

# DISRUPT DISPARITIES

ADDRESSING THE CRISIS FOR RURAL NEW YORKERS 50+

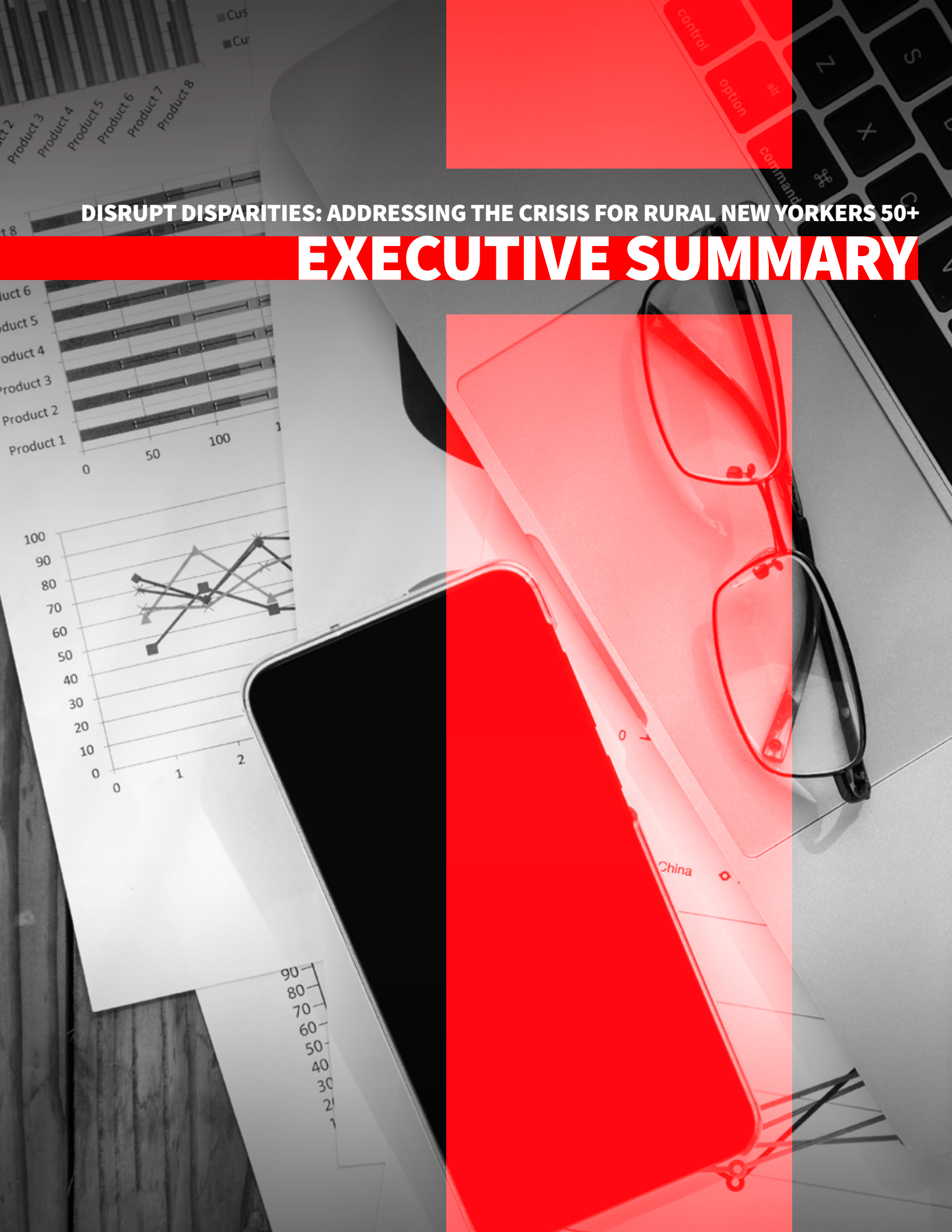


# TABLE OF CONTENTS

Executive summary .....	2
High-speed Internet .....	5
Family Caregiving .....	17
Telehealth .....	34
Health .....	46
Acknowledgements .....	69

**DISRUPT DISPARITIES: ADDRESSING THE CRISIS FOR RURAL NEW YORKERS 50+**

# **EXECUTIVE SUMMARY**



When you mention rural New York to people who live elsewhere, many seem baffled, equating the Empire State with New York City or Buffalo, maybe Rochester or Syracuse. But New York State includes wide swaths of sparsely populated rural areas from the Adirondacks to the Catskills, from the Finger Lakes to the Southern Tier, and many places in between. The Adirondacks even boasts a “Frontier Community,” defined as having fewer than six people per square mile.

But, throughout New York there are more than a million people 50 and older scattered in small towns and countryside—more than the entire population of six states and the District of Columbia.

Those million-plus older rural New Yorkers have the same needs as older urban and suburban residents, but far less access to services due to terrain, distance and the flight of potential caregivers and service providers: younger rural natives who leave to seek jobs elsewhere.

Yet the need for services is only increasing; more than 150,000 rural New Yorkers are already in the oldest, frailest age group, according to the New York State Office for the Aging. And over the next 20 years, as the Baby Boom generation ages through its late 70s and into its 80s, that number is projected to increase by about 65%, with a corresponding demand for caregivers, healthcare workers and other support services, the agency estimates.

“Rural and underserved. These terms go together—and are made all the more complicated by how fast healthcare is changing,” Dr. John Rugge of Hudson Headwaters Health Network, told us “Now as much as ever, our people need food, pharmaceuticals and transportation. But they also need computers and broadband along with caregivers at the bedside.”

AARP New York recognizes that rural New York faces serious, though sometimes different, disparities from those faced by communities of color in urban and suburban areas. This report is just the beginning of our work to focus attention on and help develop solutions for the rural 50+, a starting point for a dialogue with policy makers, advocates and the people who call rural New York home. AARP New York assigned four respected researchers the task of investigating the challenges for rural New York residents navigating access to fundamental services to help them age in place, examining telehealth, caregiving, health and internet connectivity.

Among their findings: older rural New Yorkers are sicker, more disabled, and have less access to healthcare and high-speed internet than those living in urban and suburban areas, and the population of rural New York is growing older as the Baby Boomer generation ages, younger residents leave for jobs, and retirees move in.

These trends pose significant challenges and demand a focus on solutions.



## Among the key challenges:

- Rural areas lose residents 4 to 5 times faster than more urban upstate areas do, yet New York's older rural population is increasing faster than its older non-rural population.
- Rural family caregivers are less likely to use formal support services, such as support groups, home health aides or nursing agencies, and other paid help.
- Rural residents 65+ are 1.6 times likelier to lack home high-speed internet than their non-rural counterparts. The pandemic underscored how vital this service was for everything from working to getting healthcare to life-sustaining social interaction
- There's a lack of adequate and reliable transportation.
- There are half as many critical access hospitals for every rural New Yorker than there are for every New York City resident: 18 in rural counties serving 1.4 million residents vs. 214 in New York City serving 8.4 million.

## Among the recommendations:

- Create a caregiver tax credit—Pass state legislation that would provide a tax credit to offset some of the more than \$7,200 on average that caregivers pay out of pocket for caregiving expenses annually.
- Increase access to the technology and equipment needed to support telehealth applications—Programs must also be in place for continued technical support including upgrading of equipment. Provide training on the use of telehealth to both patients and providers.
- Fund more in-home healthcare workers—In organizations where visiting nurses and direct care workers are employed, fund additional positions and training.
- Increase funding for emergency management services in rural areas—The emergency management system (EMS) needs investment to increase the workforce and the pay for first responders to address the EMS shortage.
- Adopt the goal of equalizing home high-speed internet utilization across all ages and geographies, including rural areas, by 2025, and establish an interagency working group to develop a strategy and program for reaching this goal.
- Provide tax credits and grants to help retrofit rural homes—This assistance, which would include creating “smart homes” along with modifications such as emergency pull chains in bathrooms, ramps, accessible doorways and bathrooms, chair lifts for stairwells and fire and gas detection devices linking directly to EMS, would decrease falls and increase patient monitoring, helping older rural adults age in place safely.





**DISRUPT DISPARITIES: ADDRESSING THE CRISIS FOR RURAL NEW YORKERS 50+**

# **HIGH-SPEED INTERNET**

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# HIGH-SPEED INTERNET

For older adults in rural New York, disparities in high-speed internet access and use powerfully affect the quality of life and the ability to live successfully and independently. The long distances rural older adults must travel to access services, healthcare, and social contact makes technology an essential element of modern rural life. For those with reliable, high-speed internet access and quality devices, digital participation can be a lifeline, opening connections to online banking, healthcare, education, health and wellness programs, and of course friends and family who are often spread across wide distances.

In contrast, digitally disconnected older adults in rural areas grapple with the burden of technological exclusion that can penetrate all walks of life. Those without high-speed home internet are restricted from using video calling, e-commerce, telemedicine, online banking, and health and wellness programming online. Activities as simple as applying for nutrition assistance, searching for a physician, or watching a public hearing online can be impossible without an in-home high-speed internet connection.

For those offline, these everyday tasks require more travel, more money, or simply more time to complete. What are the results? Higher rates of loneliness and isolation, higher costs and decreased access to consumer goods, less access to healthcare, and fewer social supports. In the era of COVID-19, these consequences are magnified, as older adults must sometimes make life-and-death decisions regarding the risks of in-person transactions.

A recent study highlighted the persistent problem of digital nonparticipation and exclusion in New York State, finding that nearly 27% of all households statewide lack a wired in-home high-speed internet subscription—a percentage that rises to 31% among residents of non-metropolitan areas.<sup>1</sup> Another study, supported by the Humana Foundation and Older Adults Technology Services (OATS) from AARP, found that both being over 65 and residing in rural counties correlate with lower rates of in-home high-speed internet participation, and that rural residents over 65 were 1.6 times more likely to lack home high-speed internet than their same-age non-rural counterparts.<sup>2</sup>

The New York State Comptroller reports that over one million households in the state lack high-speed internet subscriptions at home, and while the state has made strides in recent years to close the availability gap by supporting infrastructure investment (ranking second in the nation in the availability of high-speed access), there are still large numbers of unserved people, especially in rural communities. Moreover, while connectivity speeds of 25/3 Mbps<sup>3</sup> are widely available, more than 85% of households lack access to the higher speed thresholds of 250/25 Mbps at home.<sup>4</sup> While most consumers today are likely to find the 25/3 threshold adequate for common household applications such as streaming video, reading email, and participating in video calls, some experts caution that technology innovations tend to require increasing levels of connectivity over time. Bandwidth speeds considered adequate a decade ago are

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1. Horrigan, John, New York's Digital Divide, The Technology Policy Institute, Draft Report, April 2021.

2. Aging Connected: Closing the Connectivity Gap for Older Americans, Older Adults Technology Services, January 2021.

3. A connectivity speed of 25/3 Mbps means that 25 megabits of data can be downloaded from the internet each second, and three megabits of data can be uploaded from the household to the internet per second.

4. New York State Comptroller Thomas DiNapoli, Availability, Access, and Affordability: Understanding Broadband Challenges in New York State. September 2021.

# HIGH-SPEED INTERNET

insufficient for many users today. As a consequence, policymakers are advocating for higher connectivity speeds, and early drafts of the 2021 federal infrastructure bill include standards at the 100/20 level.<sup>5</sup>

Census data compiled by OATS from AARP found a gap of 17 percentage points between over-65 New Yorkers and those 18 to 64 years old in terms of their home internet participation. Just 61% of older New Yorkers subscribe to wired high-speed internet at home, compared to 78% of younger New Yorkers. By this measure, New York State ranks 35th in the nation when it comes to ensuring digital equity.<sup>6</sup>

Governor Kathy Hochul recently announced her administration is moving forward with an internet mapping provision passed in this year's state budget.<sup>7</sup> The New York State Public Service Commission will study the availability, reliability, and cost of high-speed internet services across the state. As part of this process, the Commission will:

- Identify areas at a census-block level served by only a single provider and assess any state regulatory and statutory barriers to the delivery of comprehensive statewide access to high-speed internet;
- Review available technology to identify solutions that best support high-speed internet service in underserved or unserved areas and make recommendations to help ensure deployment of such technology in underserved and unserved areas;
- Identify instances where local governments have notified the Commission of alleged non-compliance with franchise agreements and instances of commission or department enforcement actions that have had a direct impact on internet access;
- Identify locations where insufficient access to high-speed internet service, and/or persistent digital divide, is causing a negative social or economic impact on the community; and
- Produce and publish on its website a detailed internet access map of the state, indicating access to internet service by address.

The Commission's map will include advertised and experienced download and upload speeds; the consistency and reliability of download and upload speeds, including latency; the types of internet service and technologies available, including but not limited to dial-up, high-speed wireless, fiber, coaxial, or satellite; the number of internet service providers available, the pricing of available internet services; and any other factors the commission may deem relevant.

This is a major step forward because absent clear and reliable data about the extent of high-speed internet coverage, regulators and consumer advocates are forced to rely on industry and government assurances about who has and does not yet have high-speed internet at home.

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5. NBC News, "White House touts broadband part of new infrastructure deal." July 28, 2021.

6. Data from the U.S. Census, American Community Survey, 2019.

7. <https://www.governor.ny.gov/news/governor-hochul-announces-launch-mapping-survey-examine-quality-and-availability-broadband>

Finally, rural older adults in New York State face a paradox due to recent investments in building new high speed-internet infrastructure. The “New New York” initiative resulted in increased availability of high-speed internet to reach over 95% of households in the state, making New York one of the most connected states in the nation. But the New York State Comptroller estimates that as many as 253,000 households still lack high-speed access at home—with particular prevalence in rural areas—further isolating often older and lower-income individuals and families.<sup>8</sup> When government agencies have declared “mission accomplished” in extending high-speed internet to all, those who are still offline risk falling into a forgotten minority, with few resources left to help.

New York State currently has no comprehensive plan for closing the digital divide that leaves so many rural older adults disconnected and has no framework for ensuring that technology participation rates become equalized across all ages. As significant new federal funding and regulatory developments bring new public investment and changes to the economic environment, the state will have renewed opportunities to pursue solutions that combine public, private, and civic resources.

## Recommendations:

- New York State should adopt the goal of equalizing home high-speed internet utilization across all ages and geographies, including rural areas, by 2025, and should establish an interagency working group to develop a strategy and program for reaching this goal.
- New York State should empower local entities to audit high-speed internet access maps and implementation agreements.
- The state should assign independent organizations in rural counties (nonprofit or county-level public agencies) to analyze point-level data, including pricing, speed, and availability of different competitive options, and report the findings to the Public Service Commission.

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8. New York State Comptroller, op cit., page 6.

## The Four Pillars of Digital Success

Digital inclusion is sometimes described as a three-legged stool, with access, affordability, and adoption (training) forming the essential elements to get people online.<sup>9</sup> In fact, for older adults, it's more of a four-legged bench, with the addition of devices as a critical challenge for older adults to overcome. In each area, older New Yorkers in rural areas face special challenges and require new efforts to overcome the age-related technology gap.

### Access

Reliable access to high-speed internet at home is the prerequisite for meaningful participation in today's digital world, and many residents of rural New York still lack this critical resource. Some attempt to make do with satellite service, which has challenges with latency and reliability during periods of cloud cover. Others have nothing at all.

Since 2015, New York State Empire State Development (ESD) has spent more than \$500 million through an innovative reverse auction to create incentives for private companies to serve residences in economically challenged areas. The program resulted in significant improvements to access and capacity for an estimated 250,000 households and is widely viewed as having helped close a significant portion of the state's digital divide. At the same time, some residences remained unserved by the program, and experts say that analysis of this remainder is hampered by notoriously inaccurate maps utilized by the FCC to estimate high-speed internet coverage across the country.<sup>10</sup> Existing maps, which in some locales have been shown to be as much as 50% inaccurate, are simply inadequate to indicate where residents currently lack connectivity.

