

NewCourtland Center for Transitions *and* Health

UNIVERSITY of PENNSYLVANIA
SCHOOL of NURSING

Caregiving NOW: Year 1 Report (August 2023)

Caregiving NOW is a two-year initiative designed to identify ways to improve the lives of family caregivers nationally and to test promising interventions locally. In Year 1 (2022-2023), we hosted 11 webinars with national experts, each designed to explain an important aspect of caregiving and to explore promising strategies to support caregivers in their vital role. In parallel, we conducted a thorough literature review of caregiving research and innovations that will be published in Year 2. This report summarizes what we learned from our webinars, what we accomplished in Year 1, and what we are planning in Year 2. A complete list of webinars and speakers appears in Appendix 1, followed [by blog posts](#) that highlight the main points of each session. Here we summarize several themes that emerged across these webinars.

1. Increasing the visibility and awareness of caregivers

Although more than 53 million Americans are family caregivers, as our leadoff speaker [Heather Young](#) noted, they are relatively invisible in our health care system, our workplaces, our religious institutions, and our social policies. Raising awareness of caregivers, and centering them in our policies and politics, are necessary steps in understanding their burdens and addressing their needs. We heard from a number of speakers that caregivers often don't identify as caregivers, but rather, as simply doing what good partners, good children, or good humans do. They may not fully grasp the physical, emotional, and financial toll of caregiving, and may not seek out further support or resources.

Employers are often unaware of the prevalence of caregiving in their workforce, even though it has significant effects on worker productivity and turnover. Few federal or state policies are targeted to caregivers, although a policy window might be opening with the release of the first-ever [National Family Caregiving Strategy](#) last year, which included recommendations for more concrete federal actions in the future.

Promising strategies

- [Alexandra Drane](#) of ARCHANGELS discussed the development and use of the [Caregiving Intensity Index™](#), a two-minute self-assessment to measure how caregiving is affecting someone's well-being and how well they are coping with potential stressors such as money and family disagreements. It generates an intensity score and then links caregivers to resources specific to their needs and stressors. It has been implemented in workplaces and in New York and Massachusetts through "Any Care Counts" campaigns.
- [Jennifer Olsen](#) of the Rosalynn Carter Institute discussed its "[4kinds Network](#)," composed of current and former caregivers who share their stories with policymakers. Through speaking at legislative hearings, conducting media interviews, and developing documentaries, caregivers' stories are being heard at federal, state, and local levels. The 4kinds network is one way in which current and former caregivers can leverage their individual and cumulative voices to influence policy as it is being developed.

2. Centering caregivers in our health care system and policies

Despite the prevalence and importance of family caregivers, they are often ignored or an afterthought in patient care. Several speakers brought up personal experiences of clinicians not including caregivers in plans or conversations about their loved one. There may not even be a chair in the exam room for the caregiver. As more and more complex care shifts into the home (including hospital-at-home initiatives and post-acute care), the role of the caregiver becomes even more crucial and potentially more burdensome.

Ethicists ([Christine Grady, Jason Karlawish, and Carol Taylor](#)) noted that caregiving brings up complex ethical issues around surrogate decision-making, dignity, justice, and moral distress. Many clinicians do not understand their ethical obligation to caregivers, even in cases where the patient has marginal decision-making capacity.

Our health care system and policies typically categorize caregivers by the diagnosis of the care recipient, with little to no information on the lived experiences of caregivers themselves.

Promising strategies

- The Rosalynn Carter Institute is working with academic partners on a new typology of caregiving, one that could better match the individual needs of caregivers to relevant resources. A new typology would incorporate similarities and differences across caregiving experiences and pave the way for a more targeted and effective allocation of resources.
- The Rosalynn Carter Institute is also advocating for federal coordination of resources through a new Office of Caregiver Health within the Department of Health and Human Services. This structural approach can overcome silos of agencies and programs that are often geared to specific diagnoses or payers. The new office would provide leadership around effective caregiver resources and ensure that caregivers are represented in health policy and programs, regulations, and budget negotiations across federal agencies.

