of color, and about one-third are immigrants. This workforce is aging, with a median age of 43. Home healthcare workers are often without benefits, according to the Ford Foundation, leaving many dependent on public assistance for their own family's needs. In most states, they are still excluded from collective bargaining or basic workers' rights.

This stark reality does not sit well with funders seeking to advance equity.



From Caring Across Generations Instagram account. <u>Posted</u> on November 17, 2023, during Carefest.

"There's a growing recognition that caregiving should not be a barrier to economic security and economic mobility," says Lindsay A. Goldman, CEO of Grantmakers In Aging. "We also cannot prioritize the needs of one population — such as older people, children, or anyone in need of care — at the expense of another population — such as their paid caregivers. And, as funders, if we value aging, we must equally value those who provide paid and unpaid support to us as we age."

Many funders are grappling with how to address equity issues, as well as the culturally specific needs of diverse populations. "How do we support racial equity in this space?" asks Chris Lemon of Ann Arbor Area Community Foundation. "Because caregiving within the Black community versus the Latino community versus the white community can look very different."

"THE WORK THAT MAKES ALL OTHER WORK POSSIBLE"

## **BIGGER THAN ALL OF US**

Advocates coined the term "the care economy" to underscore the societal importance of caregiving. "Care had always been seen as a social issue, a women's issue, but not central to a thriving economy," explains CARE Fund's Anna Wadia.

Funders are seeing value in this framing; some are also seeing an argument with the power to move policymakers. "We know the majority of the people who make up the paid caregiver workforce are non-white women. That may not be a story that resonates with the policymakers, but perhaps if we frame the story more about how, 'this workforce is important to our economy,' maybe they will listen," says Jennifer Fuller of Cambia Health Foundation.

## **GETTING THE MESSAGE OUT**

Care economy advocates are making themselves heard. In 2023, Caring Across Generations held the first <u>Carefest</u> in Los Angeles. The conference brought together cultural influencers, corporate interests, policymakers, researchers, philanthropists, advocates and caregivers; the agenda combined community-building with a call to action that was vividly amplified through social media.

# NEW SECTORS CARING ABOUT CAREGIVING

Another exciting development: venture capitalists and philanthropists, corporations, and government agencies seeking to develop and scale technologies for the care economy, some as part of public-private partnerships.

## **Examples of new money or challenges in caregiving include:**

- Pivotal Ventures, launched by Melinda French Gates in 2015 to "accelerate social progress in the United States by removing barriers that hold people back," has encouraged private investment through the <a href="The Holding Co.">The Holding Co.</a>, a lab that partners with organizations designing the modern care system, and its <a href="Invest in Care">Invest in Care</a> guide.
- Pivotal Ventures has also backed <u>Magnify Ventures</u>, an early-stage investor in care-related companies; and the <u>Techstars Future of Longevity Accelerator</u>, which focuses on innovative solutions for older adults and the people who help them.
- The MIT Solve Challenge holds open challenges for tech-based social innovators and brings together investors to support them. In 2022, the Challenge focused on the care economy. Two winners were Pie for Providers, using open source software to unlock billions of dollars in unclaimed government funding for childcare providers and families; and Re-Assist, a digital platform to improve care transitions.
- Generation Cares is funded by the Society for Human Resource Management (SHRM). The coalition sees caregiving as an issue for workers and employers as well as families, and seeks to engage corporate peers, Congress, and the White House on solutions. (SHRM also created a Resource Guide for Employers in connection with the RAISE National Strategy.)
- The Rosalynn Carter Institute for Caregivers Innovation Lab recently <u>completed</u> a yearlong pilot program to identify and scale solutions for caregivers in the workplace and released, <u>Working While Caring</u>. "We applaud all the employers who took part in the inaugural Innovation Lab and hope that not only they,

#### NEW SECTORS CARING ABOUT CAREGIVERS

but many other employers, see the tremendous value it can bring to an organization's culture by valuing, listening and working together with employees who are caregivers and their families," says Amber Slichta, VP of Programs and Learning at the Ralph C. Wilson, Jr. Foundation, which provided grant support for the study

- The Consumer Technology Association (CTA) Foundation runs its annual <u>Eureka Park Accessibility Contest</u> to highlight promising tech-powered solutions. Recent winners include Caregiver Smart Solutions, which allows families to monitor older people at home via cellphone.
- The Elizabeth Dole Foundation funds <u>Hidden Heros</u> a first-of-its-kind website featuring stories from military caregivers, a vetted resource directory, and a private Facebook community. More than one quarter of US military veterans enrolled with the Veterans Health Administration <u>report</u> needing the support of a caregiver in addition to services they receive through their federal benefits.