From an economic standpoint, the residences that remain unserved or underserved by high-speed internet are the least cost-effective to reach. Many of these homes were included in the ESD reverse auctions, but no companies bid for the addresses due to high capital and operating costs, combined with very low densities of subscribers. Some experts argue that, even with full public financing for capital costs, these geographies are unlikely to be profitable from an operating point of view, given the minimum costs for network maintenance, utility pole rental fees, and taxes, which can total more than the income projected from the subscribers in these areas.

Access to "high-speed internet" requires agreement on its technical definition and the standards that must be reached for service that is adequate to the needs of the modern user. Policymakers must establish technical thresholds that are expansive enough to account for increasing bandwidth needs to accommodate technological innovation, at the same time recognizing that some attention must be paid to questions of efficiency. The Empire State Development Office of Broadband currently defines "unserved" households as having no service or service with download speeds slower than 20 Mbps. "Underserved" households have services with download speeds between 20 and 50 Mbps. Emerging standards at the federal level suggest that a 100 Mbps download speed (with at least a 20 Mbps upload speed) will

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9. C. Davidson, T. Kamber, and M. Santorelli and C. Davidson, "Toward an Inclusive Measure of Broadband Adoption," *International Journal of Communication*, Vol. 6, 2012, pp. 2555-2575.

10. New York State Comptroller, *op cit.*, page 6.



likely be considered adequate for most households.<sup>11</sup>

Most experts agree that fiber optic cable to the residence is the optimal technology to achieve minimum speeds of 100 Mbps (fiber also has the advantage of offering symmetrical upload speeds), and recommend that, wherever possible, a fiber be deployed as the core infrastructure when utilizing public subsidies. The American Rescue Plan Act of 2021 set a threshold of 100/100 Mbps for funded projects (where feasible). At the same time, other technologies such as cable, 5G wireless, and low orbit satellite provide multiple options for consumers wanting to get online in rural areas. Wireless advocates point out that virtually all current consumer use patterns can be adequately served with bandwidth speeds below 100/20, and that wireless technology can be deployed more quickly and at less cost than fiber to the premises. These technology options are complex and can require that consumers analyze sometimes confusing information about speed, reliability, and data caps. As additional options become increasingly available for rural subscribers, assistance with informed consumer decision-making may be a critical form of support.

Finally, infrastructure investments are a critical component in economic and jobs development for rural counties across New York State, yet there is currently no mechanism for encouraging participating internet providers to employ age-friendly hiring and retention practices to ensure that older workers are able to benefit equally from these investments. Adults have equal opportunities for employment, entrepreneurship, and economic participation.

## Recommendations:

- Complete infrastructure development to enable access to high-speed internet at future-proof speeds (e.g., 100/100 Mbps) to all rural households in the state.
- Require companies participating in public subsidies to consult with local entities in the planning and implementation phases for building new infrastructure.
- While prioritizing fiber to the premises, encourage multiple options for consumers where feasible, including cable, 5G wireless, and fixed wireless.
- Consider additional subsidies (similar to current practice for rural telephone service) to subsidize companies and/or municipalities to build and operate high-speed internet services in areas where market forces are unlikely to result in private investment.
- Support recent legislative efforts to balance the cost burden of pole attachment make-ready efforts. Companies seeking to build new high-speed internet infrastructure should not be forced to bear unfair costs for replacing and upgrading poles.

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11. At the time of writing this paper, Congress is voting on the national infrastructure bill that designates \$65 billion for high-speed internet infrastructure, including resources for rural access, consumer subsidies for low-income households, and funding for training.

## Devices

Today, consumers are faced with a sometimes bewildering array of technology options including computers, tablets, laptops, mobile devices, wearables, voice-activated devices, and smart-home systems. In addition to the substantial cost involved, there are significant risks and opportunities to be evaluated in terms of platform consistency, user-friendliness, and interoperability between devices.

For many older adults, the challenges of evaluating, selecting, purchasing, and installing appropriate technology devices in their homes are a significant barrier, not just because of cost, but also because of the lack of information and support available while making these critical choices. Older people often lack the social networks many younger individuals use for gaining informal information about devices and emerging technologies. Consequently, they are often left to rely on commercial advertisements or advice offered from retail outlets, which do not always consider the priorities of rural older adults living independently at home.

In 2021, Congress approved the Emergency Broadband Benefit (EBB), which provided funding so internet providers could offer a \$100 device discount to low-income consumers who would also receive up to a \$50 monthly subsidy for internet access.<sup>12</sup> Most large providers declined to participate in the device subsidy part of the program since they lack product offerings at the \$100 price point, leaving consumers with very limited options.

Existing education programs in rural areas focus on classroom-based training on basic computer use. Many, sponsored by libraries or local colleges, lack the funding or local capacity to present neutral, consumer-friendly, relevant information to older adults as part of their educational offerings, including opportunities to observe and experiment with new devices and emerging technologies. Consequently, older adults may experience lower levels of technology readiness and be reluctant to adopt devices that, together with internet access, are a gateway to a more connected life.<sup>13</sup>

Older adults may also face difficult choices, as many devices designed to be “senior-friendly” are not used widely by the general population. People wishing to find a phone or tablet with larger buttons or simplified interfaces may find themselves outside the technology mainstream, which can lead to increased social isolation, as not all apps or functions are supported by the simplified platforms.

A senior center in rural Malone, New York deploys a “Tech Spot,” a technology exploration wall unit that combines training equipment with displays that empower users to experiment with consumer technologies such as voice activation, companion robots, biometric devices, and “Internet of Things” equipment.<sup>14</sup> Similar opportunities for touch-and-feel technology exploration are available at the Thrive Center in Louisville, Kentucky. The use of such

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12. Current versions of the 2021 infrastructure bill have extended this subsidy program but reduced the monthly amount to \$30.

13. Giger, J, et al., “Older Adult Intention to Use the iPad: Analysis of Change and Lessons Learned.” Poster presented at the Gerontological Society of American Annual Meeting, November 2015.

14. Note, the Tech Spot is provided through a partnership with OATS, which collaborated with AARP in preparing this briefing paper.

non-commercial environments to support older adults in making informed decisions in a pressure-free setting can be a key mechanism for closing the digital divide and empowering consumers.

In recent years, there has been a growing trend toward supporting device distribution along with subsidized internet access. Cities and states have provided funding for youth struggling against the homework gap during the pandemic, with significant allocations supporting the purchasing and distribution of devices to low-income families. In 2020, New York City announced the distribution of 10,000 free T-Mobile G Pads to seniors living in public housing, including connectivity from T-Mobile and training from OATS from AARP, all free of charge to the residents. Programs such as these show great promise in eliminating barriers to technology adoption for many rural older adults who may lack access to devices.

## Recommendations:

- New York State should create a supplemental device subsidy program targeting low-income older adults living in rural counties. Such a program should maximize consumer choice in selecting devices.
- The State Office for the Aging should fund technology demonstration centers in key regions of the state to help older adults access and explore emerging technologies.

## Cost

For many people, and especially older adults on fixed incomes, the cost of high-speed internet service is a significant barrier to participation in the digital age, and one major reason so many older Americans don't subscribe to high-speed internet at home. Poverty is a serious problem for rural older adults, and with the average monthly cost of a high-speed internet subscription at around \$50, large numbers of older adults simply cannot afford to subscribe, even when they recognize the importance of access to high-speed internet service in their lives and when there is an available connection for their home.<sup>15</sup>

Many observers link competition to price and argue that areas with just one provider are more vulnerable to higher prices than those served by multiple competing providers.<sup>16</sup> In densely populated cities, competition among multiple providers is the norm, but in rural areas, the profitability of building even one connection to a remote residence is marginal, leading to less competition. Some rural residences are limited to satellite connections as their only available connectivity option. One challenge cited by experts is the high cost of attaching new telecommunications infrastructure to existing utility poles, with electric and phone companies delaying the make-ready process for new infrastructure, resulting in public investment and subsidies reaching fewer customers over time.

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15. Note, the Tech Spot is provided through a partnership with OATS, which collaborated with AARP in preparing this briefing paper.

16. "Cost of Connectivity 2020," New American Foundation, 2020.

A 2021 report that linked home high-speed internet participation rates with incomes reported by older adults participating in the longitudinal National Social Life, Health, and Aging Project suggested that approximately two-thirds of American older adults who are offline at home have incomes low enough to qualify for a potential government subsidy.<sup>17</sup> Until recently, few solutions existed for these lower-income Americans. In 2020, however, Congress enacted the previously mentioned EBB—a subsidy of up to \$50 per month (\$75 per month on tribal lands) for low-income households to help defray the cost of in-home high-speed internet service. Most internet providers across the country are participating in this program, which will expire six months after the end of the COVID-19 emergency or when the \$3.2 billion funding allocation runs out. Additionally, at the time of this writing, Congress is considering a permanent subsidy of \$30 per month that would replace the EBB and serve as continuing support for low-income households trying to afford home high-speed internet. In the meantime, there are no funds available in the EBB to support outreach and enrollment, and even though the program has enrolled millions of participants in the first few months, without concerted effort to inform older adults of the value proposition and program requirements, it is unlikely that many more will participate.

Prior to the creation of EBB, low-cost options were provided only through private subsidies sponsored by telecommunications companies. The largest such program, Comcast UC Internet Essentials, offers a \$9.95 internet connection to qualifying households and serves over 2 million families nationwide, but is not widely available in New York State, as Comcast cable service exists only in a small number of communities in the state. Spectrum offers a low-cost alternative in New York State called “Spectrum Internet Assist,” which is limited to senior citizens receiving Supplemental Security Income assistance. Unfortunately, no public information is available regarding the number of older adults who are actually served by this program, and a 2021 report from OATS estimated that as few as 2% of older adults would qualify (compared to over 50% in the Comcast program, which has much more inclusive enrollment standards).<sup>18</sup> The fate of these programs in the new era of federally subsidized high-speed internet initiatives remains unclear.

One critical element of the projected success of the new federal subsidy plans is the potential for providing outreach and enrollment support to help people understand and apply for the subsidies. Communities across the country are establishing supplemental programs to help low-income families learn about the EBB, and organizations like AARP are conducting outreach and information sessions, as well as setting up hotlines and digital resources to help people take maximum advantage of these benefits. States and localities that can enroll more participants into the program can bring more federal investment into their communities, both boosting the economic multiplier effect and reaping substantial benefits that accrue to participants.

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17. Op cit. Aging Connected.

18. Op cit., “Aging Connected.”

## Recommendations:

- Ask the Public Service Commission to investigate claims of inefficiency and anticompetitive practice in utility pole make-ready and related activities, and to recommend options for maximizing the productive use of public subsidies.
- Establish a fund to support outreach and enrollment activities to optimize enrollment in the EBB and subsequent subsidy programs by older adults in rural areas.
- Direct New York State agencies serving rural districts to conduct outreach to older adults to educate them about high-speed internet subsidies and ways to apply for them.
- Direct the ESD Office of Broadband to publish annual data regarding the number of older adults participating in both public- and industry-financed low-cost internet programs.
- The ESD Office of Broadband should publish an annual statement of the average price of high-speed internet service in each county as a percentage of the average annual income of that county.
- Authorize the Public Service Commission to exercise oversight and promulgate rules and evaluations regarding the resiliency, public safety, and quality of high-speed internet service in New York State.

## Skills Training

In many ways, technology training is the connective tissue that helps activate the benefits that flow from home high-speed internet adoption. Older adults did not grow up in a digital world and often lack access to the kind of peer-based observation and informal training that frequently forms the basis of skills development among younger “digital natives.” Since the social networks of older adults tend to attenuate, the role of nonprofit or library-based training becomes more important as people seek both information about technology and its relevance to their lives, along with the specific skills to utilize devices, apps, and connectivity.

OATS operates a training program across several counties in rural upstate New York that is being replicated in other states, including Colorado and Texas, and which has enrolled thousands of older adults in free in-person and online training. During the pandemic, participants have connected with older adults across the nation for online health and wellness programs, social events, book clubs, and even courses on e-commerce and online banking. Funding from the State Legislature and the Consumer Technology Foundation (along with grants from T-Mobile, Spectrum, and philanthropic entities) have enabled OATS to disseminate the free training across multiple counties in upstate New York in partnership with libraries, senior centers, and multi-service agencies.

A recent report from the National Digital Inclusion Alliance (NDIA) ranked New York State 46th in the nation in digital equity—that is, support for efforts to provide vulnerable people with “basic digital skills in order to be employed, fully participate in society, and access essential resources.” According to the NDIA, New York fails to collect data on statewide digital needs and has no comprehensive plan to address digital skills gaps.<sup>19</sup>

To be effective, skills training should be conducted by organizations with experience and expertise working with older adults, using age-appropriate methodologies, quality technology and connectivity, and content that has maximum relevance to older individuals. Where necessary, training should be available in multiple languages and on several mainstream technology platforms, allowing participants to engage with minimal challenges of language or interoperability. Programs should be data-driven and staffed by qualified professionals with a written curriculum that is updated as technology interfaces and designs evolve. In-person programs should be supplemented with online instruction and phone-based support where possible to optimize availability to older learners who may not be able to attend sessions in person.<sup>20</sup>

## Recommendations:

- New York State should develop a plan for overcoming the digital skills gap for people throughout the state, with special attention to rural communities and older adults.
- Funding should be provided to help local agencies, libraries, and volunteer-based organizations provide or contract for quality training to help older adults adopt home high-speed internet technology.

## Conclusion

High-speed internet technology offers extraordinary benefits for older adults living in rural communities. By enabling near-instantaneous communication and interaction over long distances, high-speed internet holds the promise of bringing the world to the doorsteps of older adults regardless of their proximity to major population centers. Connected older adults can partake in social activities, conduct business and commercial affairs, stay abreast of world and local events, communicate with friends and family, and even utilize digital fitness and wellness resources. The benefits are innumerable, as many who have become active participants in the digital age can attest.

Yet, serious disparities persist, with 40% of older New Yorkers unable to take advantage of these benefits that so many others, young and old, take for granted. Many older adults continue to live in rural areas where high-speed internet is still not available, and even more are prevented from participating due to a lack of financial resources, training support, or access to functioning devices that are the prerequisite for successful engagement with information and communications technology today. These disparities are particularly concerning, as they fall on the lowest-income

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19. National Digital Inclusion Alliance, State Digital Equity Scorecard, [www.state-scorecard.digitalinclusion.org](http://www.state-scorecard.digitalinclusion.org). Accessed 8/18/21.

20. Gardner P., T. Kamber, and J. Netherland, “Getting Turned On: Using ICT Training to Promote Active Aging in New York City.” *Journal of Community Informatics*, Vol. 8, No. 1, 2012, pp. 1-16.



older residents of rural areas, who are likely to be living alone and have health complications. While there are certainly new opportunities emerging to close the digital participation gap for older adults in rural New York, from federal subsidies to technological advances and growing networks of nonprofit training providers, the challenges remain unsolved. Only a concerted and sustained effort by public agencies and elected officials, together with telecommunications and technology companies, as well as civic and nonprofit organizations, can achieve the kind of change that will help solve the challenges of rural older adults in this time of rapid technological innovation.

