

STRATEGIC PLAN 2020-25

Overview: Midterm Goal 8

Family caregivers of older adults are valued and supported.



Context: Strategic Plan 2020-2025

In October 2020, the Health Foundation for Western and Central New York announced a new vision statement and strategic plan that will guide the work of the Health Foundation through 2025. An extensive planning process that began in 2019 has resulted in a new organizational vision statement, as well as three long-term goals and corresponding mid-term goals to pursue that vision. **Our new vision is a healthy central and western New York where racial and socioeconomic equity are prioritized so all people can reach their full potential and achieve equitable health outcomes.**

The Health Foundation's mission will continue to be improving the health and health care of the people and communities of western and central New York. The plan also reaffirmed the Health Foundation's commitment to young children impacted by poverty; older adults; and the community-based organizations that serve them.

Our new vision will be pursued through a set of long- and mid-term goals. This playbook provides an overview of why we chose a specific goal, and how we plan to pursue it.

Midterm Goal 8: Family caregivers of older adults are valued and supported.

Unpaid family caregivers are the backbone of the long-term care system in the United States. Although the number of caregivers in America is increasing with each passing year, as "baby boomers" age and move into retirement there will be an even greater need for caregivers. The growth in the number of family caregivers is simply being outpaced by the growing aging population. In 2010, the caregiver support ratio was more than seven potential caregivers for every person in the high-risk years of 80-plus. The ratio is expected to fall to less than three to one in 2050 when all boomers will be in the high-risk years of late life.

Although family caregiving is rewarding, it can take an incredible toll on the caregiver's physical and emotional health. With a shrinking ratio of caregivers to older adults, we must increase the availability and quality of supports that help sustain caregiver efforts. This will be an essential part of helping older adults age with dignity in the community and will require thinking creatively about how to mobilize the community behind this effort.

In 2017, the Health Foundation established an endowed program officer position dedicated to caregiving with funding from the Ralph C. Wilson, Jr. Foundation. The Health Foundation continues to work in partnership with the Wilson Foundation to provide expertise and bring focus to the issue of family caregiving for older adults. Together, we will continue to collaborate with local, regional, and national funders to develop and expand caregiver supports.

BACKGROUND

More than one in every five American adults is a caregiver (21.3 percent), meaning they have provided care to an adult or child with special needs at some point in the last twelve months, and these numbers continue to rise. When looking at caregivers for adults only, the prevalence

of caregiving increased substantially between 2015 and 2020, from 16.6 percent 19.2 percent. This increase represents an additional eight million caregivers in America, and it is primarily driven by an increase in caregiving for family members or friends who are age 50 or older. These unpaid family caregivers are a cornerstone of health and long-term care systems, as they are the primary providers of care for older adults living in the community. As many older adults would prefer to age in place in their homes, and as the cost of residential long-term care continues to rise, it would be impossible to overstate the importance and value of family caregivers.

According to the AARP Policy Institute, family caregiving represents a larger economic driver than total Medicaid spending; in 2018 the economic value of family caregiving was \$470 billion dollars, compared to the \$449 billion spent on Medicaid. In New York State alone more than **2.6 million family caregivers provide more than 2.4 billion hours of caregiving, which is valued at roughly \$31.3 billion.** Without family caregivers, the long-term care systems would not be able to provide care for all the older adults in our communities. Despite this, there continues to be a lack of attention to, and funding to support, family caregivers.

Caregivers are as diverse as the rest of America. The “average” or typical caregiver is a non-Hispanic white woman; she’s about 50 years old, married, with a high school education and a job, with a household income around \$67,500. However, four in 10 caregivers are men, and caregivers are overrepresented in communities of color, with 17 percent being Hispanic or Latino, 14 percent non-Hispanic African American or Black, five percent Asian American and Pacific Islander, and three percent some other race/ethnicity, including multiracial. An increasing number of young adults are becoming caregivers as well, with nearly one in four caregivers between the ages of 18-34, and another 23 percent between 35 and 49 years old. Hispanic and African American caregivers have lower median household incomes, relative to white and Asian American caregivers. 30 percent of caregivers also have children or grandchildren at home. Hispanic caregivers are the most likely to have children or grandchildren at home, with 47 percent reporting that they are caregivers to children or grandchildren in addition to an older adult.

