



The Future of Family Caregiving: LEADING THE CHANGE











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AARP is the nation's largest nonprofit, nonpartisan organization dedicated to empowering Americans 50 years of age or older to choose how they live as they age. With nearly 38 million members and offices in every state, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands, AARP works to strengthen communities and advocate for what matters most to families, with a focus on health security, financial stability, and personal fulfillment. AARP also works for individuals in the marketplace by sparking new solutions and allowing carefully chosen, high-quality products and services to carry the AARP name. As a trusted source for news and information, AARP produces the nation's most circulated publications, AARP The Magazine and AARP Bulletin. To learn more, visit www.aarp.org, or follow @AARP and @AARPadvocates on social media.

The Future of Family Caregiving: LEADING THE CHANGE

amily caregivers are the backbone of New York's long-term care system. The challenges they face are complex and diverse. The tremendous stress they face as they navigate the healthcare system on behalf of their loved ones is compounded by numerous barriers—wait lists, a lack of available home- and community-based services, limited transportation options, financial hurdles, mental health issues, social isolation, and a lack of respite. The need for caregiver support is more critical than ever. Shifting demographics mean New Yorkers are living longer, but with a higher incidence of chronic conditions. Soon, the number of those needing care will outnumber the family caregivers available to provide it. In 2010, the caregiver support ratio was more than 7 potential caregivers for every person in the high-risk years of 80-plus. By 2030, the ratio is projected to decline sharply to 4 to 1; and it is expected to further fall to less than 3 to 1 by 2050.

How does New York meet the needs of caregivers in the 21st century? How can unique models of care and services, bold technologies, practice change, and innovative state policies support family members, partners, and friends who care for the millions of adults over age 65? What can New York learn from other states to improve its response and responsibility to family caregivers?

On November 28, 2017, AARP New York convened The Future of Family Caregiving: Leading the Change, a one-day leadership summit in New York City. Experts from state government, aging-service organizations, advocacy groups, and family caregivers gathered to assess the varied and complicated needs of caregivers, as well as share insights into their personal journeys. Innovative programs and models taking place in communities throughout the U.S. and elsewhere were examined. The goal was to analyze key issues common among caregivers, share best practices, assess lessons learned from other efforts, and determine how New York could adapt successful solutions implemented elsewhere to address the unique challenges of its older residents and their caregivers.

CAREGIVER SUPPORT

7.1

4:1

3:1

 $^{^1}$ https://www.aarp.org/home-family/caregiving/info-08-2013/the-aging-of-the-baby-boom-and-the-growing-care-gap-AARP-ppi-ltc.html

KEY FINDINGS

Summit participants shared multiple perspectives on how to best support family caregivers. Common themes included:

Encourage family caregivers to embrace their role and become advocates for what they need, especially in expanding home- and community-based services. They want and need support, education, hands-on training, and services that are affordable and easily adaptable.

Help the medical community become more aware of and sensitive to the unique issues of older adults and their caregivers:

- Empower practitioners to provide more information about advance directives and end-of-life care options;
- Encourage practitioners to discuss and provide information about hospital-to-home care transitions; and
- Aid practitioners by creating a central repository of culturally appropriate statewide and local services.

Help families ease the financial strains of caregiving, whether through state payments, tax credits, expanding existing legislation that provides support for family caregivers, or other means. Employers must do more to support workers who care for an aging loved one.

Create more flexible, affordable housing options for older adults and improve public, age-friendly transportation throughout the state, particularly in rural areas.

66 Caregiving is the best job I've ever had.

— RICHARD LIU, MSNBC anchor and family caregiver

5.

Develop viable career paths and expand scope of practice for paid caregivers to reduce high turnover and improve quality of care. Recruitment and retention efforts must address barriers that extend beyond low wages.

6.

Assess and adapt best practices from other states' efforts to address their aging populations and family caregivers.



Life expectancy in New York is at a record high. The typical New Yorker can expect to live 80.6 years, two years longer than the national average.² Many older New Yorkers stay active well into their 90s, and beyond, thanks to advances in medical care and healthy lifestyles. Even those with chronic conditions like diabetes, heart disease, and Alzheimer's can live full lives with good disease management.

But even healthy people may need assistance with everyday tasks, like cooking, traveling to doctor appointments, and managing multiple medications. Others need assistance with even more complex medical tasks, like wound care. That's where the millions of family caregivers step in. The need to support these unpaid heroes is vital.

² https://www.nysenate.gov/newsroom/press-releases/josé-m-serrano/ average-life-expectancy-new-york-record-high

Who are the family caregivers?

2.6 MILLION = 2.4 BILLION

UNPAID CAREGIVERS IN NEW YORK

HOURS OF UNPAID CARE EACH YEAR

ot everyone who cares for a loved one realizes they're part of a growing contingent of family caregivers. As a wife or husband, daughter, son, or partner, they just do what is necessary to help. They are among the approximately 44 million individuals across the U.S. who provide care and support to someone because of a limitation in their physical, emotional, or cognitive functioning. About 34.2 million of them have provided unpaid care to an adult aged 50 years or older,³ and at least 17.7 million care for someone aged 65 years or older who has a significant impairment.4

Some 15.4 percent of New York's 19.3 million residents are 65 years of age or older;5 many rely on the 2.6 million unpaid caregivers who provide 2.4 billion hours of unpaid care each year to their loved ones—the equivalent of \$32 billion—care that allows their loved ones to remain in their homes and communities.