## Interviews:

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**DISRUPT DISPARITIES: ADDRESSING THE CRISIS FOR RURAL NEW YORKERS 50+**

# **FAMILY CAREGIVING**



**By Beth Rooney Suereth**

Founder and CEO, Caregiving Pathways

Rural family caregivers face many of the same challenges as others in more populated areas, but because of the geography and low population density where they live, they often find themselves without the same access to services that urban dwellers have. Across New York State, AARP estimates there are 2.5 million caregivers.

More than 1 million rural New Yorkers are aged 50 and over, with more than 150,000 in the oldest, frailest age cohort, according to the New York State Office for the Aging (SOFA). Over the next 20 years, SOFA anticipates that as the Baby Boomer generation ages through its late 70s and into its 80s, this number will increase by 65%, with a likely increase in the need for caregivers. However, the ratio of potential family caregivers (mostly adult children ages 45–64) to older adults at risk of needing long-term support services (those ages 80 and older) is projected to decline significantly, from a 2010 high of seven potential family caregivers for every person in the high-risk years of 80 and older to four to one in 2030 to less than three to one in 2050, according to AARP’s 2019 national report “Valuing the Invaluable”.

One important commonality among caregivers is their desire for their aging loved ones to remain at home for as long as possible. Some New Yorkers choose to retire in rural areas, whether it’s Central or Western New York, the Catskills, the Southern Tier, the Adirondacks, and North Country, or the outskirts of larger population centers like the Hill Towns of Albany County. Unfortunately, when younger relatives of rural New Yorkers move away due to the lack of job opportunities, their aging loved ones are often left behind, relying on a system of volunteers or limited home and community-based services (HCBS). Family caregivers who stay are often isolated and in need of help that just isn’t there.

The characteristics that help sustain rural New Yorkers—stoic independence, self-reliance, and resilience—can hinder their willingness to seek or accept help when they become family caregivers. The pressure family caregivers feel can lead to mental health issues and suicide ideation, according to the Centers for Disease Control and Prevention.<sup>1, 2, 3</sup> Caregivers in rural areas are at even higher risk of suicide ideation and face additional challenges specific to rural areas.<sup>1, 2, 3</sup> Unpaid family caregivers also reported that their mental health had worsened during the COVID-19 pandemic.<sup>3</sup>

Rural caregivers are less likely to use formal support services, such as support groups, home health aides, nursing agencies, and other paid help to assist with their caregiving responsibilities.<sup>4</sup>

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1. <https://www.cdc.gov/aging/caregiving/index.htm>

2. <https://www.cdc.gov/ruralhealth/Suicide.html>

3. <https://www.cdc.gov/mmwr/volumes/70/wr/mm7024a3.htm>

4. New York State’s Working Caregivers Fact Sheet April 2021/Rural Health Information

Hub, <https://www.ruralhealthinfo.org/toolkits/aging/1/demographics>

*Family caregivers are the family members, friends, and neighbors who help older adults and those with special needs live independently. They assist with activities of daily living (ADLs) such as bathing, toileting, and dressing as well as more complex instrumental activities of daily living (IADLs), such as grocery shopping, managing medications, and handling finances.<sup>5</sup>*

## TOP CHALLENGES FOR RURAL NEW YORK STATE FAMILY CAREGIVERS

Rural New York State family caregivers encounter several significant challenges to accessing the HCBS that will enable them to help a family member, friend, or neighbor live independently rather than enter a nursing home. These challenges can be exacerbated by the limited economic opportunities and healthcare labor shortages in rural areas.

### Family caregivers experience a lack of access to:

- 1. Information about the role and journey of a family caregiver**
- 2. Available, reliable, and affordable HCBS**
- 3. Respite care**
- 4. Financial support**
- 5. Mental health resources**

### 1. Information about the role and journey of a family caregiver

Family caregivers start their journeys in different ways. Some start by helping in small ways until one day they may realize they bear the brunt of the responsibility for the care of another adult. Others may become caregivers suddenly during an unexpected health crisis when they are emotionally stressed but must quickly make life-altering decisions. Some live near the care recipient, but in rural areas, many have moved away and experienced the additional challenge of helping from afar.

Many family caregivers are unprepared for the challenge of watching a family member or other loved one decline; the change in their lifestyle with the sometimes significant level of responsibility and the potential inability to meet the demands on their time and energy; and the sometimes overwhelming sense of isolation that can be punctuated by feelings of grief, distress, despair, guilt, or sadness.

Family caregivers often do not know that community-based resources exist. Even for those who do, managing their overwhelming new day-to-day responsibilities can make it challenging to find out whether they are eligible for such supports and learn how to access them. Supports for family caregivers often vary by municipality, creating an additional challenge.

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5, 6 Susan C. Reinhard et al., *Home Alone Revisited: Family Caregivers Providing Complex Care* (Washington, DC: Home Alone Alliance, 2019), <https://www.aarp.org/ppi/info-2018/home-alone-family-caregivers-providing-complex-chronic-care.html>



## 2. Available, reliable, and affordable HCBS

HCBS resources in rural New York State are limited in number and scope. AARP has continually advocated for more funding for SOFA, which oversees and partially funds the county aging offices in providing these services. Many rural communities offer significantly fewer of these services compared with non-rural communities, due to low population density.

In rural New York State, the limitations are more pronounced because rural populations skew older.<sup>7</sup> Many workers leave rural regions for better economic and social opportunities in urban and suburban areas.<sup>8</sup> Some people buy a second home in a rural area of New York, then retire there from elsewhere. Rural areas lose residents 4 to 5 times faster than more urban upstate areas do; rural and upstate metropolitan areas combined lost 54,600 residents or 4.3% of their population from 2010 to 2018.<sup>9</sup>

The remaining workforce is not sufficient to meet the demand for in-home care, a situation that fosters low-supply/high-demand pricing. Even with that dynamic at play, the hourly wages that direct care workers earn in a 40-hour week are so low that they cannot afford to live on that income alone. Because the workers are hourly earners rather than salaried employees, they often do not have health insurance or other benefits, thereby effectively reducing their earning power even further.

*HCBS (Home and Community-Based Services) are health and human services and programs that address the needs of people who require assistance with everyday activities. HCBS is designed to help people receive care at home rather than move to a facility.*

*Home and Community-Based Health Services that meet medical needs include skilled nursing care; caregiving training; occupational, speech, and physical therapy; client training; pharmacy; health promotion and disease prevention; medical equipment; and hospice care.<sup>10</sup>*

*Home and Community-Based Human Services that support daily living needs include senior centers and adult daycare; personal care like dressing, bathing, eating, and toileting; congregate meal sites; home-delivered meals; transportation; housekeeping and chores; home safety assessments, repairs, and modifications; legal services such as will preparation; financial services; and information and referral services.<sup>11</sup>*

7,8. <https://www.pressconnects.com/story/news/local/2019/07/25/new-york-growing-older-heres-where-population-graying-most/1802814001/>

9. <https://www.news10.com/news/report-people-are-leaving-rural-areas-of-new-york/>

10,11. U.S. Centers for Medicare and Medicaid Services

<https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/hcbs>

Because there are so few HCBS providers in rural areas, the network they comprise is very closely connected, a situation that serves family caregivers well. But when family caregivers learn about HCBS and begin to navigate them, the hope that the services offer to overwhelmed family caregivers is often dashed when they are placed on waiting lists because agencies and programs do not have enough staff to meet the demand and because state funding, while increased in recent years, remains insufficient.<sup>12</sup>

## Diversity and Cultural Concerns

Caregiving resources must be accessible to everyone in New York State, regardless of the family caregiver's race, ethnicity, or culture.<sup>13</sup> Rural communities increasingly include populations with language, culture, or family structures that differ from those of the dominant culture.<sup>14</sup> In the rural farming community, despite the decline in the number of farms, the 2007 USDA Census of Agriculture found that farmers and ranchers are becoming more diverse and that the number of Asian, Spanish, Hispanic or Latino, Black and African American farm operators continues to rise (U.S. Department of Agriculture, 2007 Census of Agriculture, 2012).<sup>15</sup>

Many family caregivers of color, and from indigenous, or other culturally diverse groups who live in rural areas, face the same barriers to services that other rural caregivers do. In addition, these caregivers often experience obstacles such as language barrier, mistrust of service providers—particularly when the providers are from a different culture—and fear of seeking providers or feeling or being excluded from services because of their immigration status or perceived biases.<sup>16</sup>

## 3. Respite Care

All family caregivers need respite at some point, whether it's to run errands, take care of their own health, or simply have time to rest. In many rural areas, the isolation of family caregiving and the lack of available respite care is compounded by geographic isolation. Limits in transportation options, including minimal public transportation, pose significant barriers to respite workers trying to reach family caregivers' homes or even to get to a place of employment.<sup>17</sup> Respite workers or volunteers may also have to travel long distances; when long distances are coupled with high gas prices and adverse seasonal road and weather conditions, transportation barriers can be even more imposing.<sup>18</sup>

Family caregivers face a number of barriers when attempting to access respite care. Respite programs available in rural New York are typically small and locally funded, without enough professionals to meet the needs of local family caregivers.<sup>19</sup> Families may not use facility-based programs because they are not comfortable asking for help and accepting it from people they do not know.<sup>20</sup> Programs that match care receiver and provider by cultural identity—which would help encourage respite program uptake, especially in underserved communities—often do not exist at all.<sup>21</sup>

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12. [https://static1.squarespace.com/static/57f118b446c3c49d11570ef4/t/5bd895dba4222f299c00aed5/1540920829677/AARP+NY\\_Family+Caregiving+Whitepaper\\_finalpages.pdf](https://static1.squarespace.com/static/57f118b446c3c49d11570ef4/t/5bd895dba4222f299c00aed5/1540920829677/AARP+NY_Family+Caregiving+Whitepaper_finalpages.pdf)



According to AARP's 2020 Caregiving in the U.S. report, caregivers recognize that support programs, like respite care, would be helpful to their own situation. However, the actual use of these services remains low. Just 14% report having used respite, though 38% feel it would be helpful (up from 33% in 2015).

## ***A Regional Respite Success Story Worth Modeling***

*In the Adirondacks region, Mercy Care has made great inroads in providing respite care through its programs staffed by volunteers. The Sisters of Mercy mission of long-term care began in the Adirondacks in 1895 to serve the growing number and needs of older adults attempting to age in place.*

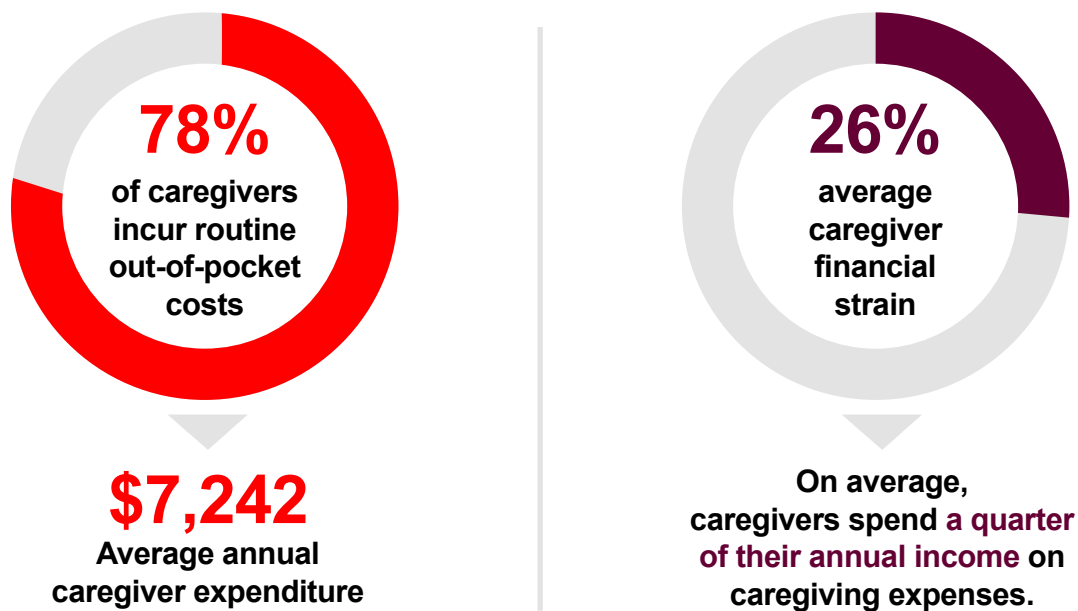
*Much of Mercy Care's success with providing respite care today comes from removing a significant barrier: discomfort in asking for and accepting help from strangers. It capitalizes on the connections that sometimes flourish more naturally in a small community than in a big city. Many professionals, family caregivers, and volunteers in the same community know one another, so an underlying level of trust exists that helps families feel comfortable using the resources that professionals recommend. Such close connections also foster Mercy Care's ability to attract and retain volunteers, many of whom are older adults eager to simultaneously help and socialize.*

*The most frequent request at Mercy Care is respite. A typical example would be an older woman caring for a husband with dementia. She would contact Mercy Care to request a nurse or volunteer to stay with her husband while she goes to a medical appointment or an outing with a friend. A caregiver advocate, Mercy Care friendship volunteer, or parish nurse goes to the family's home to stay with the family caregiver's husband.*

*Mercy Care, which doesn't charge family caregivers, serves the tri-lakes region of the Adirondacks through more than 100 volunteers and in collaboration with aging and health service organizations. It's funded by individuals, private foundations, and local organizations and businesses, receiving referrals from the Essex and Franklin County Offices for the Aging, Adirondack Health, and physician practices. More information about Mercy Care is available at [www.adkmercy.org](http://www.adkmercy.org).*

## 4. Financial Support

A 2021 AARP study showed that 78% of unpaid family caregivers incurred costs related to the care they provide, spending an average of over \$7,200 of their own money every year.<sup>22</sup> Only 5% of caregivers reported having no caregiving expenses in the past year.<sup>23</sup>



When a family member provides more than 10 hours of assistance per week or helps with activities of daily living, they often spend more money than the average caregiver does.<sup>24</sup>

The same study also found a correlation between increased work strain and higher out-of-pocket costs. Nearly 6 in 10 caregivers are currently working either full-time or part-time.<sup>25</sup> Those finding it more difficult to juggle work and caregiving responsibilities while reporting two or more work strains (like having to take time off or adjust their work schedule) spent an average of \$10,525 per year on caregiving expenses—almost double the spending of caregivers with no or only one work-related issue.<sup>26</sup>

Average caregiving expenses also vary based on caregiver and recipient demographics. The financial strain of caregiving is greater on Latinos and African-Americans—and on younger caregivers, who have had less time to work and build up resources—as well as those caring for someone with dementia.<sup>27</sup> Women, on average, spend more hours per week caregiving and have lower incomes. The cost of caring for female recipients is higher than it is for male recipients.<sup>28</sup>

22-26 <https://www.aarp.org/caregiving/financial-legal/info-2021/high-out-of-pocket-costs.html>

27-34 <https://www.aarp.org/research/topics/care/info-2016/family-caregivers-cost-survey.html?CMP=RDRCT-PPI-CAREGIVING-102416>

About half of caregivers say they used their own money for household-related caregiving expenses.<sup>29</sup> Thirty percent covered rent or mortgage payments for the person in their care, while 21% financed home modifications.<sup>30</sup> Medical costs (paying for healthcare, therapists, in-home care, or medical equipment) accounted for 17% of caregiver spending.<sup>31</sup>

About half of caregivers also say they have experienced financial setbacks.<sup>32</sup> This may mean they have had to curtail their spending, dip into personal savings, or cut back on retirement contributions.<sup>33</sup> The recent COVID-19 pandemic magnified sacrifices for caregivers, with 42% of respondents spending more time and money on caregiving.<sup>34</sup>

## 5. Mental Health Resources

In rural New York State, family caregivers' adverse mental health symptoms are exacerbated further by the issues raised in this paper—increased isolation caused by large and mountainous geography, long winters, lack of available, reliable, and affordable access to resources like transportation, financial support, respite care, and adequate numbers of trained staff providing other support services, including mental health professionals. These challenges affect even people who are very socially or professionally connected with others. Family caregiver mental health issues can lead to physical health issues.