Caregiving NOW accomplishments

- Mary Naylor and colleagues, including speaker [Susan Reinhard](#), published an [article](#) in JAMA Forum on the need to consider caregivers in hospital-at-home programs. It lays out a research and policy agenda that requires that clinicians, administrators, policymakers, and payers commit to family-centered care and embrace family caregivers as true partners in hospital-at-home care.

3. Supporting caregivers in the workplace

National data indicate that 60% of caregivers are employees, and 60% of them are working full-time. But employers rarely assess the prevalence of caregivers in their workforce and even less frequently engage caregivers in designing benefits that enhance their work and home life. Benefits are often targeted to new parents and families with young children, rather than family caregivers of elderly or serious ill relatives.

In interviews, caregivers report that they value scheduling flexibility, remote work arrangements, paid leave, and respite services. Employers can play a key role in supporting their caregiving employees by increasing the flexibility of existing benefits and employee assistance programs to better meet caregiver

needs. Several speakers noted that enhancing benefits can have a significant positive impact on a firm's ability to recruit and retain productive employees.

Promising strategies

- A recent Bank of America [report](#), written by Mary Naylor and colleagues in Penn Nursing, offers a path for employers to change benefits or add programs to support working caregivers. Recommendations include offering financial planning to employees, as well as preparing them for their potential role managing someone else's finances; considering benefits specific to caregiver needs, such as access to geriatric care management services and emergency backup care; and building the human resources infrastructure to identify caregivers in their workforce and continuously engage them in benefit design and implementation.
- Jennifer Olsen of the Rosalyn Carter Institute discussed their collaboration in SE Michigan with a coalition of employers seeking to support employees who have jobs that are not flexible in time or place. These caregiver-employees cannot benefit from strategies such as remote work. Instead, this group is exploring different ways to schedule shift work and pool resources so that their employees can fulfill their caregiving responsibilities and stay in the workforce.

Caregiving NOW accomplishments

- Mary Naylor disseminated information to the [Society for Human Resources Management](#), the largest membership organization of human resource professionals in the country. She provided them with a one-page bulleted summary describing Caregiving NOW and key recommendations targeting employers and linked the organization to the recent Bank of America report.

4. Supporting caregivers financially

Family caregiving has significant direct and indirect financial impacts, especially on women and minority populations. On average, caregivers spend more than \$7,000 each year to help their loved ones, often making tradeoffs between present spending, saving for large expenses, and saving for retirement. Further, many employed caregivers reduce hours, refuse promotions, or leave the workforce entirely to meet their family responsibilities. This can have an enormous impact on retirement readiness, something often not considered in financial planning.

Financial caregiving also includes handling someone's financial affairs, such as paying taxes, managing bank accounts, filing insurance claims, or identifying a Power of Attorney. These duties can sometimes extend beyond the loved one's death.

Promising strategies

- Amend tax policies to promote the use of personal savings for caregiver expenses ("found money"). This could include expanding Health Savings Accounts to include long-term care expenses and allowing withdrawals for long-term care expenses from 401K plans without a tax penalty.
- Provide federal or state support directly to caregivers ("new money"). This would help address the disproportionate financial impact of caregiving on women and minorities. One example is the proposed \$5,000 refundable federal tax credit in the 2021 Caregiving Act.

- Reframe retirement planning to incorporate longevity and the likelihood of caregiving expenses. [Surya Kolluri](#) of the TIAA Institute presented research on the concept of “longevity literacy” and its connection to retirement savings.

5. Bolstering the direct care workforce

The burden of family caregiving is directly related to the large and growing deficit in the direct care workforce, including home health aides and nursing assistants. The supply is decreasing even as demand is increasing, because of low pay, poor training, and the absence of career growth potential. There are no federal standards for training or assessing competencies for direct care workers. Low pay is the result of reimbursement levels of state Medicaid programs, which pay for a majority of long-term care in the home.