In New York State and across the U.S., there's a growing need for family caregivers. By 2040, more than 3.5 million New Yorkers will be age 65 years or older; more than a half-million will be age 85 years or older.⁶ Nationally, the burgeoning older population is projected to reach 83 million by 2050; the number of those in the 85-plus years old age range will more than triple by then to 19.4 million. By then, as many as one third (34 percent) of older adults could experience functional limitations, and require full or part-time help to avoid or delay institutional care.7

Caregiving has many rewards, but family caregivers tell us they often feel alone and adrift in a sea of responsibilities: juggling a job, responsibilities toward their own families, and civic or volunteer activities while caring for their loved one.8 Despite the challenges, most don't hesitate to take on these tasks—from driving a parent or spouse to doctor appointments to shopping or managing paperwork, or helping with bathing, dressing, and feeding. Caregivers are performing increasingly complex medical tasks for their loved ones, tasks that at one time would have been performed only in a hospital or by a nurse.9

No matter how it's described, the responsibilities and challenges of family caregivers are very real. Many caregivers are overwhelmed, over-burdened, financially and emotionally drained, and feel lost. Most don't know where to turn for help, or even what help is available. Lack of time, energy, and chronic burnout means self-care falls by the wayside. They want to keep their loved ones at home while still going about their own lives. But they need the services, programs, and resources to do so.

³ AARP Caregiving in the US 2015 https://www.aarp.org/content/dam/aarp/ppi/2015/

caregiving-in-the-united-states-2015-report-revised.pdf

National Academies http://nationalacademies.org/hmd/Reports/2016/families-caring-for-an-aging-america.aspx

https://www.census.gov/quickfacts/fact/table/NY/AGE775216#viewtop

https://pad.human.cornell.edu/counties/projections.cfm
Congressional Budget Office, 2013 https://www.slideshare.net/cbo/44363-ltc #32 https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/

home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf

https://www.aarp.org/home-family/caregiving/info-04-2014/family-caregivers-providing-complex-chronic-care-to-spouses-AARP-ppi-health.htmld

How can we do better for our fellow New Yorkers?

66 This is not the life we want for our loved ones or for our future selves. We owe it to them to help them live a fulfilling life for as long as possible in a place they love. When we make communities more age friendly and livable, we are providing great support not only to those we care for but to caregivers as well. 99

- DR. DANIELLE GREENE, New York State Department of Health



ood ideas are not limited by state borders. We must learn from and adapt successful programs and best practices from other communities to meet the needs of New York's caregivers. By adapting what works, we ease the burdens on today's family caregivers and help lighten the load for the unforeseen challenges of tomorrow's family caregivers throughout our state.

There is no one-size-fits-all approach. Each family caregiver's situation is unique. Solutions must be just as varied and innovative as the diversity of issues family caregivers face. One quality that participants and even elected officials agree on is that efforts to help family caregivers keep their loved ones at home, or in their communities, must be bipartisan. Caregiving is an issue that transcends political, racial, ethnic, geographic, and economic lines, and it is one in which those who need the most are often the ones with little time available to raise their voices.

Boosting caregiver mindset

amily caregivers experience a roller coaster of emotions. It starts with little details, like noticing your aging parent or spouse needs some extra help with an everyday activity, or is increasingly forgetful about taking medications or managing paperwork. Family caregivers soon find themselves taking on more and more duties, yet don't identify as a "family caregiver." It's just what they do.

As family caregivers become swept up in the day-to-day needs of their loved one, they may find themselves losing their own identity. They may have to take time off from work or give up activities they enjoy. Lost time at work may impact income, affect potential promotions, or require the caregiver to explore other employment opportunities. Adult children may struggle to balance caring for a parent with raising young children. The stress and anxiety of caregiving can quickly become overwhelming¹⁰ as family caregivers find themselves having to juggle more than they can handle. A recent study from Yale University finds that family caregivers help with a much wider range of tasks than what was previously thought.11

Self-care often takes a back seat to caregiving priorities. Isolation from friends and colleagues becomes more common. Many family caregivers don't know where to turn for help. Some may not want to admit they need help, because they fear it may reflect poorly on them as a child, spouse, or partner. Even if they do agree that help is necessary, Summit participants said that fear of strangers and financial concerns over hiring outside help often overrode the desire for additional help. Acceptance of help is often further complicated by being unable to find someone qualified, affordable, and available.