According to the New York Caregiving Coalition, 2021 Employed Caregiver Survey conducted by the U.S. Department of Health and Human Services/the CDC's National Center for Chronic Disease Prevention and Health Promotion, suicide ideation among family caregivers is considerably higher than it is in the general population. The survey revealed:

- 70% of parents and/or caregivers reported adverse mental health symptoms:
  - o 55% reported anxiety or depression,
  - o 54% reported COVID-19-induced stress and trauma, and
  - o 32% reported passive or serious suicidal thoughts; and
  
- Among those caring for both people under and over 18, including the so-called “sandwich caregivers,” who take care of children and older adults:
  - o 52% reported serious suicidal thoughts or 12 times the rate of non-parents/non-caregivers, and
  - o 58% reported passive suicidal thoughts or 6 times the rate of non-parents/non-caregivers.

The ongoing study is part of a 2021 collaboration among New York public and private organizations resulting in the launch of a public-private partnership to survey businesses and their employees.<sup>35</sup>

## The Rural Caregiving Situation

Additional data are needed to drive deep, long-term change in rural New York State. Some actions in support of rural family caregivers can be implemented legislatively in the near future (see the short-term recommendations toward the end of this paper), but the most significant reforms will be long-term and data-driven (see the long-term recommendations toward the end of this paper).

The lack of data available on the topic of rural caregiving in New York is itself a data point. The county aging offices need to gather local data on rural family caregivers' needs and collaborate further among themselves and with local healthcare organizations and communities to provide the caregiving support that rural New York families so desperately need.

We must enable rural New Yorkers to care for family in the community by providing them with options that do not entail being economically forced into placing a family member in a facility far from the care recipient's home, like a nursing home that could cost over \$100,000—an expense that, in many cases, is borne by taxpayers through Medicaid.

Rural New Yorkers must serve as family caregivers because the alternatives in terms of long-term services and supports (LTSS) are so limited and the barriers to the small number of options are immense. There is a dearth of long-term care facilities, as some areas do not have a large enough population to incentivize the development of even a single long-term care facility.

In much of New York State, the geography is vast, and some of the terrains are mountainous. Several New York State counties are considered frontier areas because residents are so isolated from one another and from even the most basic of services.<sup>36</sup> The isolation can be exacerbated in some places by limited public transportation and long, severe winters with snowy and icy conditions.

In warmer weather, family caregivers may be able to take an older adult to the local market or out for a meal. But during long winter months, they may be unable to leave the house for days or weeks on end, especially when the care recipient cannot be left unsupervised at home. Loneliness and isolation of family caregivers can lead to declines in physical and mental health—including suicidal ideation.<sup>37</sup> When family caregivers experience a hospital stay due to poor health, the level of care provided to the care recipient declines or vanishes entirely, creating a crisis for all involved. The COVID-19 pandemic has intensified the isolation rural family caregivers experience.

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35. 2021 collaboration among public New York organizations and private organizations resulting in the launch of a public-private partnership to survey businesses and their employees: New York State Office for the Aging, New York State Department of Labor, Association on Aging in New York, New York State Respite and Caregiver Coalition, ARCHANGELS, and University of Wisconsin Cooperative Extension  
[https://www.health.ny.gov/press/releases/2021/2021-06-30\\_support\\_working\\_caregivers.htm](https://www.health.ny.gov/press/releases/2021/2021-06-30_support_working_caregivers.htm)

36. <https://www.ruralhealthinfo.org/topics/frontier#my-county>

37. <https://www.npr.org/sections/health-shots/2021/06/17/1007579073/unpaid-caregivers-were-already-struggling-its-only-gotten-worse-during-the-pande>

The prevalence of family caregiving is increasing because people throughout the country are living longer and with more chronic health conditions.<sup>38</sup> The situation is exacerbated even further in rural New York, where the population is older than the general population and the incomes are lower on average than those of the general population.<sup>39</sup>

Older adults require more care from family caregivers. As individuals, young or old, are discharged from the hospital increasingly earlier in the recovery process, they are increasingly in need of complex care at home.<sup>40</sup> Family caregivers routinely perform medical/nursing tasks previously performed by trained professionals and typically learn on their own how to deliver that care.<sup>41</sup> Half of family caregivers care for someone who has challenges in physical, cognitive, and/or behavioral health.<sup>42</sup> The level of care intensifies immediately after discharge from the hospital and toward the end of life.

#### *The “Typical” Caregiver in a Rural Area*

*The typical rural family caregiver is a non-Hispanic, white, 48.8-year-old woman. These family caregivers have lower education and household income than caregivers in suburban or urban areas do, but many don’t live in the area where they are administering care so must travel. They care for a parent or parent-in-law who is 66.9 years old and male. The rural care recipient has more long-term physical conditions, memory problems, or short-term physical conditions than do those in urban areas.*

*Compared to those in cities and suburbs, caregivers of those living in rural areas have been providing care for an average of 4.2 years. They provide more hours of care weekly (26.3 on average) and more often help with medical/nursing tasks, as well as helping with 1.7 activities of daily living and 4.5 instrumental activities of daily living. Rural caregivers are usually the primary unpaid caregiver, and most have no paid help.*

*Caregivers of rural-living recipients typically work in addition to providing care, for 34.8 hours per week, and more often in an hourly job. Caregivers of rural-living recipients report high levels of financial strain and have experienced a greater number of financial impacts from caregiving (1.9 on average), including stopping saving, taking on more debt, unpaid or late bills, and borrowing from friends and family.*

*Caregivers of rural-living recipients more often have difficulty taking care of their own health and less often report having health insurance. Caregivers in rural areas more often provide care for multiple people and more often report helping with medical/nursing tasks.*

#### **SOURCE:**

<https://www.aarp.org/content/dam/aarp/ppi/2020/05/rural-caregiver.doi.10.26419-2Fppi.00103.015.pdf>

38. <https://publichealth.jhu.edu/2014/life-expectancy-gains-threatened-as-more-older-americans-suffer-from-multiple-medical-conditions>

39 New York State’s Working Caregivers Fact Sheet April 2021/Rural Health Information Hub

<https://www.ruralhealthinfo.org/toolkits/aging/1/demographics>

40–42, Reinhard et al., Home Alone Revisited.

To enable older adults to live independently in rural areas of New York, family caregivers require foundational assistance from health, social, economic, and LTSS systems. Specifically, family caregivers need family caregiver support that is culturally competent and includes HCBS, respite care, and financial assistance.

Rural New York family caregivers need training and educational resources for how to manage their roles without becoming physically and socially isolated; task-specific instruction on how to provide complex hands-on care; financial assistance for their out-of-pocket caregiving costs; and practical and emotional support to manage their own physical and mental health.

The high prevalence of rural caregiver suicide ideation demonstrates the devastating emotional effects many caregivers endure because of their caregiving responsibilities—and highlights the lingering consequences of the COVID-19 pandemic, which have significantly exacerbated all the challenges family caregivers face.

A large number of veterans in rural areas, many of whom may have health and social service needs, also drives an even greater demand for caregiving services.<sup>43</sup>

Typically, family caregivers of those living in rural areas do not live in the rural area themselves.<sup>44</sup> The plight of long-distance family caregivers is complicated by a lack of familiarity with the local healthcare landscape and potential backup plans through local agencies or friends or neighbors who could help out in a pinch. They often feel obligated to quit a full-time job and move to a parent's house to provide care long-term or have the parent move to the family caregiver's home temporarily or permanently.

## ***The Economics of Working Family Caregivers***

*There are an estimated 2.5 million caregivers in New York State who provide 2.1 billion hours of unpaid care.<sup>45</sup> If paid for at the market rate, the cost of that care would be \$31 billion annually.<sup>46</sup>*

*One in six family caregivers in the United States provides more than 20 hours of care per week in addition to working.<sup>47</sup> Sixty-nine percent of working family caregivers report having to rearrange their work schedule, decrease their hours, or take unpaid leave to meet their caregiving responsibilities.<sup>48</sup> Almost half report arriving to work late, leaving early, or taking time off.<sup>49</sup> These numbers are projected to increase: By 2030, 1 in 5 New Yorkers are expected to be over age 60.<sup>50</sup> This ratio is set to grow in the state's rural areas, where there is a disproportionately large number of older adults.<sup>51</sup>*

43 <https://www.ruralhealth.va.gov/aboutus/ruralvets.asp>

44 <https://www.aarp.org/content/dam/aarp/ppi/2020/05/rural-caregiver.doi.10.26419-2Fppi.00103.015.pdf>



## Recommendations

The recommendations listed below would help individual rural New York State family caregivers and those for whom they care. These policy recommendations can profoundly affect the care recipients' ability to continue living in their community and their day-to-day quality of life. The recommendations will also help protect and bolster the economies of the communities in which those in need of care currently live.

## Short-Term Recommendations

Each family caregiving challenge has actionable cultural and economic aspects that current legislative efforts can address in the short term through existing channels.

<b>1. Enable home accommodations</b>	<b>5. Involve faith communities</b>
<b>2. Fund more in-home healthcare workers</b>	<b>6. Deploy awareness campaigns</b>
<b>3. Create a caregiver tax credit</b>	<b>7. Recruit volunteers</b>
<b>4. Collaborate with local businesses</b>	<b>8. Provide mental health assistance</b>

**1. Enable home accommodations**—Provide additional funding to local offices for aging, SOFA, and New York State Homes and Community Renewal (HCR) to help them deliver products and services directly to older adults that will help them continue living in their homes when mobility becomes limited.

- Much of the housing in rural New York comprises older homes with steps leading up to the front door to keep the doorway above the snow line during long, snowy winters. The steps can be a significant impediment for older adults. Such houses also generally do not have modern safety features or first-floor bedrooms or bathrooms.
- Provide education, funding, and mechanisms to enable accommodations such as exterior wheelchair ramps and bathroom grab bars that can help prevent falls that lead to emergency room visits, hospital stays, and further health complications. Fall prevention also helps entire families avert the emotional and financial upheaval that accompanies a health crisis. The Access to Home Program administered by HCR provides financial assistance to make residential units accessible for low- to moderate-income persons with disabilities.

45–46 <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>

47–51 New York State's Working Caregivers Fact Sheet April 2021/Rural Health Information Hub  
<https://www.ruralhealthinfo.org/toolkits/aging/1/demographics>

52–55 <https://www.aarp.org/livable-communities/tool-kits-resources/info-2019/rural-livability-focus-group.html>

Assistance with the cost of adapting homes will enable individuals to safely and comfortably continue living in or return to live in their residences, rather than being left no choice but to move to an institutional setting – likely at a high taxpayer cost. <https://hcr.ny.gov/access-home>

- Include a home assessment to determine the unique needs of the care recipient and the willingness and ability of the family caregiver to participate in care.
- Update and review possible program criteria that may restrict how the county-level offices can distribute funds to allow them to provide support according to each family's needs.

**2. Fund more in-home healthcare workers and increase state funding for HCBS**—In organizations where visiting nurses and direct care workers are employed, fund additional positions and training. Increased state HCBS funding could help end waiting lists.

**3. Create a caregiver tax credit**—Pass state legislation that would provide a tax credit to offset some of the more than \$7,200 on average that caregivers pay out of pocket for caregiving expenses annually.

**4. Collaborate with local businesses**—Engage the business community to:

- Create flexible schedules for family caregivers.
- Offer social adult day care just as companies do for child care; potentially pool the resources of multiple employers where possible.
- Encourage employers to learn about family caregiving and how they can support their employees to enhance retention and productivity.
- Teach employers how to address the issues that 95% of public and private human resources departments know about but do not know what to do to solve regarding how family caregiving affects their workforce. Seventy percent of employees look to human resources departments for help with personal issues, including family caregiving, according to SOFA.

**5. Involve faith communities**—Engage the 5,300 faith-based communities in New York to educate and support family caregivers, focusing primarily on smaller organizations, which in rural areas often have many older adult congregants but do not have strong networks or funding. Like physicians, faith leaders are trusted advisors. Having faith leaders give people permission to accept help may turn the tide for a family that needs help but is too proud at first to accept it.

**6. Deploy awareness campaigns**—Create systemic culture change by developing public awareness campaigns through public, private, and state and county government collaborations to promote family caregiving and available resources.

- Engage family caregivers by communicating to them that they are not alone and the resources available to help them reduce stress, improve their wellbeing, and gain access to programs and services. Achieve this by gathering input from working family caregivers living in the area and featuring positive language that is relatable to them and their family caregiving experience.
- Include existing resources, such as New York Connects at <https://www.nyconnects.ny.gov/> and <https://www.ny.gov/services>, where New York families can find services to help with food, healthcare, COVID-19 assistance, and other social determinants of health that affect a family’s ability to cope with the need for caregiving.

**7. Recruit volunteers**—Develop programs to recruit and train volunteers to provide a variety of supports to family caregivers.<sup>52</sup> Much can be achieved through partnerships among local rural private and public sector organizations.<sup>53</sup> The strategic recruitment and deployment of volunteers by these organizations can also make a significant difference in providing services for family caregivers.<sup>54</sup> Many older adults, particularly in rural areas, want to socialize and share their time and expertise as they engage in meaningful activities, and many are happy to do so in a volunteer capacity.<sup>55</sup>

**8. Provide mental health assistance**—Increase funding to SOFA for mental health resources for family caregivers to help them better manage their caregiving responsibilities and help prevent suicide ideation.

## Long-Term Recommendations

Future policy development can focus on more deeply influencing cultural change; coordinating existing home and community-based services, transportation, and housing; and creating new channels to meet family caregiver needs.

<b>1. Gather data</b>	<b>5. Create adult foster care programs</b>
<b>2. Expand PACE</b>	<b>6. Provide mobile adult day care respite</b>
<b>3. Recruit direct care workers</b>	<b>7. Turn senior centers into community centers</b>
<b>4. Create jobs across industries</b>	<b>8. Provide mental health research support</b>

1. **Gather data**—Collect and aggregate data on rural New York family caregivers and those for whom they care to identify the most pressing needs and determine how to meet them. As a starting point, hospital electronic health records should include detailed data on the preparation of family caregivers for the care they deliver at home immediately following hospital discharge. Collaborate with organizations that handle requests for support to see where the greatest needs exist.
2. **Expand PACE**—Pass legislation to expand the government’s existing Program of All-Inclusive Care for the Elderly (PACE), which provides support primarily to individuals who are dually eligible for both Medicare and Medicaid.<sup>56</sup> Participants are certain frail older adults (ages 55 and over) who receive comprehensive medical and social services that enable them to continue living in the community.<sup>57</sup> There are only 9 PACE programs in New York; most are in urban areas.<sup>58</sup> New York should support innovative funding strategies for establishing PACE programs in rural counties.
3. **Recruit direct care workers**—To address the dearth of rural New York workers who provide home-based skilled nursing and personal care, give financial incentives to home care and home health provider companies to develop programs that increase the number, retention, and training of nursing and direct care workers in rural New York areas. In parallel, motivate younger workers to remain in or move to rural areas by providing financial incentives to these employers to enable them to pay their workers a livable wage and benefits and provide them with training and credentialing.

Although New York had workforce development strategies (such as recruiting, training, and credentialing) in place in 2019, the state did not increase or expand these strategies in 2020 as ten other states did.<sup>59</sup>

4. **Create jobs across industries**—Encourage people to seek employment and live in rural New York to help older adults there continue living in the community rather than in a facility—the nearest of which may be far from the care recipient’s familiar surroundings, faith community, and social network.