As older adults continue to live longer, they often have more complex long-term medical issues. Consequently, caregivers are increasingly required to provide more complex medical care at home and navigate complex care systems to help their care recipient get the care needed. These difficulties can result in both financial and emotional strain for caregivers. Twenty percent of caregivers report significant financial strain as a result of caregiving, and 40 percent report at least some financial impact. Most caregivers with full-time jobs report going in late, leaving early, or taking time off to accommodate care, and 10 percent have had to leave their jobs entirely as a result of their caregiving responsibilities. Employer policies such as paid family leave and paid sick days have become more common since 2015 (and New York State made paid sick days mandatory in 2021), but 61 percent of caregivers nationwide still report no paid family leave in their workplace.

In addition to financial strain, many caregivers experience tremendous emotional stress as a result of caregiving. More than a third of caregivers find their caregiving situation to be highly

stressful, and 28 percent consider it to be moderately stressful. However, some groups of caregivers report significantly higher emotional distress; 72 percent of caregivers who feel alone report high emotional stress, as do 48 percent of caregivers who had no choice in assuming the role of caregiving.

Of special note is the fact that caregivers who co-reside with their care recipient more often report feeling lonely (29 percent) than do caregivers who do not live with their recipient (16 percent), and as noted above, 72 percent of caregivers who feel alone report higher emotional stress. This is noteworthy given that loneliness is a significant risk factor for early mortality, as well as physical and emotional health problems.

Programs and supports for family caregivers traditionally fall into three broad categories:

- Individual level interventions targeted at the caregiver and/or care recipient, such as education, coping skills, social support groups, and therapy.
- Organizational level interventions, such as workplace benefits, employee education, adult day services, care coordination programs, and in-home and out of home respite programs.
- Society level interventions, such as policy changes to insurance and Medicare reimbursement, family leave policies, the CARE act, and other policy changes.

In their report on “Families Caring for an Aging America,” the National Academies of Science found that caregiver interventions had not been tested in real world delivery systems, were extremely complex but failed to address the complexity of caregivers’ needs, were primarily developed and tested on white, female caregivers, lacked long term outcome data, and lacked reimbursement methods for sustainable implementation. However, under research conditions, individual caregiver interventions were found to significantly delay nursing home placement, reduce caregiver depressive symptoms and distress. This suggests that these programs have promise and could result in significant healthcare savings if more widely implemented.

Organization level interventions also show promise for improving the well-being of caregivers and care recipients, such as care coordination programs for older adults with dementia and respite care. However, families are not always aware of the availability of these services, cannot or do not want to leave their family member, or do not have access to such services.

The COVID-19 pandemic has highlighted the challenges many caregivers face on a daily basis and exacerbated some of the most pressing challenges of caregiving, such as loneliness, coordinating care between providers, and juggling multiple responsibilities. These challenges are even more present for “sandwich” caregivers who may be responsible for homeschooling children while also caring for an older adult during this time.

WHAT THE FOUNDATION HAS DONE TO DATE TO ADDRESS THIS GOAL

The Health Foundation previously supported caregivers as part of their overall body of work related to older adults. Because the Health Foundation’s older adult work focused on adults

living at home in the community, this work naturally included caregivers. The explicit focus on caregivers and caregiving began under the Foundation's 2014-2019 strategic plan, and work in this area accelerated with the partnership with the Ralph C. Wilson, Jr. Foundation. Consequently, most of the work specifically with caregivers is relatively recent. Prior to current work, some efforts targeted specifically at caregivers including disseminating the *Powerful Tools for Caregivers* evidence-based model to five counties across western and central New York. This project highlighted the need for increased attention to the diversity of caregivers and their needs.

Scans and Reviews: The Health Foundation has co-sponsored and sponsored several scans and reviews aimed at understanding caregivers' needs and building the evidence base for caregiver-focused interventions and supports. These include the co-sponsored *Families Caring for an Aging America* report, which was a national report on caregiving that highlighted many of the challenges facing caregivers and evaluated the existing evidence for interventions. Additionally, the Health Foundation partnered with the Ralph C. Wilson, Jr. Foundation to conduct a scan of Memory Café programs to better understand how these types of joint enrichment programs can benefit caregivers and care recipients.