A substantial body of research has examined the impact of family caregiving on the psychological and physical health of family caregivers. Findings from the Stress in America survey show that those who serve as family caregivers to older relatives report higher levels of stress and poorer health than those of the population at large. More than half (55 percent) of family caregivers surveyed reported feeling overwhelmed by the amount of care their family members required. Family caregiving can be especially overwhelming and stressful when caring for someone with dementia. Changes in memory, personality, and behavior (such as wandering or asking questions repeatedly) can be challenging for family caregivers. Research has shown that the stress of family caregiving for people with dementia is associated with high emotional strain, poor physical health outcomes, and increased mortality.12

66 After having seen the long-term care system up close, you realize it isn't a system at all, it's a bunch of episodes of care—some good, some bad, some lucky, some unlucky. 99

- ELAINE RYAN, AARP Vice President of State Advocacy and Strategy Integration and family caregiver

National Institutes of Health https://newsinhealth.nih.gov/2015/12/coping-caregiving

¹¹ http://onlinelibrary.wiley.com/doi/10.1111/jgs.14910/full

¹² https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-

What do family caregivers need?

n November 2017, AARP New York convened *The Future of Family Caregiving Leadership Summit*—a symposium of aging advocates, health experts, policy makers, and family caregivers—to examine some of these issues and share insights on what New York and other communities are doing to address these challenges.

At the Summit, caregivers agreed that accepting and embracing their role will help to empower them and strengthen their voices. They want support, education, and services tailored to their situation that won't cause a financial burden or create major upheaval for themselves or their loved ones.









Photographs by Ferdinand Lee

WHAT DO FAMILY CAREGIVERS NEED?

Respite and self-care services, such as respite and support groups (both in-person and online), were at the top of the list. No matter how passionate caregivers were about caring for their loved ones, family caregivers verbalized a need for a temporary break from their duties to recharge. Respite break and self-care could include taking an afternoon off to run personal errands, going on a weekend away to reconnect with the family, or recharging with a week's vacation at the beach. Respite care helps family caregivers reduce stress, and take care of their own physical and mental health.¹³ However, adult day centers, in-home volunteers, and paid caregivers can be difficult to find, or prohibitively expensive. According to Summit participants, finding respite and self-care services can be an especially tough challenge for New Yorkers living in rural communities, where resources are scarce.

Some communities are giving back to their older residents to ease family caregiver burden. Local volunteer organizations^{14, 15} offer friendly visiting programs for an hour or two weekly, allowing the family caregiver to take time off for him or herself. Volunteers even offer assistance with minor home repairs, transportation to doctor appointments, reading, or shopping. However, finding these services remains challenging for time-deprived and overburdened family caregivers. Information is scattered across websites and directories. It may take phone calls to multiple agencies to determine eligibility.

Summit participants recommended developing and promoting an easily accessible, streamlined, and culturally appropriate compendium of statewide and local services, which includes paid and volunteer assistance, eligibility requirements, and costs.

One model that addresses many of these concerns is the Respite, Education, & Support Tools (REST) initiative. 16 This Chicago-based Train-the-Trainer program creates networks of volunteers who provide

local respite services for family caregivers. Social service organizations, state agencies, palliative care, faith-based organizations, hospitals, and corporations receive appropriate education and training, and then share this information in their communities.

• **Education** is a common struggle for family caregivers. Some family caregivers may be suddenly thrust into their new roles due to a loved one's sudden injury or illness, such as a stroke; others take on responsibilities more gradually. Many family caregivers readily admit they have little idea how to safely and effectively accomplish important tasks, like helping a loved one in and out of bed or the shower, and little confidence in caring for them after discharge from a hospital or skilled nursing facility.

Family caregivers want and need basic, hands-on education, including improving their health literacy. They are living in a new world, requiring a new vocabulary to navigate hospitals, insurance, physicians, and community services.

Advance care planning helps family caregivers feel better prepared. Family caregivers want a better understanding of how to help their loved ones plan for the future: how to have the conversation with their family, put the appropriate paperwork in place, and ensure their loved ones' wishes are honored. Advance care planning encompasses everything from long-term services, support, and finances to living arrangements and navigating legal, family, and social dynamics.¹⁷

Advance care planning includes the completion of advance directives such as a living will or healthcare proxy. These documents allow care recipients to tell

⁴ https://volunteercaregiving.org/programs/

¹⁵ http://nnecaregivers.org/services.htm

http://restprogram.org/about-rest/
 https://longtermcare.acl.gov/the-basics/index.html

their families, friends, and medical professionals what kind of care they would want or who should make decisions for them if they are unable to speak for themselves.¹⁸ They guide the types of treatments a care recipient wants in case of a future unknown medical situation.19

Another document known as a Medical Orders for Life Sustaining Treatment (MOLST) specifies the precise medical treatment(s) a person wants during medical emergencies. This order identifies whether emergency personnel should intervene and which, if any, life sustaining measures (e.g., CPR, intubation, antibiotic use, feeding tubes) should be used. A MOLST is appropriate for those with a serious illness or advanced frailty near the end of life.20

Templates and discussion ice breakers like those from The Conversation Project²¹ can help facilitate the often difficult task of talking to loved ones about future care needs and wishes. This national initiative, started by former journalist Ellen Goodman, is designed specifically to address the needs of family caregivers and their loved ones. Physicians, nurse practitioners, social workers, advocacy organizations, and other groups can help caregivers begin the conversation on end-of-life wishes before a crisis occurs.