- Entice healthcare workers of all ages, whether or not they are family caregivers, to move to rural New York State for in-demand healthcare jobs with training, livable wages, benefits, and rewarding work. Examples of these jobs are direct care workers, nurses, physicians, and social workers.

People who do have a family member who needs care will move to rural New York to provide that care themselves, oversee the care others provide in the home of the older adult, and/or drive an older adult to an

52–55 <https://www.aarp.org/livable-communities/tool-kits-resources/info-2019/rural-livability-focus-group.html>

56, 57 <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/PACE/PACE>

58 <https://www.npaonline.org/pace-you/pacefinder-find-pace-program-your-neighborhood>

59. <https://www.kff.org/report-section/a-view-from-the-states-key-medicare-policy-changes-long-term-services-and-supports/>

adult daycare program. People who do not have a family member who needs care will move to rural New York State for good jobs and the many desirable aspects of rural living.

- Entice family caregivers who want to help a rural older family member and want a non-healthcare job such as builder, hairdresser, electrician, real estate agent, accountant, or entrepreneur. These family caregivers can pay local healthcare workers to provide in-home care and non-healthcare workers to make internal and external home modifications, among other services. Some of these workers will need additional financial support to afford their bills and the caregiving costs they incur.
- Encourage property ownership and small businesses. The additional property and income taxes collected from new rural New York State wage earners will help offset the financial supports the state provides to residents in that region.

**5. Create adult foster care programs**—To reduce the need for nursing home placements, make-at-home care more affordable for more low-income older adults by developing Medicaid-funded HCBS waiver programs that pay family caregivers.

Two such programs include adult foster care in a small group home or adult foster care at home, in which a family member or other individual receives a stipend to provide live-in care to a care recipient who has certain health and functional needs.<sup>60</sup> These structured care models may entail periodic assistance throughout the day at a small group home or around-the-clock care in the care recipient’s own home or in the home of a family member or friend.<sup>61</sup>

Variations on such programs exist in dozens of states.<sup>62</sup> Adult foster care can cost states and the federal government significantly less than nursing homes do.<sup>63</sup>

**6. Provide mobile adult day care respite**—The Mobile Daycare Program in Georgia provides respite for rural family caregivers providing care for a person with dementia and can be seen as a successful model for this type of program.<sup>64</sup> Mobile daycare enables rural communities to have their own day care program while sharing staff who travel among locations.<sup>65</sup> Collaboration among local organizations is key. The Greater Georgia Chapter Alzheimer’s Association developed the innovative concept with funds from the Administration on Aging’s Alzheimer’s Demonstration Grants, and the program was implemented by the Augusta Area Chapter Alzheimer’s Association, with technical assistance from the Central River Savannah Area Agency on Aging.<sup>66</sup> More information is available from the Georgia DHS Division of Aging Services at <https://fsrtc.ahslabs.uic.edu/promising-practices/mobile-day-care-program/>.

60, 61. <https://assets.aarp.org/rgcenter/ppi/liv-com/fs174-afc.pdf>

62. <https://www.payingforseniorcare.com/medicaid-waivers/adult-foster-care>

63. <https://assets.aarp.org/rgcenter/ppi/liv-com/fs174-afc.pdf>

64–66. The Technical Assistance Center for Lifespan Respite Fact Sheet Number 35, October 2012

**7. Turn some senior centers into community centers**—Rural New York family caregivers and care recipients alike need places like community centers—in addition to senior centers, because many older adults may not identify as “seniors” and prefer to meet people of all ages. They can gather in community centers to help prevent social isolation, and the space can function as a central location for integrative activities such as learning new technologies that can keep them connected while at home. Community centers are especially helpful for older family caregivers who are unable to learn new technologies because of limitations such as arthritis or blindness and for enabling them to obtain information in face-to-face interactions. Gathering places such as community centers, libraries, and faith-based organizations can serve as hubs for creating awareness that the caregiving work that families and friends do is a critical function for which support is available.

**8. Provide mental health research support**—Increase funding to SOFA to research how to best provide mental health resources to family caregivers to help them better manage their caregiving responsibilities and help prevent suicide ideation.

## Conclusion

Rural caregivers face unique challenges and increased burdens when compared with their urban counterparts. Those challenges will only be exacerbated as the population of rural New York grows older and more in need of care with the aging of the Baby Boomer generation—and as younger rural New Yorkers continue leaving to pursue jobs in urban and suburban areas.

What’s more, the increasing diversity among older rural New Yorkers will pose language and other cultural challenges to ensuring their care.

Addressing these challenges through a variety of short- and long-term policy changes can help alleviate some of the physical, mental, and financial stress that New Yorkers face when caring for a loved one living in a rural community.

Mercy Care of the Adirondacks, with its network of volunteers, provides one blueprint for the effective delivery of family caregiving support. Increased state funding for in-home services for older adults, along with the recruitment of more direct care workers in rural New York, would help older rural New Yorkers on waiting lists—and their family caregivers—finally receive the support they need.

Tax credits would help offset the over \$7,200 the average family caregiver spends each year to provide and secure care for loved ones, while credits and support for home modifications could also help ease rural family caregivers’ financial burden.

And a focus on gathering data from rural New York would help inform policy decisions aimed at supporting family caregivers and ensuring their loved ones receive the care they need.



**DISRUPT DISPARITIES: ADDRESSING THE CRISIS FOR RURAL NEW YORKERS 50+**

# TELEHEALTH



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## INTRODUCTION

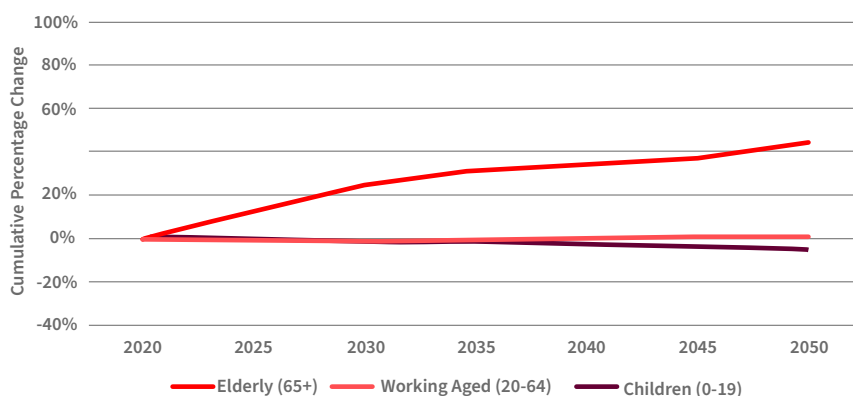
Access to quality healthcare services is important for health maintenance and promotion, disease prevention and management, the reduction of unnecessary injuries and disabilities, and the prevention of premature death. Healthcare access is particularly important for aging adults, especially those in the older cohorts (i.e., 85+), given that age is an independent risk factor for the onset of disease and chronic conditions, especially among underserved older adults. About 80% of adults aged 65+ have at least one chronic condition (e.g., heart disease, diabetes), and 60% have two or more chronic conditions (Federal Interagency Forum on Aging-Related Statistics, 2020). The following sections discuss characteristics of the New York older adult population, barriers to healthcare access among older New Yorkers, and how increased access to telehealth services can eliminate some of the barriers older New Yorkers—particularly those in rural communities—face when seeking care in a traditional healthcare setting. In fact, during the early days of COVID-19, throughout New York State, telehealth became the norm for many individuals seeking healthcare, as people sheltered in place and avoided leaving their homes.

### The Older Population in New York State

Currently, people aged 55 or older represent 30% of the New York State population, and those aged 60 or older number 4.3 million. It is estimated that the number of New Yorkers 65 and over will increase to more than 5.3 million by 2030 (Figure 1). The aging of the population will have an unprecedented impact on the healthcare system within New York as older adults use a disproportionate share of healthcare services. For example, older adults in the New York Medicaid program have been shown to consume well over twice as much healthcare as the average enrollee in terms of total spending (New York State Health Foundation, 2020).

According to data from the Kaiser Family Foundation (2020), 21% of those aged 65 to 74 years and 45% of those aged 75+ have a disability, compared to 9% of those aged 19 to 64. Further, 44% of those 65 years old or older have multiple chronic conditions and 25% are obese (United Health Foundation, 2021).

**Figure 1. Projected Cumulative Growth in New York State Population By Age Group 2020-2050**



**Source:** Hauer, M. E. (2019). Population projections for U.S. counties by age, sex, and race control to the shared socioeconomic pathway. *Scientific data*, 6, 190005.

Growth of the older population is expected to occur across all counties in New York State. However, the projected growth rate will be greater for non-metro areas. In 2018, the proportion of the population that are older adults in designated metro counties ranged from 16% to 18%; by 2035, this is expected to increase to between 20% and 22%. In contrast, in 2018, the proportion of older adults in non-metro areas ranged from 17% to 31%; by 2035, these ranges are expected to increase to between 23% and 34% (Table 1).

**Table 1. The Proportion of Elderly Population in Rural and Urban Areas Across New York State: 2018–2035**

Rural-Urban Continuum Category	Number of counties	2018 total Population	Proportion of the population 65 years or older	
			2018 Actual	2035 projected
Metro areas of 1 million population or more	20	15,507,286	16%	20%
Metro areas of 250,000 population	12	2,065,300	18%	22%
Metro areas of fewer than 250,000 population	6	602,863	18%	22%
Non-metro areas of 20,000 population or more, adjacent to a metro area	10	769,645	19%	24%
Non-metro areas of 20,000 population or more, not adjacent to a metro area	1	80,695	17%	23%
Non-metro areas of 2,500 to 19,000 population, adjacent to a metro area	9	355,514	22%	27%
Non-metro areas of 2,500 to 19,000 population, not adjacent to a metro area	3	156,472	19%	23%
Non-metro areas of 2,500 population, adjacent to a metro area	1	4,434	31%	34%

**Source:** Hauer, M. E. (2019). Population projections for U.S. counties by age, sex, and race control the shared socioeconomic pathway. *Scientific data*, 6, 190005.

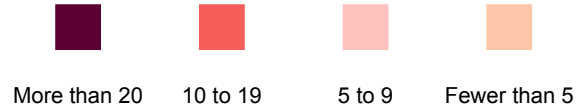
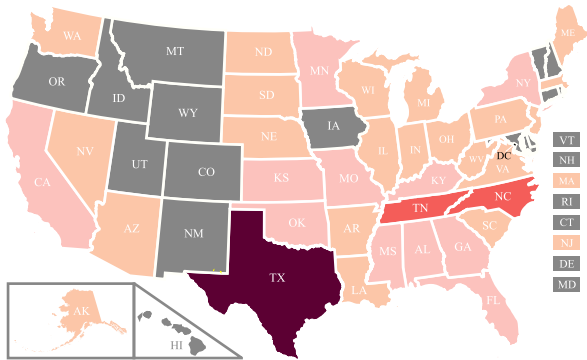
## Barriers to Healthcare Access for Rural Older Adults

As New York State residents age, consistent access to quality healthcare is essential—especially for those in rural communities. Access to quality healthcare impacts an individual’s physical, cognitive, and mental health, as well as ability to socialize and quality of life. In this regard, a stated objective of the New York State Government is achieving health equality for all residents. In 2017, then-Governor Andrew Cuomo directed state agencies to foster programs to improve New Yorkers’ health. As part of this agenda, New York State launched the Health Across All Policies approach to foster collaboration among health and non-health agencies to promote health for New Yorkers of all ages and geographic areas. In addition, the state launched the Age-Friendly Health System Initiative to help ensure 50% of all health systems will be age-friendly by 2023. In fact, in 2017, New York became the first state to enroll in the AARP Network of Age-Friendly Communities.

Unfortunately, despite the abundance of these programs and services, and a commitment to health for older New Yorkers, access to high-quality healthcare is not equitable across the state. Overall, New Yorkers of color, those of lower socioeconomic status living in non-metro areas, and older adults experience health inequities such as differences in disease burden, diagnoses, and access to quality care for health promotion and maintenance, and treatment of illnesses and chronic conditions. People who live in rural areas, for example, are more likely than urban residents to die prematurely from the five leading causes of death: heart disease, cancer, unintentional injury, chronic lower respiratory disease, and stroke. People who live in rural areas are also 19 times more likely to suffer from diabetes than those in urban areas (CDC, 2019). Rural residents also have higher mortality and higher rates of suicide (JAMA, Network, 2020). Furthermore, rural residents, especially aging adults, face unique risks for social isolation and loneliness, which are strongly associated with increased risks for morbidities and mortality and higher healthcare costs.

The causes of healthcare inequities for those who live in rural locations are complex. Common barriers to healthcare include a shortage of local providers and care facilities, lack of insurance, poverty, low health literacy, and lack of affordable and convenient transportation to medical offices and hospitals. Rural hospitals and clinics are closing at an alarming rate. Since 2005, at least 163 rural hospitals have closed; rural health clinics are also in peril (UNC Sheps Center for Health Services Research, 2021) (Figure 2). For example, according to recent data from HRSA (as reported in Rural Health Information Hub, 2021), as of 2021, there were only 18 critical access hospitals, 41 rural health clinics, 96 Federally Qualified Health Centers, and 39 short-term hospitals across rural New York, to serve a population of 1.4 million. In contrast, in New York City alone, there are 214 hospitals to serve a population of 8.4 million. Further in 2018, while Long Island alone had 148 primary care doctors for every 100,000 patients, the number in the Southern Tier of New York was 89, and 83 in the Mohawk Valley (Robinson, 2020). In fact, rural New York is often referred to as a “healthcare desert.”

**Figure 2. Rural Hospital Closures**



Of the 163 rural hospitals that have closed since 2005, more than 60% shut their doors since 2012

Source: Cegil G Sheps Center for Health Services Research, University of North Carolina

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Barriers to high-quality healthcare are particularly pronounced for older adults in rural locations, who tend to be poorer, less educated, in worse health, less socially active, and less likely to live in skilled nursing facilities. Further, the quality of care that is available is quite often lower. Older adults in these communities are less likely to have access to public transportation or transportation services such as ride-share services, thus making accessing healthcare facilities, especially for specialty services, particularly challenging (Rural Health Information Hub, 2021). The challenges confronting rural older New Yorkers were especially pronounced at the onset of the COVID-19 pandemic, as New York was one of the states most impacted by the initial wave of the virus. Currently, about 14% of New York State’s 65-and-over population live in rural areas, and as noted above, these numbers are expected to increase in the coming decades. Telehealth, which uses communications technology to deliver healthcare, health information, and health education at a distance, can help ensure older adults living in rural communities have access to care while minimizing some of the challenges this population often experiences with traditional in-person care.

**Improving Rural Healthcare Access Through the Use of Telehealth**

“Telehealth” refers to the array of services that use electronic information and telecommunication technologies to support the delivery of clinical care, patient and professional health education, public health, and health administration without the physical presence of all parties in the same room. Technologies commonly used in the delivery of telehealth include computers and mobile devices such as tablets and smartphones. Telehealth applications usually include videoconferencing, remote monitoring, store and forward imaging (a method by which healthcare providers share patient medical information like lab reports, imaging studies, videos, and other records) with a physician, wireless communications, and other internet-accessible information (e.g., health websites). Telehealth encompasses clinical services as well as educational services such as provider training, medical education, and administrative services.