Respite Research Consortium: In 2014, the Administration for Community Living, in conjunction with the ARCH National Respite Network, convened the Expert Panel on Respite Research to assess what was known about the effectiveness of caregiver respite programs. The conclusion of the panel was that there was a lack of rigorous research on respite, and that more work needed to be done to establish both an evidence base and a stronger value proposition for increased investment in this type of caregiver support. The recommendations of the panel included forming a consortium of philanthropic funders to help support original research. The Health Foundation was the first funder to commit to joining the Respite Research Consortium and we are currently supporting a study being conducted by Dr. Tiffany Washington at the University of Georgia entitled *Building Evidence for Respite*.

In addition to Dr. Washington's study, the work being done by the Health Foundation as part of the Communities Care Family Caregivers Respite Pilot Program will be a valuable contribution to the overall understanding of respite programs. The Health Foundation is contributing to the national conversation by participating in the Coalition to Advance Respite Research, led by ARCH National Respite Network as part of a new five-year initiative supported by a grant from the Administration for Community Living.

Western New York Respite Pilot: Through the Communities Care Western New York Family Caregivers Respite Pilot Program, the Foundation is partnering with the Ralph C. Wilson Jr. Foundation to learn how to provide community-driven support and compassion through respite to family caregivers in the rural WNY counties of Allegany, Cattaraugus, Chautauqua, and Wyoming. The Respite Pilot Program was designed to help teams of organizations learn and apply Creative Problem Solving techniques and work together to increase respite opportunities for family caregivers of older adults. Three pilots were funded as part of this work and began implementation at the end of 2020. Further details about these projects are included below in the section on upcoming work.

Faith Leaders: The Health Foundation is providing tactical and leadership support to an effort launched by the Wilson Foundation to reach out to faith leaders in the city of Buffalo and engage them in efforts to support caregivers. This project included providing support for these faith leaders to participate in a national summit to learn more about caregiving and how to support caregivers. Currently work is underway to develop a plan to leverage the relationships that have been established with faith leaders to provide increased support to the caregivers in their communities.

Brookdale Respite and Relatives as Parents Program: The Health Foundation funded one Brookdale National Group Respite program and two Relatives as Parents Program sites. These programs are nationally recognized models for supporting caregivers. The goal of these programs is to provide better support to both caregivers of older adults with dementia, as well as relatives raising children. Both programs include support groups as a primary component, and these support groups are supplemented by other services and linkages to community supports for caregiving. The grant included support for participating in a national caregiving conference, as well as ongoing technical assistance with program implementation.

Project SECURE: This CALL to Action project is being undertaken by a coalition of agencies in Onondaga and Erie Counties to devise and test innovative approaches to assist family caregivers of older adults. Project SECURE (Supporting the Experience of Caregivers to Upstate Region Elders) is designed to test the hypothesis that the caregiving experience can be qualitatively and cost-effectively improved by adding a new non-medical Caregiver Partner to the care team. The Caregiver Partner will receive additional training in gerontology, active listening and teamwork and will provide direct services in the home while serving as a point of connection to the rest of the care team and a broad range of community services.

Strategies Moving Forward

The Health Foundation will continue implementation of EXHALE: The Family Caregiver Initiative in western New York, in partnership with the Ralph C. Wilson, Jr. Foundation. This effort supports the development of innovative, collaborative projects that increase respite opportunities for family caregivers of older adults in rural Western New York and beyond.

The Health Foundation will also explore innovative models for joint enrichment, as well as caregiver education and training programs. Promising models for caregiver support developed in western New York will be shared with central New York funders as part of an effort to identify new partners to expand successful caregiver programs to the region.

Moving forward, the Health Foundation will work with caregiver-serving community-based organizations to increase their capacity to work with health systems, and to advocate to integrate caregiver-focused components into broader Age Friendly Health Systems work.

KEY PERSONNEL

[Ken Genewick](#)

[Diane Oyler](#)
[Jordan Bellasai](#)
[Nora OBrien-Suric](#)

Additional Reading:

AARP 2020 Report: Caregiving in the US

<https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>

Families Caring for an Aging America: <https://nam.edu/families-caring-for-an-aging-america/>

National Institute on Aging, Caregiving: <https://www.nia.nih.gov/health/caregiving>

Burning the Candle at Both Ends: Sandwich Generation Caregiving in the US:

https://www.caregiving.org/wp-content/uploads/2020/05/NAC-CAG_SandwichCaregiving_Report_Digital-Nov-26-2019.pdf