Discharge planning can overwhelm family caregivers. Integrating family caregivers in hospital discharge planning can significantly cut down on hospital readmissions.²² Thanks to the Caregiver Advise, Record, and Enable (CARE) Act passed in New York in 2015, collaboration is now legislatively required and being implemented.²³ The CARE Act, now law in 39 states, allows the care recipient to name a friend or relative as his or her caregiver upon hospital discharge

and return to the community. The named caregiver must be included in discussions and planning for care at home, and, if they choose, may obtain instruction from hospital staff on the medical tasks they will be performing once their loved one is discharged.

While healthcare settings do their best to educate family caregivers and patients to prepare for transition to the community, family caregivers say they do not always understand the medical jargon, do not know what questions to ask, or become confused about processes. The Duke Elder Family/Caregiver Training (DEFT) Center²⁴ at Duke University School of Nursing has developed a scalable model to teach, train, and support family caregivers following a loved one's discharge from the hospital. Adapting this program could supplement the requirements of the CARE Act and establish best practices for family caregiver training throughout New York State. The next step could be expanding the CARE Act to include skilled nursing and rehabilitation facilities. In addition, AARP has developed family caregiver training videos to serve as a model for healthcare institutions to use as they develop training modules.²⁵

Without appropriate community supports and services, transitioning out of the hospital to homebased family caregiving can be impossible. Access issues are particularly challenging in rural parts of the state. A lack of programs, services, a qualified and affordable home-care workforce, and transportation and housing options only increases the burden on already overwhelmed family caregivers. This issue further highlights the need for effective communication so that health professionals, government, private agencies, and service organizations can educate family caregivers on available services and how to access them.

https://www.medicare.gov/manage-your-health/advance-directives/advance-directives-and-long-term-care.html

¹⁹ https://www.nolo.com/legal-encyclopedia/new-york-living-will-health-care-power-of-attorney-31853.html

polst.org/advance-care-planning/polst-and-advance-directives/

²¹ https://theconversation/project.org
²² Caregiver Integration During Discharge Planning for Older Adults to Red...17 - Journal of the American Geriatrics Society - Wiley Online Library)

²³ https://www.nysenate.gov/legislation/bills/2015/S676/amendment/a

WHAT DO FAMILY CAREGIVERS NEED?

One such successful initiative discussed at the Summit is Idaho's Lifespan Family Caregiver Action Plan,²⁶ an alliance of government, non-profits, advocacy groups (including AARP Idaho), medical professionals, and corporations. This alliance provides caregiver support, training, and resources—from respite and self-care to a telephone and online "careline." Plans include increasing public and employer awareness of caregivers' vital role and contributions, and incorporating caregiver voices and perspectives in policy decisions.

Social connections and communication help family caregivers feel less alone. The risk of social isolation for caregivers and care recipients is real. Family caregivers tell us that connecting with others in similar situations and sharing their stories helps ease anxiety and make them feel less alone. Discussing common experiences can help family caregivers learn new coping strategies, find out about community resources or programs, and feel less alone.²⁷

Silver Line²⁸ is a confidential, free helpline that has strong potential to alleviate some of this isolation. It originated in the United Kingdom, and is specifically targeted to older adults. The program matches volunteers and older adults by phone or letters based on interest, and helps connect people with local services in their area. The success of this program in alleviating isolation prompted New York State to begin a pilot program²⁹ in Monroe County. If the pilot is successful, the state plans on expanding the program to more counties.

 Age-friendly Emergency Departments (EDs) and added support from clinicians and hospitals can reduce anxiety. A trip to the hospital can be scary for an older adult and his or her family caregiver. Stress, confusion, and fear can be all-consuming, particularly when long-term illness or diseases like Alzheimer's are involved. Older adults comprise a disproportionate share of emergency department visits,30 and the constant noise and activity can easily become overwhelming for both the care recipient and family caregiver.

Some hospitals are recognizing that older adults require a different approach. Age-friendly emergency departments are starting to catch on throughout the U.S.³¹ These can produce better outcomes, and make the experience less frightening and disorienting for older adults.³² Facility design includes features like non-glare lighting, non-skid flooring, large print information, and handrails. Specially trained staff work in designated areas that feature warmer room temperatures, improved sound-proofing, and room for a family caregiver to remain with his or her loved one. This creates a more comfortable environment that helps minimize confusion and anxiety.

When a loved one is admitted to the hospital, it can be stressful for everyone. Family caregivers are finding places for comfort and encouragement within hospital walls thanks to the growth of caregiver respite centers like those at Montefiore Medical Center³³ in the Bronx and Northern Westchester Hospital.³⁴ Whether it's a few minutes to decompress, a shoulder to cry on, or just talking with someone who understands what caregivers are going through, expanding hospital and community-based services like these provide vital support to family caregivers when they need it most.

https://legislature.idaho.gov/wp-content/uploads/sessioninfo/2017/standingcommittees/ 170216_sh&w_0300PM_Attachment_2.pdf

Thttp://www.ascseniorcare.com/how-support-groups-can-help-caregivers/.

https://www.thesilverline.org.uk/what-we-do/

²⁹ http://www.co.livingston.state.ny.us/598/Caregiver-Support-Services

³⁰ https://www.cdc.gov/nchs/data/databriefs/db130.htmff 31 http://www.caringfortheages.com/article/S1526-4114(12)00017-0/fulltext

³² https://www.acep.org/content.aspx?id=87577#sm.0001s1vrw3tw9euyut61wupngnofo

http://www.montefiore.org/caregiversupport

³⁴ https://nwhc.net/for-patients-and-visitors/ken-hamilton-caregivers-center



Most older adults and their family caregivers would prefer avoiding an emergency room visit altogether. Community paramedicine programs are an increasingly accepted approach to helping older care recipients avoid trips to the hospital for non-life-threatening health issues.