# New public-private partnerships

State agencies that support caregivers are also finding new partners.

"Public-private partnerships are critical to the success of serving older adults and their caregivers, says Greg Olsen, Acting Director of New York State Office for the Aging (NYSOFA). "Partnerships enable us to expand services, test and measure new models, and fill in existing gaps."

#### NYSOFA's collaborations include:

- The Any Care Counts New York <u>campaign</u>, funded in part by the Ralph
  C. Wilson, Jr. Foundation, linking caregivers to free <u>resources</u>, including
  <u>Trualta</u> (evidence-based, skill-based training); the EXHALE Family Caregiver
  Respite program; and the Archangels caregiver support <u>platform</u>.
- Coming soon: access for New York dementia caregivers to programs like
   <u>Relish</u> (products like toys, puzzles, and radios); <u>Memory Lane TV</u> (programs
   adapted for people with memory loss); and <u>MapHabit</u> (support for
   schedules and activities of daily living.)

# **GETTING STARTED**

The growth in caregiving investment reflects decades of work by committed funders coupled with the unique circumstances of the pandemic. This urgent and cross-cutting issue will affect us all and offers powerful opportunities for funders. Here are some strategies to consider.

> Explore the intersections and shared values between caregiving and work that you already support. Funders who care about older people, children and youth, disability, health equity, economic justice, or women's or immigrants' issues will find resonance in caregiving.

"My recommendation for funders in the aging space is to engage more with funders in other spaces across the care continuum," says Anna Wadia of the CARE Fund.

- > Start small. Even if your institution doesn't make it a specific priority, there are still many ways to infuse caregiving into your existing work. Consider asking nonprofit partners if they see a caregiving angle in their mission or if they could add or elevate one with the right support.
- Co-fund or join ongoing funding for an existing caregiving initiative. Fund expansion or dissemination of a promising practice, or help a nonprofit add staff or build evaluation capacity.
- > Listen. Whether they are direct care workers or unpaid family members, caregivers have historically been ignored. Be a convener by funding town halls or small group meetings and allow diverse caregivers to describe the challenges they face and the help they think would be most valuable.

"How do we make sure that we are helping caregivers from a variety of backgrounds?" reflects Amy Eisenstein of RRF Foundation for Aging. "We implemented an advisory board of people who have lived expertise in the areas we're funding. Last month, we had a session on caregiving and got their feedback and their input. Where do we need to be heading? Are there gaps that we're not covering?"

#### **GETTING STARTED**

- > Fill a gap. What are the unmet needs in your community? Invest in research, data collection, focus groups, or surveys, both to educate your own institution and to help build a value proposition for other partners, including local policymakers, cultural institutions, or health systems. Or look at the five goals of the National Strategy to Support Family Caregivers which need support.
- > Partner with an academic. More investigation is needed in this growing field. "Our researchers, students, and trainees ... have the skills to identify a caregiving challenge, examine the existing evidence, develop a project to address the challenge, then evaluate the success of the project," says Leah Buck, Director of the Csomay Center for Gerontological Excellence at University of Iowa College of Nursing.
- > Know you don't have to go it alone. GIA is here to help connect you to other funders. Attend a meeting of the GIA Family Caregiving Funders Community and learn where you can plug in.
  - "I feel like there's more I get to learn every time I talk with other funders in caregiving," says Jasmine Lacsamana of Archstone Foundation. "It's all part of this tapestry of how different funders are finding something that resonates with their foundation's priorities."

# **ACKNOWLEDGMENTS**

# **About Grantmakers In Aging (GIA)**

GIA is a community of funders mobilizing money and ideas to strengthen policies, programs, and resources for all of us as we age, and the only global membership organization focused on aging and philanthropy. GIA creates opportunities for funders to connect, collaborate, co-fund, and learn from one another. We help funders who are already investing in aging to fund more strategically, and we help funders who are not funding in aging to identify the intersections of aging and every other funding priority. Our vision is a just and inclusive world where all people are fully valued, recognized, and engaged at all ages. To learn more, please visit <a href="https://www.GIAging.org">www.GIAging.org</a>.

# **Editorial and Design**

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# About The Ralph C. Wilson, Jr. Foundation

The Ralph C. Wilson, Jr. Foundation is a grantmaking organization dedicated primarily to sustained investment in the quality of life of the people of Southeast Michigan and Western New York. The Foundation focuses on active lifestyles, caregivers, preparing for success, entrepreneurship and economic development, as well as nonprofit support and innovation, with a structure that dictates spend-down of funds by 2035. To learn more, please visit www.ralphcwilsonjrfoundation.org.