Promising strategies

- In New York State, [Carol Raphael](#) has worked with a consortium of unions, health plans, providers, and direct care workers to design a new model of training and compensation. The model includes an annual salary of \$40,000, with benefits and performance bonuses, as well as ongoing training and peer networks. The model is now “shovel-ready” and she is now discussing the investment the state would need to make (by increasing Medicaid payments) to cover funding gaps in the model. She is using economic models to predict cost offsets from increased productivity, decreased administrative costs, and reduced public benefits for direct care workers.
- Other states are taking steps to promote a more accountable, better trained, and more highly paid workforce. [Tennessee](#) reimagined training with a 1-year on the job apprenticeship, more pay, and college credits. [Arizona](#) moved to a competency-based training program with modules on specific populations to address client complexity. [Michigan](#) has instituted an advisory council on the direct care workforce.

6. Meeting caregivers’ spiritual needs

Caregiving can be both spiritually fulfilling and draining. We heard from religious leaders ([Rabbi Richard F. Address](#) and [Reverend Tyrone Pitts](#)) that cross many religious traditions, faith, and caregiving are deeply connected, and caregiving can be considered “a sacred act”. This spiritual dimension is rarely discussed among health care professionals and researchers, although it can be key to caregiver well-being.

In addition, faith-based communities are a central part of a community’s infrastructure and are natural partners for supporting caregivers. Partnering with established churches, synagogues, temples, and mosques could significantly impact the estimated 150 million Americans who are members of a religious congregation.

Promising strategies

- [Fayron Epps](#) has partnered with faith-based organizations in African American communities to support families affected by dementia. She created the [Alter Program](#) to equip faith-based communities to better serve their parishioners with cognitive impairment. Currently partnering with faith communities in seven states (Arkansas, Florida, Georgia, Illinois, Kentucky, North Carolina, and Minnesota), her educational program is expanding to Tennessee and Pennsylvania.

- In Detroit, the Southeast Michigan Care Alliance created “[Caregiver Sundays](#)” in which the pastors preach sermons on caregiving, and invite caregivers to come to the front to receive a certificate and be honored. Pastors have lunch with the caregivers after the church meetings and serve them meals. Similarly, Jewish congregations hold Friday night services to honor caregivers. During high holiday services, caregivers are invited to come up as a group to say the blessings before the Torah is read.
- The [Alameda County Care Alliance](#) worked with six local churches to launch a program with navigators and training to support family caregivers.

Caregiving NOW accomplishments

- Mary Naylor and colleagues at Penn Nursing published an [editorial](#) in Nursing and Health on how religious organizations can partner with public health agencies to support older adults with dementia and their caregivers. It calls for increasing partnerships with faith-based organizations to help bridge health education with support, and to access the respite caregivers so desperately need.
- Mary Naylor joined Rabbi Richard Address as a special guest on his weekly [Seekers of Meaning](#) TV show and podcast. The conversation focused on Caregiving NOW goals and the important role that religious organizations can play in supporting caregivers.

7. Using technology to improve caregiving and care

No aspect of modern life is untouched by technology, and family caregiving is no exception. Several speakers pointed to the potential for technology to enhance the coordination of care across settings, improve communication between providers and both paid and unpaid caregivers, remotely monitor signs and symptoms in the home, and enable more remote caregivers to stay involved in their loved one’s care. However, implementing new technologies in the home and with caregivers poses challenges, particularly for populations with fewer resources and technological capabilities.

Technology commonly used in retail shopping can be applied to organizing existing resources so that they are more accessible to caregivers when they need them. This approach can be used to a develop clearinghouse (“one-stop shopping”) that helps caregivers find existing local resources and organize them to make them more consumable on demand.