These programs broaden the role of emergency medical technicians, paramedics, and emergency medical systems, in collaboration with other providers, to deliver higher quality patient-centered care and prevent emergencies.35 By triaging and treating a patient at home in consultation with a doctor on call, paramedics can avoid costly, time-consuming, and stressful trips to the emergency department for those who need only non-urgent care. This is a particularly effective strategy for rural areas like Livingston County,36 where residents live far from the nearest hospital and, without the program, may opt to forego care.

— Randi Kaplan, LSMW, co-founder of the Arthur D. Emil Caregiver Support Center at Montefiore Health System, Bronx, NY

Family caregivers and advocates say it can be difficult getting physicians to understand the challenges of family caregiving. Family caregivers who work outside the home may have only a brief time, such as during their lunch break, when they can make appointments or speak with doctors about their loved ones' health. Summit participants encouraged physicians and other health care providers to be more aware and accommodating of the needs and schedules of family caregivers.

⁶⁶ What they ask for is somebody to listen to their heart and for somebody to really look into their eyes and understand that the family is the unit of care. 99

http://nycommunityparamedicine.org
 https://www.ruralhealthinfo.org/community-health/project-examples/360

Money issues create constant pressure

AVERAGE AMOUNT FAMILY CAREGIVERS SPEND PER YEAR ON CAREGIVING-RELATED COSTS



amily caregiving puts tremendous financial strain on families and is among the top concerns of family caregivers. Family caregiving often means a personal financial contribution, loss of income, loss of future financial security, and a lack of affordable care options.

On average, family caregivers spend nearly \$7,000 per year on caregiving-related costs, from building wheelchair ramps to purchasing food and medical supplies. Long-distance family caregivers spend about \$11,000 annually, and those caring for loved ones with dementia have nearly twice the out-of-pocket costs of family caregivers caring for someone without this condition (\$10,697 vs. \$5,758). The average family caregiver spends about 20 percent of his or her income on caregiving expenses.³⁷ Nationally and at the state level, a middleclass tax credit would ease the financial burden on many family caregivers, and could help delay or avoid costly taxpayer-funded institutional care.³⁸ Caregivers from middle class families are often hit the hardest-earning too much to qualify for Medicaid-financed caregiver assistance but not enough to comfortably support their loved ones.

Family caregiver stipends could make the difference between keeping an older loved one at home or placing the loved one in institutional care. Other states have recognized and addressed this dilemma. Hawaii's Kupuna Caregivers Program³⁹ eases the financial burden on family caregivers who work at least 30 hours outside the home, allowing them to stay in the workplace. Qualified caregivers may receive up to \$70 per day in benefits, paid directly to contracted service providers, to

 $[\]frac{7}{2} \text{https://www.aarp.org/research/topics/care/info-2016/family-caregivers-cost-survey.html}$

³⁸ https://states.aarp.org/aarp-family-caregiver-tax-credit-would-provide-critical-help-to-nyss-middle-class/

³⁹ http://www.care4kupuna.com/#introducing

¹⁰ https://www.aarp.org/home-family/caregiving/info-11-2013/employed-family-caregivers-providing-complex-chronic-care-AARP-ppi-health.html

⁴¹ sfgov.org/dosw/gep-work-life-balance-indicators

help cover costs for adult day care, chore services, home-delivered meals, homemaker services, personal care, respite care, or transportation.

In Connecticut, the Adult Family Living/Foster Care program allows an elderly individual to move into a family member's or friend's home, or have a family caregiver move into the elderly individual's home. Family caregivers receive compensation for helping care recipients with daily living activities. Depending on the level of care needed, family caregivers can receive up to \$108 daily.

Family caregivers who work outside the home face the additional dilemma of possibly having to change or decrease work hours due to caregiving demands. Future financial security is at risk through the possibility of missed promotions, lost income or raises, and missed opportunities to save for retirement. This particularly affects women, as women are the primary providers of family caregiving. A recent survey found that 73 percent of family caregivers who worked outside the home were between the ages of 35 and 64; the majority (56 percent) were women.⁴⁰ Replacing experienced workers is costly to employers and damaging to the economy, according to the survey. Employers can help by encouraging an appropriate work-life balance. The city of San Francisco has developed a toolkit to aid companies in establishing and maintaining fair, equitable policies. It includes suggestions about family leave and flexible work arrangements for all employees, including low-wage and hourly workers.41

Employee resource groups (ERGs) like iCare at the Royal Bank of Canada provide a place to champion the needs of family caregivers, including experienced, new or expecting parents, or those caring for elderly, sick, or disabled relatives.⁴² Further, as the demand for familyfriendly policies increases, more companies are subsidizing paid eldercare for their workers, according to the 2017 Working Mother 100 Best Companies.43

Whether or not their employer offers these benefits, some financial relief is available for working New York family caregivers. On January 1, 2018, the Paid Family Leave Act went into effect. Among its provisions is one by which family caregivers can receive up to 12 weeks off, once the program is fully implemented, to care for their loved ones⁴⁴ while continuing to receive a percentage of their wages, and know their jobs are protected for when they return.