Access to telehealth can be particularly important for rural providers and patients, as it can assist providers and healthcare organizations to expand access to care and improve the overall quality of rural healthcare. Telehealth applications can be used to deliver healthcare services—especially specialty services that may be available only in non-rural settings—to those in rural locations and can help reduce logistical challenges for patients, caregivers,

and providers. Telehealth can greatly facilitate the ability of patients to receive treatments that are not available within their geographic area. For example, a radiologist in an urban location may read and interpret the imaging results for a patient in a rural county whose hospital or clinic does not have a radiologist on staff. Physicians may also conduct an urgent care visit with a patient who has a concern about the onset of an illness or problematic symptoms.

Telehealth can also facilitate remote monitoring and improve ongoing care for patients who have a chronic condition. This may be especially beneficial for family caregivers not physically present with the older relatives they care for. Further, telehealth applications can expand a patient’s ability to communicate with providers and access health information. Patients can also track health measurements (e.g., blood pressure, blood glucose), set reminders for medications and appointments, and share information with providers.

Increased availability of telehealth services was particularly beneficial during the early stages of the COVID-19 pandemic when stay-in-place measures were implemented, especially for older patients, who were disproportionately impacted by the pandemic. In fact, at the onset of the pandemic, the Centers for Medicare & Medicaid Services (CMS) temporarily expanded traditional Medicare coverage of telehealth services, while the state of New York granted similar flexibilities for Medicaid and private insurance coverage, to facilitate access to medical care among beneficiaries and minimize their exposure to COVID-19 in healthcare settings. The expansion allowed Medicare beneficiaries to receive services through telehealth that included evaluation and management visits (common office visits), mental health counseling, and preventive health screenings. (Table 2).

**Table 2. Summary of Medicare Telemedicine Services (Source: CMS.GOV)**

Type of Service	Nature of Service	Patient/Provider Relationship
Medicare Telehealth Visits	A visit with a provider that uses telecommunication systems between a patient and provider	For new or established patients
Virtual Check-In	A brief (10-15 minute) check-in with a practitioner via telephone or another telecommunication device to determine if a visit or other service is needed. A remote evaluation of video or images submitted by an established patient.	For established patients
E-Visits	A communication between a patient and their provider through an online patient portal.	For established patients

A recent report, based on an analysis of Medicare data (Koma, Cubanski & Neuman, 2021), indicated that one in four Medicare beneficiaries had a telehealth visit between the summer and fall of 2020, which represented a general increase in the use of telehealth. Across all beneficiaries, the number of visits was higher among those under the age of 65 (30%) than among those aged 65 to 74 (27%) and those aged 75 or older (25%). Telephone-only visits—as opposed to a video or telephone-plus-video visit—were also higher among those aged 75 or older. However, not all beneficiaries have taken advantage of expanded access to telehealth. About one quarter (23%) of beneficiaries indicated they did not know if their provider offered telehealth services. Telehealth services were also less available in rural areas. Fifty-two percent of Medicare beneficiaries living in rural areas

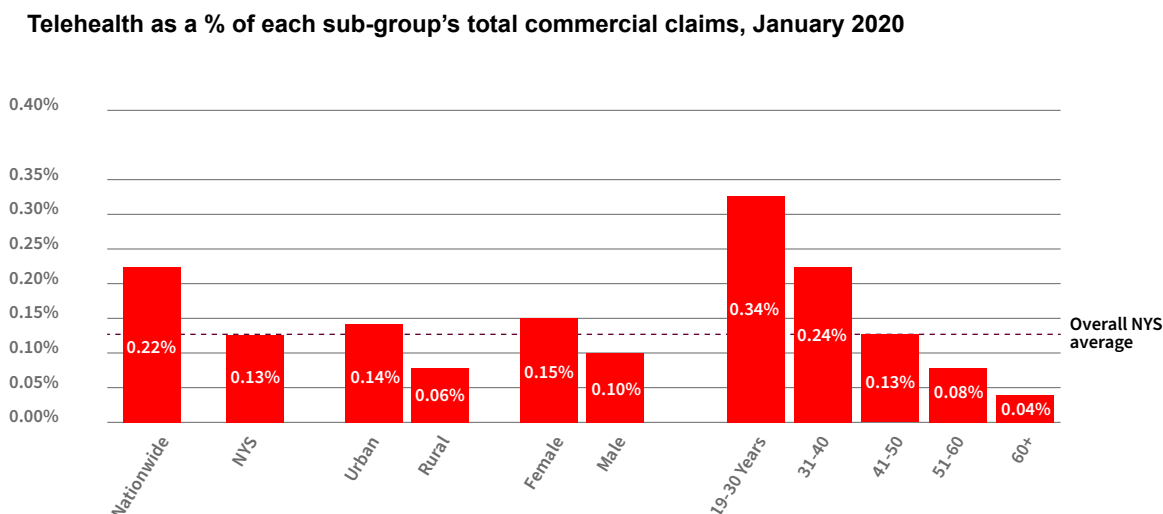
indicated that their provider offered telehealth as opposed to 67% of those living in urban areas. Further, a larger percentage (30%) of those living in rural communities indicated they did not know if telehealth services were available than among all beneficiaries (23%). Respondents in rural areas also indicated that, if they did participate in telehealth, they were more likely to do so via telephone as opposed to video. Technological barriers are a problem, as the types of telehealth services that can be provided to patients via audio-only communication are more limited.

### Telehealth in New York State

Until the COVID-19 pandemic, telehealth utilization across New York State was limited. According to a recent report, prior to the COVID-19 crisis, telehealth represented a small percentage of medical claims: in January 2020, only one in 700 commercial medical claims (approximately 0.13%) were for telehealth, ranking New York 18th of 50 states on the metric. Further, the type of telehealth applications used in New York State prior to the pandemic was restricted, and use was not equal across specialties. For example, use for behavioral health services was significantly higher than it was for other specialties. The other most common uses of telehealth were for acute respiratory diseases and conditions (12%), skin infections or issues (4%), urinary tract infections (3%), and contraception (2%) (FAIR Health, 2020).

However, since the outset of the pandemic, the use of telehealth services in New York State has increased dramatically: between January and April 2020, the use of telehealth increased by 130% (Reimagine NY Commission, Telehealth Working Group, 2021). However, the use of these services is uneven across the state (Figure 3). As shown in Figure 3, rural communities and older adults used telehealth less often than their urban and younger counterparts did. The use of telehealth is also lower among the 2.1 million New Yorkers enrolled in Medicare (Reimagine NY Commission, Telehealth Working Group, 2021).

**Figure 3. Use of Telehealth Services in January 2020 based on Commercial Claims (Source: FAIR Health, 2020)**



Statutory restrictions have prevented permanent telehealth reforms. Based on current law, Medicare, Medicaid, and commercial insurance plans include limitations on the usage of telehealth. For example, prior to the emergency flexibilities issued at the onset of the COVID-19 pandemic, Medicare reimbursed the costs of only a limited set of telehealth services and settings.

However, since the onset of the COVID-19 pandemic, both the federal government (Medicare) and New York State (Medicaid and Commercial Coverage) have removed many restrictions to expand coverage and telehealth delivery. While the federal government has made few permanent changes for Medicare beneficiaries, New York State has proposed many changes for Medicaid and private insurance. These include changes to expand telehealth in the 2021-22 New York State budget to eliminate originating-site and distant-site restrictions, and to authorize peer recovery advocates, those facilitating outreach with individuals currently in a program or considering treatment, certified by the New York State Office of Mental Health or the New York State Office of Alcoholism and Substance Abuse Services to provide services.

The increased focus on telehealth during the pandemic has resulted in a general expansion of telehealth services in the state. For example, the Nascentia telehealth program runs a health monitoring program that allows patients to send information regarding health indices such as blood pressure and weight to clinicians, in addition to an app that allows patients to talk directly to their physicians. Nascentia has deployed 145 units across Central New York, including Onondaga, Oneida, Oswego, and Cayuga counties, and in the town of Webb in Herkimer County (Robinson, 2020). Additionally, part of former Governor Cuomo's Build Back Better Program focused on telehealth, including establishing the Reimaging New York Commission Telehealth Working Group. As part of this initiative, the New York State Telehealth Training Portal was launched in December 2020. The working group has also held numerous focus groups with patients across the state, including those in rural locations.

### **Disparities in Access to Telehealth**

Despite the increased use of telehealth across New York State, disparities in access to this healthcare option remain and are believed to have increased during the pandemic for those who are older, underserved, and who live in rural locations. Reasons for these disparities may include a patient's lack of equipment and technology to access telehealth appointments – including devices or internet connectivity— discomfort with technology or lack of technology skills, lack of access to technical support, or a combination of these factors. Although New York State is the second-most well-connected state in the United States, broadband access is not equitable across the state. Broadband access is generally lower in rural counties. For example, about 99% of those who live in New York, Albany, Monroe, and Erie Counties have broadband access, compared to only 24% of those who live in Hamilton County, 73% of those who live in Yates County, and 77% of those who live in Allegheny County (broadbandnow.com, 2021).



The use of telehealth, however, goes beyond simply having access to the internet and a technology device: individuals must also have the requisite technology skills and access to technical support. Further, programs for training and support must be ongoing, given the dynamic nature of technology. Other reasons for disparities in the use of telehealth include a lack of understanding of telehealth and awareness of telehealth service, poor health literacy, confusion over reimbursement regulations, or concerns about privacy. These disparities underscore a need for action by providers, insurers, and the state to ensure broader access to telehealth for all New Yorkers.

## Recommendations

The increase in the number of older adults in New York State living in rural areas, the existing disparities in access to quality healthcare among this population, and the generally increased reliance on technology within the healthcare domain have the makings of a perfect storm. While the rural population of New York State is aging, rural healthcare facilities are closing and leaving a shortage of providers. New models of care, which include the use of existing and emerging technologies, are required. Unless aging New Yorkers in rural areas have meaningful access to telehealth services, healthcare disparities will increase. The following recommendations can make meaningful access a reality:

1. Increase the connectivity of rural New York to ensure that all New Yorkers have in-home access to affordable high-speed internet services. Broadband is a vital resource and critical to the future of healthcare. The NYS Broadband Program is a promising step in that direction, as is the United States Department of Agriculture's commitment to invest in the provision of broadband service in rural areas.
2. Require up-to-date, systematic, and comprehensive data regarding internet connectivity and the use of the internet and telehealth applications among aging New Yorkers in rural locations. These data should also include information regarding challenges and barriers to accessing telehealth.
3. Increase access to the technology and equipment needed to support telehealth applications, as well as technical support, for rural communities. Programs must also be in place for continued technical support including upgrading of equipment and programs and provision of help and repairs. Patients also need to be made aware of these services and how to access them.
4. Raise awareness among providers in rural locations of the potential of telehealth with respect to patient care and educational opportunities. In addition, ensure providers have access to the needed technology to support telehealth applications as well as ongoing technical support.
5. Increase the awareness of the availability, applications, meaning, and value of telehealth among aging rural New Yorkers. Our research has shown that aging adults are receptive to using new technology but more likely to adopt technology applications if they perceive value with respect to everyday life and independence. Further, people need to be aware of providers that offer telehealth and the type of services they offer.

6. Provide training on the use of telehealth to both patients and providers. Training programs must be offered at schedules that are convenient. Further, programs must be designed according to existing principles and guidelines for training and instruction, especially for older adults whose learning needs and preferences generally vary from those of younger learners.
7. Conduct a general needs assessment across rural locations to understand the telehealth needs of both patients and providers. The focus groups being conducted by the Reimaging New York Commission Telehealth Working Group are consistent with this recommendation.
8. Design telehealth technology and systems with a user-centered iterative design approach that includes diverse and representative user groups including older New Yorkers and those living in rural locations.
9. Ensure any new policies related to telehealth coverage improve access by addressing the barriers faced by older adults in rural communities, and ensure the quality, equity, and safety of care delivered via telehealth.

## Conclusion

The COVID-19 pandemic has brought to light the clear importance of New Yorkers having access to high-quality healthcare as they experience increased difficulty in obtaining in-person care. COVID-19 has made New Yorkers more aware of telehealth, and how it can help provide patient care and serve as a valuable tool for caregivers working to ensure their loved ones have the care they need.

Access to telehealth can be particularly important for rural providers and patients, as it can help providers and healthcare organizations expand access to care and improve the overall quality of rural healthcare.

New York State lawmakers must examine what worked to expand telehealth during the onset of the pandemic under the state of emergency declared at the time and use their learning as a blueprint for future policy.

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**DISRUPT DISPARITIES: ADDRESSING THE CRISIS FOR RURAL NEW YORKERS 50+**

**HEALTH**

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From 2009 to 2019, New York State's population of adults aged 50 years and older increased from 6.2 million to 7.2 million. The percentage of this population relative to the overall New York State population increased from 32.3% to 36.9%.<sup>1</sup> In 2019, the largest percentage of New Yorkers were between the ages of 50 and 59 years, and their numbers are growing faster than they are for any other age group in New York.<sup>2</sup> Unfortunately, New York State is not prepared to support this booming older adult population, many of whom live in rural regions. The State cites efforts to support this booming population of older adults, many of whom live in rural regions, but calls it "a difficult task." Rural service delivery is inherently more resource-intensive compared to urban areas, due to longer travel times and fewer economies of scale. These and other factors also complicate outreach efforts aimed at identifying adults aged 50 and over in rural communities. Yet, they are a rapidly growing population already numbering over one million.<sup>1,3</sup> The average age of rural New Yorkers remains higher than the national average of all older adults.

As rural New Yorkers age, they will require increased support from families, neighbors, and professional healthcare workers. Moreover, New York's aging population is more diverse than past generations were, meaning cultural sensitivity will be an essential component of providing quality and appropriate care.<sup>2</sup> At the same time, the younger adults who could provide these necessary services to help their neighbors age in place are moving out of rural areas or out of New York State entirely in search of better opportunities.

### Top Challenges

1. Health and social workforce shortages across the healthcare continuum are becoming a tremendous problem that affects the health and well-being of older adults. There are not enough paid home care workers, emergency management service (EMS) workers, primary care providers, behavioral health providers, dental providers, and social service professionals to meet the needs of the rural older adult population.
2. Older rural adults struggle to access healthcare, particularly specialist care such as chronic disease, behavioral health, and rehabilitation specialists. Rural areas have a long history of losing primary care providers to urban and suburban areas. The lack of interest in providing rural healthcare and the workforce shortages combine to create a significant healthcare access crisis that will lead to premature poor health and premature death.
3. Rural older adults have many unmet basic needs such as adequate and nutritious food, affordable and appropriate housing, flexible transportation, and social engagement. Transportation is the most salient problem identified by health and service providers. These unmet needs limit the ability to access healthcare and manage diseases and increase the risk for illness and death.
4. Although loneliness is a major concern for all older adults, rural older adults are particularly vulnerable to social isolation because they faced significant barrier to social engagement. Social isolation increases the risk of poor quality of life, poor disease management, and early death.



5. The lack of data on New York's growing rural older adult population is a major barrier to addressing disparities and social determinants of health. It is not possible to differentiate the multiple demographic characteristics and their intersectionality. The lack of data masks disparities in the health status, health behaviors, and unique social determinants of health among rural older adults in New York. Available data are hard to locate and often only collected from small, specific populations for program-specific reasons, which makes it impossible to generalize to the broader rural older adult population.