Promising strategies

- [George Demiris](#) of Penn Nursing described [Sense4Safety](#), a project that evaluates a passive monitoring system for at-risk older adults in their homes. The research team places commercially available depth sensors that can identify escalating risk for falls in real time. These sensors calculate gate parameters, such as stride, length, or speed, which may indicate an increased risk of falls. That information can alert the family caregiver or a nurse to develop an individualized plan to reduce the risk and possibly prevent a fall from happening.
- We heard from a number of speakers about commercial entities using technology to improve the coordination of services and facilitate communication between providers and caregivers. They include home agencies such as ConcertoCare ([Julian Harris](#), CEO) and Home Instead ([Jisella Dolan](#), Chief Global Advocacy Officer), which use a combination of high-touch and high-tech care. These technologies include advanced data analytics for providers and easy-to-use online dashboards for caregivers. We also heard about a platform and network from [Ashish Shah](#), CEO

of Dina, which allows older adults and their families to coordinate all in-home and post-acute services, such as personal care, home health, medical equipment, meal delivery, and home modification. It also features interoperability with medical record systems, which addresses workflow problems in managing care across settings.

Year 2 Caregiving NOW Initiatives

Our conversations with experts in Year 1 yielded insights about caregivers and the support they need. We heard about promising programs and strategies, which now informs our plans for year 2. Our goals center around the importance of **linking working caregivers to important resources** that can improve their well-being. We are now actively planning the following initiatives in that context:

1. Implement an “Any Care Counts” campaign with a local employer to a) raise awareness (including self-identification) of caregiving in the workplace, and b) connect caregivers to existing local and state resources.
2. Develop a white paper on financial caregiving to: a) raise awareness on the need to prepare for longevity and retirement, and b) recommend ways that individuals, financial planners, employers, and society can support a more inclusive retirement ecosystem that empowers people to plan for and address the financial challenges they are likely to face as family caregivers.
3. Hold an interactive summit with a broad range of employers to discuss opportunities for businesses to adopt policies addressing employee caregivers’ needs. Three questions will be considered: a) What can small employers do, within the constraints of their business, to help employee caregivers? B) How can large businesses become the hub for testing actions to evaluate viability and transferability to businesses of other sizes? and c) What public policies could help pave the way for businesses to support employee caregivers?

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Caregiving NOW



Our webinar series has finished, but the work is continuing. Over the next several months, we will be widely disseminating immediate and longer-term opportunities to enhance programs, services, and policies that can improve the lives of caregivers. If you missed any of the Caregiving NOW webinars, we invite you to visit our website to read the blogs or watch each session. Just scan the code or go to <https://www.nursing.upenn.edu/ncth/caregiving/caregiving-now-blog/>

Seeing and Supporting Family Caregivers



- Susan Reinhard
Director, AARP Public Policy Institute



- Heather Young
Professor of Nursing, UC Davis

Teaming Up with Caregivers



- Julian Harris
Chairman and CEO, ConcertoCare

Keeping the Faith with African American Families Living with Dementia



- Fayron Epps
Assistant Professor of Nursing
Emory University

Hope and Possibility for Improving the Caregiving Experience



- Jisella Dolan
Chief Global Advocacy Officer
Home Instead

Investing in the Direct Care Workforce of the Future



- Carol Raphael
Senior Advisor,
Manatt Health Solutions

The Sacred Art of Caregiving



- Rabbi Richard Address
Founder and Director, jewishsacredaging.com



- Reverend Tyrone Pitts
General Secretary Emeritus, Progressive
National Baptist Convention Inc.

How Do We Help Caregivers Who Don't Know They Are Caregivers?



- Alexandra Drane
Co-Founder and CEO, ARCHANGELS

Dollars and Sense: The ABCs of Financial Caregiving



- Surya Kolluri,
Head of TIAA Institute

Smart Home, Smarter Care: Enhancing Caregiving Through Technology



- George Demiris
Penn Integrates Knowledge Professor
University of Pennsylvania



- Ashish Shah
CEO and Co-Founder, Dina

Ethical Dimensions of Caregiving: The Lived Experience of Being a Bioethicist, a Healthcare Clinician and a Caregiver



- Christine Grady
Chief, Department of Bioethics
National Institutes of Health Clinical Center



- Carol Taylor
Professor of Medicine and Nursing
Georgetown University



- Jason Karlawish
Professor of Medicine, Medical Ethics and
Health Policy, Neurology
University of Pennsylvania

From the Margins to the Middle: Centering Caregivers in Policy and Research



- Jennifer Olsen,
CEO, Rosalyn Carter Institute for Caregivers