⁴² www.rbc.com/diversity/employee-resource-groups.html

 ⁴³ https://www.workingmother.com/sites/workingmother.com/files/attachments/2017/09/100best-chart-finalv3.pdf
 44 https://www.ny.gov/programs/new-york-state-paid-family-leave

More affordable housing options needed

early 90 percent of older adults want to age in their own homes.⁴⁵ Emphasis on innovative housing models can help many older adults remain in their homes and communities. Housing options should include accessibility to stores, services, and transportation while addressing the needs of affordability, social connectedness, universal design, and availability of support services. 46 This is especially challenging for older adults living in car-dependent suburban and rural areas, where walkability and public transportation options may be limited.

Older adult and caregiver-friendly housing options include village models, grassroots membership-based organizations that empower older adults to remain active and engaged in their communities as they age. Most provide volunteer services, such as transportation, home repairs, social and educational activities, and other support that help members age safely and successfully in their own homes.⁴⁷ There are currently about 200 villages in operation and 150 more in development in 45 states plus the District of Columbia.

Cohousing is another model whereby residents actively participate in the design and operation of their neighborhoods, share common facilities, and connect with neighbors. These initiatives support the creation of age-friendly cohousing communities in the U.S.—both multi-generational and elder-only, such as Manzanita Village near Prescott, Arizona, Silver Leaf cohousing in Paonia, Colorado, and Common Place Cooperative in

Cambridge, Massachusetts. 49 These communities are designed or retrofitted specifically to address the evolving needs and abilities of elder residents.⁴⁹ Various communities exist or are in development in 36 states, including New York, and the District of Columbia.

Home sharing is a viable option for some older adults, and one that can give long-distance family caregivers additional peace of mind.⁵⁰ It is especially popular among older women, who are more likely to live alone than older men are. Housemates help with household maintenance, chores, or transportation in exchange for free or reduced rent. Elder adults get to remain in their homes, maintain social connectedness, and reduce their financial burden. Family caregivers know there is someone around in case of a medical emergency, such as a fall.

There is an urgent need to expand home and community services, reported Summit participants. Doing so requires thinking beyond the institutional setting. For example, one Summit participant proposed looking at ways to "use the currency of Medicaid and private insurance to wrap around families," rather than putting their loved ones in institutional care. This may include services like companionship or light-duty caregiving by volunteers or paid professionals to augment what family caregivers provide. It may be home-delivered meals or grocery shopping services, transportation to and from medical appointments, more adult day services, affordable downsizing options so care recipients can remain in their community near family and friends, or increased access to virtual services like telehealth or tele-mental health.

https://assets.aarp.org/rgcenter/ppi/liv-com/ib190.pdf
 https://assets.aarp.org/rgcenter/ppi/liv-com/ib190.pdf
 http://www.jchs.harvard.edu/sites/jchs.harvard.edu/files/jchs-housing_americas_older_adults_2014-ch1.pdf
 http://tvnetwork.org/content.aspx?page_id=0&club_id=691012

⁴⁸ http://www.cohousing.org/directory

⁴⁹ http://www.cohousing.org/aging of https://www.aarp.org/home-family/your-home/info-05-2013/older-women-roommates-house-sharing.html



Aging-in-community is not always possible, and finding affordable alternatives to institutional care can be futile. There was universal agreement among Summit participants about the lack of affordable assisted living facilities and continuing care retirement communities throughout the state.

Regardless of where a loved one lives, affordability is the moral imperative for any service or program, family caregivers said.

For older LGBT adults, finding affordable, non-discriminatory services and housing options can be especially problematic. LGBT adults are often subject to harassment and intimidation, both in the community and in supportive housing. This puts additional stress on their physical

and emotional health. LGBT elders also have higher lifetime levels of financial insecurity than their non-LGBT counterparts.51

While some LGBT-specific elder adult housing is available in urban areas of New York State, older LGBT individuals may still worry about discrimination when purchasing a home or moving into retirement communities in other parts of the state. Nationally, as many as one third of LGBT respondents felt they would have to hide their identity when moving into a retirement home, according to one survey.⁵² Affordability is also a big concern. Although several LGBT continuing care and assisted living communities exist in places like Santa Rosa and Palm Springs, California, these are high-end facilities that come at a steep price.53

https://www.lgbtagingcenter.org/resources/resource.cfm?r=399
 https://www.lgbtmap.org/file/lgbt-older-adults-and-exclusion-from-aging-programs.pdf
 https://sageusa.org/lgbthousing/

Workforce challenges create added caregiver stress

urther driving these issues is the insufficient supply of a well-trained, adequately paid caregiving workforce. Many family caregivers and advocates say it is nearly impossible to find qualified home care workers in some parts of New York. Wait lists can be long for agencies and programs that do offer help. Cost of care is compounded, since insurance does not cover what many consider essential services that allow older adults to age in place with some assistance. Providing true career paths to home care aides and Licensed Practical Nurses (LPN) may help increase recruitment and retention of more qualified, dedicated workers. Suggestions ranged from expanding LPN scope of practice to increasing wages, providing additional training and education, setting higher skills criteria, and conducting more diligent background checks to assure high workforce standards.