### **New York's Rural Older Adults Face More Economic Constraints**

Older adults living in rural areas tend to be poorer and less educated than those in urban and suburban areas.<sup>4</sup> The number of older adults with very low income (<50% of area median income) is expected to grow significantly as the U.S. population ages. Cost-sharing in Medicare can also leave older adults with large bills.<sup>5</sup> For example, as of publication, Medicare Part D does not have a hard cap on out-of-pocket spending, so enrollees can face costs that exceed \$7,000 per year if they are taking several expensive medications.<sup>6,7</sup> These additional costs lead to medical expenditures consuming large proportions of older adults' income, which puts a huge financial strain on older adults.<sup>5</sup> This financial burden is worse for rural older adults, who tend to have lower household incomes.<sup>8</sup>

### **Racial and Other Diversity**

New York State has the second-largest African American/Black and fourth-largest Hispanic/Latino population in the nation. Nationally, the most rapid growth of the Hispanic/Latino population is in areas where few Latinos have traditionally settled.<sup>9</sup> The population of rural African American/Black, Hispanic/Latino, and Asian American Pacific Islander older adult populations is increasing exponentially (e.g., Rensselaer County's non-White population tripled between 2007 and 2017).<sup>2</sup> With racial diversity among older adults continuing to grow, there are also growing racial disparities in rural areas. Rural racial groups experience geographic isolation and race-related rural health and mortality disparities.<sup>10</sup> Nationally, rural African American/Black and Hispanic/Latino populations have higher all-cause mortality than do Whites, and rural African American/Black residents have higher rates of co-morbid conditions and cancer morbidity and mortality. These data imply that rural racial health disparities likely exist in New York State.<sup>11</sup> Recent data suggest race all-cause mortality rates vary by region of the country, indicating there may be state or other geographic differences.<sup>10</sup> In rural New York, the intersection of race and other demographic characteristics is not known, because studies rarely include a large enough sample size to break down data into multiple demographic categories. In general, little is known about the race, disability, socioeconomic status, and location of rural adults in New York State.

### **Perspectives from the Community**

The Health Foundation for Western and Central New York found that LGBTQ+ adults are often hesitant to access services because of experiences of trauma from societal expectations of heterosexual relationships. Many have

experienced insensitivity from service providers. To address the issue, the Health Foundation for Western and Central New York created a cultural competency course for older adult services staff to increase staff comfort and improve the interactions of staff with this population. At this time, this course is not widely available to staff serving older adults across the state.

### **Disability and Declining Health Among Rural Older Adults**

People living with a disability have an increased risk for poorer health outcomes at any age, but people with a disability who are older can experience more health and social difficulties.<sup>4</sup> Older adults experience declining cognition vision, hearing, and balance, which increases the likelihood of falls (over 1 million in the 55-64 age group and 2.97 million in the 65+ age group, nationally).<sup>12</sup> Falls increase the risk of further decline and death among the elderly. The percentage of rural older adults living with a disability is 9% higher than that of those living in large metropolitan counties.<sup>13</sup> The 50-and-older population includes a growing number of people with disabilities who will survive to older ages because of improved healthcare.<sup>14</sup> Almost 19% of adults 50 and older in rural counties have one or more disabilities. Individuals with disabilities are more likely to lack access to services in urban or suburban areas and have increased barriers to accessing appropriate healthcare and meeting their daily needs.<sup>15</sup>

Rural older adults with disabilities face financial constraints and are even more at risk for social isolation when compared to non-rural or abled adults.<sup>14,15</sup> Rural homes and stores are far less likely to be handicap accessible. Rehabilitation services for people with disabilities increase healthcare costs but also offer the potential to improve mobility, independence, social engagement, and prevent more severe health conditions later. Unfortunately, rural older adults experience many environmental challenges that limit their independence and social engagement even if rehabilitation is an option. Further, rehabilitation services in rural areas are limited, meaning rural residents need to travel long distances to obtain them.

Since the 1980s, there is a growing rural-urban divide in health outcomes and mortality in which rural older adults are faring far worse than urban populations.<sup>11,10</sup> The age-adjusted mortality rates for cardiovascular disease declined more slowly in rural regions, which has created a widening of rural/urban health disparities over the decades.<sup>16</sup> Also, diabetes prevalence is 17% higher in rural areas than in urban areas.<sup>17</sup> Disparities in these major diseases contribute to higher mortality rates among rural older adults. Several rural counties have older adults that are particularly vulnerable to the impact of hotter temperatures. These include Hamilton, Warren, Essex, Fulton, Green, Schoharie, Delaware, Sullivan, Green, Ulster, and Otsego Counties.<sup>18</sup>

### **Continuum of Care: Home Caregiving to Hospitals and Long-Term Care Facilities**

#### **Primary Care**

Rural older adults experience multiple barriers to accessing the continuum of healthcare. Rural areas, in particular, have persistent difficulties meeting the healthcare needs that were exacerbated during the COVID-19 pandemic.

There, older adults must travel farther to providers than their urban counterparts do. While the pandemic increased the use of telehealth appointments, many rural New Yorkers still do not have the high-speed internet access needed to attend them, and some older rural New Yorkers who do have access struggle with using telehealth technology.

New York's rural counties experienced a decrease in physician density. From 2010 to 2017, there has been an overall decrease of 3.1 physicians per 100,000 population due to the aging rural physician workforce seeking retirement and the current incentive structure. This has led to a consolidation of physicians in larger physician groups and healthcare systems largely based in urban locations.<sup>19</sup> All counties in the Adirondacks and the remainder of the rural counties in New York have experienced health professional shortages,<sup>20</sup> particularly in dental health.<sup>21</sup>

Federal and state programs provide repayment of student loans to primary care providers who meet service obligations in underserved areas. Providers include physicians, nurse practitioners, nurses, and physician assistants. As of March 2020, the North Country had the highest rate of service-obligated providers, with 10.5 per 100,000 people, and the Mohawk Valley and Finger Lakes regions had the next highest rates, with 6.2 and 6.1 per 100,000, respectively. However, these rural areas experience provider shortages even with these programs, indicating the need for additional investment in these programs to solve provider shortages.<sup>22</sup>

### **Perspective from the Community**

There is a long history of doctors providing home visits in rural New York State, but this practice dramatically decreased from the 1980s and into the 1990s when Medicare reduced inflation-adjusted payments to doctors for home visits. This decrease, combined with the failure of medical schools to train students in low-technology diagnostic techniques, has resulted in very few medical doctors, especially younger ones, providing home visits.<sup>23</sup> There are many benefits to home visits. Doctors can see if the patient can keep up their home if the home environment is safe and manageable for the patient if the patient has food in their refrigerator and is taking their medications. Some healthcare providers in rural New York have had to become creative to serve the healthcare needs of older adults. Some conduct home visits for disabled older adults on their drive home from the clinic, while others have this as a regular part of their practice. Some practices have nurses conduct home visits to save on personnel costs while providing healthcare for chronic disease management. Even though this historically effective strategy facilitates the ability to manage chronic diseases and maintain routine healthcare, it is not aligned with reimbursement structures. Travel costs are absorbed by the practice or individual provider. Therefore, home visits in rural areas are not commonplace.<sup>54</sup>

### **Race Disparities in Health Provider Racial Concordance**

Although rural areas tend to have a much smaller proportion of underserved race groups than urban areas do, there are very few health providers from those race groups serving rural areas, especially for African American/Black

populations. For example, in the North Country, 4% of the population are African American/Black and 2% are Hispanic/Latino. However, only 1% of the nurse practitioners are African American/Black. The exception is the Hispanic/Latino population in the North Country where 6% of nurse practitioners are Hispanic/Latino. Disparities are greater in the southern Adirondack area, where there are larger proportions of underserved race groups in the population.<sup>24</sup> Other than these data, there is little information on other healthcare workforce diversity.

### Care in the Community

Older adults are aging at home for longer periods than ever before, and if they eventually enter a long-term care facility, they tend to need much more assistance than the previous generation did. Residents of long-term care facilities in rural areas tend to be older than 85 and require less physical assistance than urban residents but possess higher rates of cognitive impairment and behavioral challenges.<sup>25,26</sup> Rural areas experience mental healthcare shortages, including limited facilities to provide care for the mental health needs of older residents. Home and community-based services remain a challenge for rural areas because of the rural home care worker shortages and because of improved but still insufficient state funding.<sup>25</sup> The waitlists in some parts of the state leave people without help for months. Only 54% of those with Medicare who are referred to home healthcare receive it. African American/Black and Hispanic/Latino older adults as well as those who experience poverty are less likely to receive needed home healthcare. This increases their risk of falls and neglect.<sup>27</sup> As a result, even if older adults want to remain in their homes, they end up in facilities, where there are also nursing shortages.<sup>25</sup>

Providing adequate ambulance and emergency services continue to be a major challenge for rural areas.<sup>28</sup> The number of certified emergency management providers in New York State has declined 9% in the past decade, and the decline is expected to continue, creating even more shortages. This decline is due to the aging workforce and the fact that emergency management agencies are expensive and difficult to operate in rural areas.<sup>28</sup> Rural areas tend to have volunteer services. A recent survey found that 59% of rural volunteer responders and 68% of paid responders reported that their ability to respond to the community was impacted by staff shortages. To make matters worse, emergency management and paramedics are paid far less than other public safety and healthcare professionals, causing them to take on additional employment or leave their jobs.<sup>29</sup> These rural care disparities increase the risk of poor health outcomes and death before a patient even reaches the hospital. While there are negatives due to the shortages, investment in EMS providers can be helpful for community care of rural older adults if the care is expanded to provide vaccinations and perhaps other forms of social care and engagement.<sup>30</sup>

### Hospital and Specialty Care

Although primary care is still available in rural areas, specialty care is almost exclusively located in urban and suburban areas, limiting rural older adults' access. Many rural New Yorkers lack access to a Level III trauma center within 45 minutes. This lack of access is associated with increases in cost and mortality among adults aged 65 years and older.<sup>31</sup> For example, most rural New Yorkers in the Adirondack area seek care for their major healthcare needs in Glens Falls or Plattsburgh. In Central and Western New York, Buffalo, Rochester, and Syracuse are

centers for specialty care. Rural hospitals have fewer resources and are financially challenged under most circumstances, and with social distancing and the cancellation of routine and elective procedures and appointments, they are experiencing an even worse financial crisis now than they were before the pandemic.<sup>32</sup> There is some positive change: Rural healthcare networks are connecting with academic centers using online telehealth networks to improve access to specialty physicians, lifesaving treatments, and enhancing care coordination. This strategy could prove an effective model for other areas.<sup>33</sup>

### Perspectives from the Community

Lake Placid, New York, is surrounded by small rural towns, mountains, and many lakes. Tourists are drawn to the community, the site of two winter Olympics, and the location of a hospital that serves a large swath of the Adirondacks. Emergency Care at the Adirondack Health Center is open only from 8 a.m. to 8 p.m. Down the road, 20 minutes in dry weather, Saranac Lake has 24-hour care but no trauma center. The nearest trauma center is over an hour away in Plattsburgh, New York, but patients are flown to Burlington, Vermont, or Albany for high-level trauma needs. Rural Western New Yorkers need to travel to Buffalo for similar services.

### The Role of Community Health Centers

Primary care is the foundation of healthcare in rural New York due to the limitations in the sustainability of hospitals and specialty practices. The federal program funding federally qualified health centers (FQHCs) is essential for access to primary healthcare in rural areas. The private practice physician is becoming rare due to being unable to receive adequate reimbursement to sustain the personnel, finance, compliance, and medical technology aspects of practice.<sup>34</sup> For a health provider practice to be feasible, it has to have scale, so multiple rural health locations are often under one group. This structure creates additional costs due to providers needing to travel significant distances among sites. Community health centers (CHCs) provide most of the primary care for rural residents, and they are FQHCs so that they are financially sustainable. These CHCs see proportionally more older adult patients in rural areas than they do in urban areas, but they are challenged by not being able to provide specialty care such as geriatric care. They are also struggling with health provider shortages.<sup>34</sup>

#### **Perspectives from the Community**

*Hudson Headwaters has 22 health centers located between Northern Saratoga County and the Canadian border. It serves one-third of New York's rural population, and 24% of its patients have Medicare - the largest proportion of Medicare patients among Federally Qualified Health Centers (FQHCS) in the nation. As the population ages from the 50-59 age group into the 60s, the portion of Hudson Headwaters' patients using Medicare is expected to skyrocket, as it likely will for other rural FQHC's in New York State. Hudson Headwaters has deployed a mobile health center to provide care to rural patients, a creative solution to improve healthcare access that, with investment, could be expanded to other areas of the state.*



## COVID-19

Because rural older populations are more likely to have underlying chronic conditions and face challenges getting their healthcare needs met, they are at greater risk for poor COVID-19 outcomes. Rural hospitals are also at risk for reaching capacity quickly and experiencing workforce challenges in the event of an outbreak.<sup>26,35</sup> Finally, COVID-19 brought to light the issue of social isolation and loneliness, which is a growing problem among older adults—especially those in rural areas. All the challenges to social engagement mentioned below were exacerbated during the pandemic.

### **Social Determinants of Health and Healthcare Access Among Rural Older Adults**

Whether it's the National Academy of Medicine or healthcare experts in New York State, the consensus is that between only 10% and 20% of a person's health status depends on healthcare.<sup>36,37,34</sup> Healthcare alone is insufficient to ensure substantially better health outcomes. The rest depends on a person's genetics (estimated to account for 30%), behaviors, and social determinants of health (SDOH). An individual's social determinants, defined by the conditions in which people are born, grow, live, and age, influence changes in genetics, health behaviors, access to and use of healthcare, and care management once an individual has a health condition. The SDOH are considered such a powerful influence on health that the World Health Organization and the United States Department of Health and Human Services (DHHS) consider them a priority to understand and address. The DHHS sets national, data-driven objectives every decade, which guide national research, program, and policy decisions. SDOH is one of the five primary Healthy People 2030 objectives. Healthy People 2030 objectives are data-driven national objectives with the aim to "improve health over the next decade."<sup>38</sup>

### **Food Insecurity and Hunger**

Older rural adults are particularly vulnerable to hunger and food insecurity due to their lower-income and poorer health.<sup>39,40</sup> Food insecurity is associated with depression, chronic disease,<sup>41,42</sup> and greater healthcare usage<sup>41</sup> among older adults. Older adult women, as well as Black and Latino New Yorkers, have, on average, lower incomes and are more likely to live in poverty. These groups are therefore more likely to be food insecure<sup>43</sup> and often face barriers to accessing affordable nutritious food due to limited supplies of fresh food such as produce and meat in these areas. These barriers make it difficult to maintain a healthy diet,<sup>6</sup> further contributing to hunger and food insecurity.<sup>3</sup>

### **Limited access to adequate grocery stores**

In New York State, 12.1% of adults age 60 and older experience food insecurity.<sup>45</sup> Older adults facing food insecurity have lower intakes of important nutrients, and they report poorer health status compared to those who are not food insecure.<sup>42,45,46</sup> One challenge among rural older adults is their limited access to grocery stores with fresh, affordable food.

Rural grocery stores are often challenged by a limited workforce and increased costs. With small rural stores closing, many rural areas are now considered food deserts, forcing residents to travel long distances to reach grocery stores or emergency food sites.<sup>47</sup> People also rely on expensive convenience stores with very limited fresh produce. For those near a rural grocery store, the cost of food is typically high compared to urban and suburban areas. To save money, many rural New Yorkers use dollar stores, which are ubiquitous in rural areas but do not provide the fresh produce, meat, or dairy found at traditional grocery stores.

### **Workforce shortages and food insecurity**

Workforce and staffing shortages in local communities also have an impact on food security. Currently, many businesses in rural areas have signs on their doors asking for help. There is a lack of staff and volunteers to address food insecurity in rural areas. Rural grocery stores cannot find enough staff to stay open or provide all their services while open. Meals on Wheels and other meal programs also cannot find enough volunteers and staff to support the demand for their services. Due to these shortages, the Rural Health Network serving South Central New York has a waiting list of seniors, because they cannot find enough volunteers to deliver enough meals to all those who want and are eligible for them.<sup>48</sup>

### **Programs addressing food insecurity and hunger among older New Yorkers**

Despite challenges due to volunteer shortages as a result of COVID-19, New York State's aging network experienced a 69% increase in the number of meals it provided to older adults between 2019 and 2020. Home-delivered meals, such as the Meals on Wheels program, provide two meals per day, five days per week to support the health and independence of the recipient. The average meal recipient is female, lives alone, is 75 years old or older, and has four or more chronic conditions.<sup>49</sup> While congregate meal programs help to address nutrition deficiencies and social isolation, these have been limited due to the risk of COVID-19 exposure and spread.