Those who do choose to receive services in their own homes and in other community-based settings often utilize informal channels to locate workers, but finding qualified workers through these informal channels can be challenging. Creation of an in-home services provider registry would allow consumers to connect with qualified long-term services and support (LTSS) workers in their area who provide the services the consumer needs.

Through the Medicaid system, some states already maintain extensive lists of qualified home care providers, which could form the basis for a public-facing registry.

Such a registry would offer a dynamic platform for matching supply and demand by allowing consumers to tap into an up-to-date bank of LTSS workers. It has the potential to play a significant role in filling the need for in-home services and support, thus helping meet expanded demand and continue diversion from costlier institutional settings.

Even when outside help is available, family caregivers often find the out-of-pocket costs are more than what they can afford. Programs like New York's Expanded In-home Services for the Elderly Program⁵⁴ (EISEP) and Community Services for the Elderly (CSE) program may be good options but may require a cost-sharing component, putting them out of reach for some.55 The same is true for state-supported respite care programs, where paying even a modest hourly wage for home attendants can strain family budgets.⁵⁶ These and other programs for older adults also suffer from flat funding, despite growing demand for services, as demonstrated by extensive wait lists.57

Widespread disparities in access, affordability, and other socioeconomic factors contribute to family caregivers' inability to access services. Family caregivers' out-ofpocket costs average 20 percent of their incomes.⁵⁸ For Hispanic family caregivers, it more than doubles to 44 percent of their incomes. New York also has the highest income-inequality of any state, with the top 1 percent earning 45.4 times more than the bottom 99 percent.⁵⁹

⁵⁴ https://aging.ny.gov/NYSOFA/Services/Index.cfm?id=CSVCS,#CSVCS

https://www.health.ny.gov/health_care/medicaid/program/longterm/expand.htm https://www.nyconnects.ny.gov/results?page=2&pageSize=10&orderby=3&desc=false

⁵⁷ http://www.agingny.org/Portals/13/Advocacy/New%20York%20State/testimony.final.pdf

https://18672-presscon-pagely.netdna-ssl.com/wp-content/uploads/2018/01/AARP_DisparitiesPaperSummary_Booklet_81-2X11_01192018_FINAL.pdf https://fiscalpolicy.org/nys-leads-nation-in-income-inequality

Additionally, although one third of the state's population are persons of color, only 20 percent of those persons are homeowners. Those who are homeowners find themselves significantly burdened by housing cost, with over half of their income going toward housing. 60 There is little left over to hire paid help or pay for other LTSS.

Family caregivers are also hesitant to allow someone they don't know to care for their vulnerable loved ones. It takes time and effort to check references, build trust, and reduce anxiety. Home care aides and LPNs are high-turnover occupations^{61,62} which can lead to fragmented care. Not only is this disorienting and stressful for the family, but it means family caregivers must start the process all over again.

Despite rapidly increasing demand for personal care aides and home health aides, these jobs are often considered low-esteem and not valued by society.63 More than 90 percent of in-home workers are female, and overwhelmingly immigrants.⁶⁴ Pay rates are often barely above minimum wage. In New York, the median hourly wage for home health aides in 2016 was \$11.20; personal health aides received an average of \$11.45 per hour.65 Many work part-time, and few have benefits like pensions or health insurance.

The Economic Policy Institute notes that in-home workers have a higher proportion of poverty than other occupations do—nearly one in four home workers (23.4 percent) live below the poverty line. Paid caregivers often face economic challenges similar to those of the clients they care for, like inaccessible public transportation, unreliable or non-existent personal transportation, and trouble paying their rent and putting food on the table.

Wisconsin's innovative caregiver career program is a workforce development initiative to recruit and retain more than 3,000 nurse aides. 66 While this program is designed to supplement staff at nursing homes, it could easily be adapted to address similar needs among the home health workforce.

^ahttps://18672-presscdn-pagely.netdna-ssl.com/wp-content/uploads/2018/01/AARP_DisparitiesPaperSummary_Booklet_81-2X11_01192018_FINAL.pdf

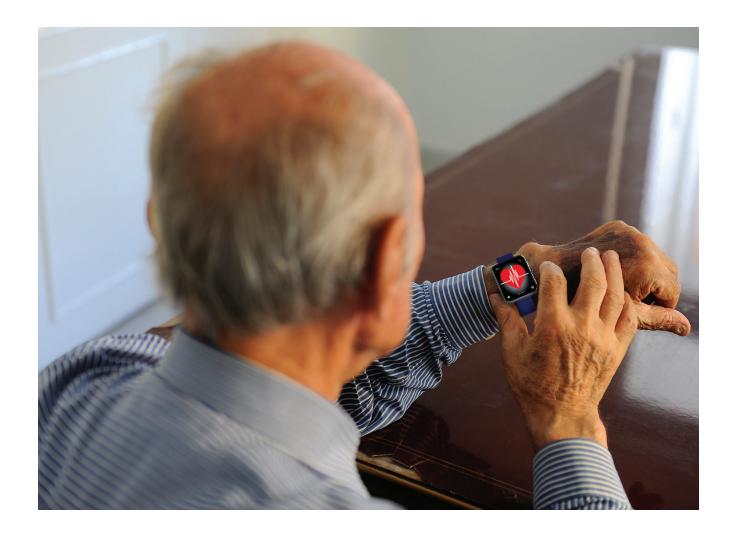
https://phinational.org/survey-home-care-worker-turnover-topped-60-percent-in-2014/https://www.hanys.org/workforce/data/docs/2011-06-10-workforce_survey_results_2011.pdf

⁶³ http://fortune.com/2014/09/15/home-care-workers/

http://www.epi.org/publication/in-home-workers/ 65 https://phinational.org/policy-research/workforce-data-center/#states=36

⁶⁶ https://content.govdelivery.com/accounts/WIDHS/bulletins/1909369

Emerging technology can aid family caregivers



oday's digital lifestyle provides a wealth of innovative and potentially game-changing developments to supplement family caregiver needs. Mobile telehealth has quickly become a popular option for non-urgent care and mental health support, and a boon to residents in rural communities. 67, 68 Mobile apps and devices allow physicians to remotely monitor an older

adult's vital signs like heart rate, blood pressure, and blood sugar via smartphone. Apps, cameras, and sensors can alert family caregivers whether medication has been taken, if the stove was left on, or if there's been a fall.⁶⁹ These and other technological advances help keep older adults out of nursing homes and provide family caregivers with added peace of mind.

⁶⁷ https://seniorcitizens.westchestergov.com/nutrition-health-safety/telehealth-intervention-programs-for-seniors

https://www.ruralhealthinfo.org/topics/telehealth
https://www.newenglandcollegeonline.com/resources/healthcare-administration/telehealth-technology-elder-care/



Family caregivers often learn the most when sharing stories and resources with others in similar situations. Mobile apps and online portals can also foster connections between family caregivers, or between primary family caregivers and other family members. Many family caregivers say they lack time or energy to attend in-person support groups. Virtual support groups, online chats, and hangouts are helping family caregivers feel more connected and less isolated. Technology supporting these personal relationships will be adopted more quickly. However, one Summit panelist stressed that websites and apps must build trust and confidence; otherwise, it's just a waste of time. Tele-mental health is a crucial way to support family caregivers who desperately need supportive and flexible self-care options. Despite being one of the most widely used applications and one that is evidence-based, barriers do exist that can be addressed by expanding health insurance to cover tele-mental health, and by expanding the reach of broadband services to underserved areas of the state.

How can caregivers mobilize and act?

erhaps the last issue time-deprived, exhausted family caregivers want to deal with is the political side of the equation. It is one of those difficult but critical areas where family caregivers are their own best advocates. Sharing their stories with policymakers and the media keeps a light shining on their often ignored contributions to the well-being of our elder citizens and the cost savings achieved by their help in keeping millions of older adults out of taxpayer-funded institutional care. We need to make it as easy as possible for them to engage, whether through texting, phone calls, online or smartphone apps, share anecdotes⁷⁰ and push for more help.

One promising development is the recent passage of the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act. 71 This federal effort will establish a national strategy for family caregivers, including a coordinated plan to leverage resources, promote best practices, and expand available caregiver services and training.

https://act.aarp.org/iheartcaregivers/
 http://docs.house.gov/billsthisweek/20171218/HR3759.pdf)

CONCLUSION

s the elder population of New Yorkers continues to grow, so do their caregiving needs. Family caregivers are already doing much to ensure their loved ones avoid ending up in institutional care and can live out their lives at home, surrounded by family and friends. Many family caregivers are at their breaking point and do not know where to turn for help. State experts are working to address these many challenges with initiatives like Health Across All Policies, 72 which focuses on creating age-friendly communities and health-conscious policies across all state agencies and programs.

It is a good start, but the demand for affordable, home- and caregivercentered services increases daily. Major issues must be sustainably addressed throughout the state, for all residents, regardless of income, race, ethnicity, and sexual orientation. Solutions must be tailored to individual and community needs. Family caregivers must find and use their collective voice to help make this a reality.

New York State must find, develop, or adapt creative solutions to juggle these demands with the need for fiscal responsibility.

The answers are out there. Finding the best ideas and modifying them to the needs of New York's family caregivers is an achievable goal. Just as other states have learned from New York's leadership in socially relevant and economically wise programs, New York policymakers and aging advocates must learn from efforts by other states to meet the needs of its aging population and those who care for it.

⁷² https://www.health.ny.gov/prevention/prevention_agenda/health_across_all_policies/



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