Two other important nutrition programs, overseen by the United States Department of Agriculture (USDA), are the Supplemental Nutrition Assistance Program (SNAP) and Senior Farmers' Market Nutrition Program. About 605,000 older adults in New York State participate in SNAP, which provides financial assistance to eligible low-income individuals to buy the food they need. In 2019, 48% of SNAP-receiving households in New York included at least one eligible adult aged 50 years or older.<sup>50</sup> Similarly, the USDA's Senior Farmers' Market Nutrition Program provides low-income older adults with fresh produce. In 2020, New York State received \$1.7 million to fund this program.<sup>52</sup> There are many barriers rural older adults face when trying to participate in these two nutrition programs. The barriers include distance, access to transportation, homebound status, and embarrassment.<sup>44</sup>

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1. <https://sf.gov/calculate-your-rent-burdenii>

2. Housing America's Older Adults 2019; Joint Centers for Housing Studies of Harvard University

([https://www.jchs.harvard.edu/sites/default/files/reports/files/Harvard\\_JCHS\\_Housing\\_Americas\\_Older\\_Adults\\_2019.pdf](https://www.jchs.harvard.edu/sites/default/files/reports/files/Harvard_JCHS_Housing_Americas_Older_Adults_2019.pdf))

## Affordable and Appropriate Housing

People of retirement age are increasingly living in low-density locations.<sup>53</sup> Like other regions, rural areas are facing affordable housing shortages, which impact rural older adults on fixed incomes. These issues intensify as urban residents engage in retirement or second home migration. In particular, the second home migration has intensified pressure on the housing shortages in the Adirondacks and the Hudson Valley.

At the same time, rural New York residents who own homes are burdened by increasing property taxes. By 2017, nearly 10 million older adults in the U.S. were housing cost-burdened, meaning they spent more than 30% of their income on housing costs – which include utilities, taxes, mortgages, rent and maintenance.<sup>1</sup> This is the highest number on record.<sup>2</sup>

This makes it difficult for seniors to maintain their own homes, experiencing issues such as leaky roofs, mold, asbestos exposure, and general disrepair. There are examples of programs to address this problem in Western New York. A handy helper program was developed by Meals on Wheels in which New York State provides some resources for repair, but the amount is not nearly enough to make an impact on the problem of supporting older adults to age in place safely and affordably.<sup>48</sup>

In rural counties of New York State, 9% of the 50-64 age group and 7.6% of the 65 and older age group rent their place of residence. The population of adults between 50 and 64 years old has lower homeownership rates and higher debt rates compared to earlier generations. There is also a widening gap in racial disparities in homeownership, which will likely impact the growing aging population of people of color in rural New York.<sup>53</sup>

Advocates consider housing a crucial part of healthcare, in that poor housing can greatly impact health and well-being, and adequate housing also can provide a location for the provision of health and social services. Homes or apartments that are not accommodating to changing movement abilities may increase older adults' risk for falls and disability or death. Medicare provides wellness assessments that can raise awareness of patients' home modification needs. Medicare also provides information on home modification to improve safety.<sup>54</sup> The Older Americans Act provides funds for modifications that are distributed through Agencies on Aging, but there are still many challenges to obtaining modifications. First, there needs to be an assessment of how to modify a home safely, such as building a ramp. The modifications often require a permit and, for some projects, a certified contractor, which may be difficult to find in remote areas. Second, older adults renting or who experience poverty may still have limited ability to afford home modification. It is important to note that members of the younger end of the aging population are less likely to own their own home,<sup>55</sup> which suggests less wealth than the older population has and that they may not be able to afford to age in place.

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1. <https://sf.gov/calculate-your-rent-burdenii>

2. Housing America's Older Adults 2019; Joint Centers for Housing Studies of Harvard University

([https://www.jchs.harvard.edu/sites/default/files/reports/files/Harvard\\_JCHS\\_Housing\\_Americas\\_Older\\_Adults\\_2019.pdf](https://www.jchs.harvard.edu/sites/default/files/reports/files/Harvard_JCHS_Housing_Americas_Older_Adults_2019.pdf))

### *Perspectives from the Community*

*A former utility worker who used to drive around to shut off services for unpaid bills or empty homes said he has found older adults living in homes that were filthy and unsafe because they were unable to maintain their house and pay their bills. Staff who work with New York rural seniors have found seniors who no longer have a mortgage are still paying over 30% of their income in housing expenses due to high property taxes and utility costs. This limits seniors' ability to cover the costs of housing maintenance, which can lead down the path of having to move into senior rental housing. There are currently about 3,750 rural older adult New Yorkers living in senior rental housing. Residents living in those units are older than residents of previous decades and are often sicker and have more disabilities. Property managers of these units are often the point of contact for these seniors, but property managers have little to no resources to help their tenants connect with social services.<sup>48</sup>*

### **Social Isolation**

Older adults are at risk of social isolation due to physical, cognitive, and other changes that influence a person's ability to have regular social relationships. Social isolation—having infrequent social interaction and few social relationships—is associated with decreases in cognitive functioning, and increases in depression,<sup>56,57,58</sup> mortality, and premature death.<sup>57</sup> Social isolation is associated with an increased risk of mortality among older adults after accounting for cardiovascular risk factors. Therefore, it is a stronger risk factor than hypertension.<sup>59,60</sup> Social isolation is considered “a trigger of decline.” Older adults are at greater risk for social isolation than younger adults are. They have less opportunity for social interaction due to retirement, loss of spouses, family, and friends, and decreases in health and mobility.<sup>61</sup> About 24% of adults 65 and older are considered socially isolated and even more, 43%, of adults aged 60 and older report feeling lonely.<sup>56</sup> It is estimated that by 2038, 10.1 million older adults (65+) will be living alone. Older women are at greatest risk for social isolation because they are more likely to live alone than men are.<sup>26</sup>

Rural older adults have fewer family supports because younger generations often move to urban areas for jobs.<sup>62</sup> As mentioned before, the rural areas of New York have the oldest population in the country. Rural New York is continuing to experience a trend in a population loss of younger age groups. Rural older adults are more likely to live alone, less likely to be able to seek out social interactions and face greater barriers to social interactions than those living in urban environments. Barriers include less access to the Internet and cellular service, transportation, and a built environment that does not support the population.<sup>63</sup> Another important factor in rural New York State is the winter and extreme weather, hindering travel.

## Behavioral Health

Mental health problems are associated with poor quality of life and poor chronic disease management.<sup>60,64,65</sup> Older adults are experiencing worsening behavioral health outcomes. The national rate of suicide among older adults increased 3% between 2017 and 2019, prior to the pandemic. The pandemic likely increased social isolation in acute ways and may have longer-term reverberations on the mental health of older adults. Data show that there have been increases in mental health distress and drug-related deaths among older adults during the pandemic.<sup>66</sup> One in nine adults 65 years old and older have dementia, and the number of adults with dementia will grow as the bubble of adults 50 to 64 years old ages. Those with dementia often experience behavioral health issues that can result in their avoiding public settings or their participation in social engagements, which can perpetuate mental health decline.<sup>67</sup> The challenge for rural older adults is that mental health problems such as depression are often under-identified and undertreated. Those needing treatments may feel stigmatized and avoid seeking help. In rural areas of New York State, community health centers and primary care offices often play a key role in behavioral health. Given that a large proportion of rural older adults seeks care at community health centers, there needs to be a training of providers in geriatric mental health and investment in rural behavioral health providers.

### *Perspectives from the Community*

*A 72-year-old woman with worsening dementia stopped attending church and other community events with many people. The Dementia affected her speech, embarrassing her. She rarely left her home and would become lost in her immediate neighborhood if she went for a walk. At first, she rejected medicine to treat her depression, because she did not believe her issues were related to mental health. She started having panic attacks when she was supposed to travel. As time went on, she became very depressed and stopped eating. At that point, her family had to take her to the emergency room so that she could be treated in the senior psychiatric unit. Once she was treated with medicine for a few weeks, she was able to leave her home for walks and go out in public without experiencing panic attacks.<sup>68</sup>*

## Transportation

Transportation is a necessary part of everyday life and a major social determinant of health. Access to regular transportation influences the ability of rural older adults to take care of their basic needs and healthcare and to have social engagement. The flexibility of transportation is important to accommodate the various needs of older adults. Most older New Yorkers in rural areas face limited transportation. Although the use of and need for transit among older adults in rural areas is not tracked, transportation issues have been identified as a challenge for healthcare access by multiple providers and rural serving organizations.<sup>34,69</sup> Medicaid provides Medicabs, but older adults on Medicare do not have a similar option for healthcare access and therefore depend on family (many of



whom may not live in the area), friends and volunteers. Considering the distances that older adults need to be driven to medical appointments, particularly specialty care based in urban areas, family and friends may have time and transportation cost constraints that limit their ability to help.<sup>34</sup> Because of the lack of tracking, documenting the extent of the problem is challenging. Interagency partnerships to maximize resources and outreach to older adults could increase ridership on public or other forms of transportation if they are available.

### **Perspectives from the Community**

*The Rural Health Network serving South Central New York considers lack of transportation a major barrier to older adult health and well-being, which is echoed by organizations across the state. The Rural Health Network serves an area the size of Washington, D.C., but with a population of only 6,600. Coordinator of the Northern Broome CAARES Program Michael Treiman sees a trend in seniors' losing their driving privileges, and many of these seniors live five or more miles from the nearest health provider. Few have family members who live close enough to provide transportation. The one provider in the area is attached to the Whitney Point Senior Center, but it does not have a medical doctor on staff.<sup>48</sup>*

### **Nonprofit and Local Government Funding**

One concern of rural-serving organizations is that many foundations, government grants, and other grantmakers are less inclined to fund rural organizations, because they have a more difficult time demonstrating impact, traditionally measured by the number of people served. Because rural programs serve fewer people and do so across larger geographic areas, the impact of money spent providing the service is perceived to be less than urban and suburban programs. Until the culture of impact shifts to be accommodating to rural areas, they will continue to have less access to grants and other types of funding.

### **Short-Term Recommendations**

#### **1. Address workforce issues in rural areas**

There are workforce shortages all over New York, but rural areas are disproportionately impacted by these because the population is smaller, which makes sustainability of jobs difficult. Increased pay and accommodation of worker needs are common recommendations. Others include using medical students to bridge the gap<sup>70</sup>, but this is more challenging in rural areas, where medical schools are few and far between.

#### **2. Increase transportation access for rural older adults.**

Increase taxi or shuttle service administered through senior centers across rural areas.

### **3. Increase funding for emergency management services in rural areas.**

The emergency management system (EMS) needs investment to increase the workforce and the pay for first responders to address the EMS shortage. There is a demonstration model that suggests incorporating nurses, nurse practitioners or physician assistants, and social workers into the EMS team to triage and avoid unnecessary emergency room visits and to increase patient's access to health and social resources.<sup>71,34,54</sup>

In addition the State should establish a task force to examine and make recommendations to enhance the ambulance services in rural areas. Legislation passed by the New York State Legislature in 2021, which as of publication had not yet been sent to the Governor but should be signed into law, would create such a task force.

### **4. Increase funding for nutrition programs.**

It is impossible to solve food insecurity in rural New York State with only one program. Increasing SNAP participation among rural older adults is a good first step. However, transportation and access to fresh and healthy foods come with challenges in rural areas. Therefore, rural senior farmer's markets, home grocery delivery, meal delivery programs, emergency food programs and congregate meals can all help alleviate food insecurity. Some of these programs can also be designed to increase social engagement for rural older adults. There are some demonstration projects in which social workers and nurse practitioners or physician assistants serve on the EMS team to triage patients in the community and decrease the use of emergency departments.<sup>71</sup> These can be modeled and evaluated for effectiveness.

### **5. Develop policy and regulations to establish reimbursement for care management that includes team-based care of health and social providers.**

Medicare and private insurance reimbursement structures need to incentivize the management of the social determinants that influence a person's health and well-being. Management of social determinants should include a care team with care managers whose time is reimbursable. The time this care team spends working with patients to address social determinants needs to be reimbursable to be sustainable and effective. Whether coming from the National Academy of Medicine or healthcare experts in New York State, the common conclusion is that between only 10% and 20% of a person's health status depends on healthcare.<sup>36,37,34</sup> Care management to manage chronic diseases and SDOH is essential for preventing disability, morbidity, and mortality among the aging rural adult population in New York State. Although there is a growing expectation for healthcare providers to understand and address SDOH, most healthcare providers are not trained in this area and often lack knowledge and strategies to ameliorate these factors. However, professionals trained in public health and social welfare are trained to understand and address these important health determinants. Therefore, the incorporation of these professionals in team-based care would improve care management.

**For care management to be effective, there needs to be a(n):**

1. Single communication platform for all aspects of health and social care to facilitate care management across the needs of a patient;
2. Increase in the reimbursement for primary care and geriatrics to incentivize the medical workforce to enter these fields; and
3. Regulation and reimbursement structure for prevention and home visits for at least two reasons: to 1) teach telehealth literacy and 2) conduct baseline health and social determinant assessments for homebound or older adults who lack the ability to get to appointments.

**6. Create a funding mechanism for retrofitting homes for the rural aging population.**

Provide tax credits and grants for the creation of accommodating and smart homes for passively assessing risk related to determinants of health and disability to decrease falls and increase patient monitoring. The goal of this recommendation is to help older, rural adults age in place without increasing risk for disability, morbidity, and mortality. Two examples are to put an emergency pull chain in bathrooms and install fire and gas detection devices that link directly to EMS. The smart home mechanisms require broadband access. More major retrofitting needs are ramps, accessible doorways and bathrooms, and chair lifts for stairwells.

**7. Modify local regulations to ease the building permit process to retrofit homes for older adults.**

Community leaders need to reconsider the residential building codes and ordinances in their area to accommodate and encourage universal design and visibility features.

8. The New York State Rural Task Force should be given the authority and budget to conduct large-scale rural health and SDOH assessment of older adults. Although time and cost are often cited as reasons for not collecting data on specific sub-populations like rural older adults, the lack of information contributes to disparities.

## Conclusion

The needs of the growing older adult population in rural New York State are likely the bellwether demonstrating the inadequacy of the current healthcare and social care systems to address the health and social determinants of health for this growing population.<sup>34,54</sup> Nonetheless, most, if not all, adults aged 50 and older engage the healthcare system, placing the healthcare system in a strategic position to assess health and social care needs and develop meaningful connections to give older adults increased access to needed public health and social care. Both current health disparities research and interviews conducted for this report identify the need for engaging older adults in program design.

Frequent themes across all disparities discussed include both volunteer and professional workforce shortages and transportation barriers. In addition to workforce shortages in healthcare, another common theme is the inadequacy of reimbursement mechanisms to support rural healthcare access.<sup>34</sup> Rural older adult health disparities can be disrupted, but not without addressing major SDOH that are distinct from urban areas of New York. Yet, addressing these challenges is essential for curtailing disability, morbidity, and mortality among the aging rural adult population in New York State.

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**DISRUPT DISPARITIES: ADDRESSING THE CRISIS FOR RURAL NEW YORKERS 50+**

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