

# Community Health Needs and Opportunities in Rural Central New York



**CENTRAL NEW YORK** IS A VERY PRODUCTIVE AGRICULTURAL REGION, WITH FARMS THAT BEGIN JUST BEYOND THE SYRACUSE SUBURBS AND SPREAD THROUGHOUT THE SURROUNDING COUNTIES. ALTOGETHER THERE ARE OVER 2,600 FARMS IN RURAL CENTRAL NEW YORK, AND FARM ACREAGE ACCOUNTS FOR ABOUT A THIRD OF ALL LAND IN THE FOUR-COUNTY REGION.

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# Executive Summary

This report describes health and social issues impacting people in four rural central New York (CNY) counties: Cayuga, Cortland, Madison, and Oswego. It is based on dozens of interviews with staff at agencies serving these counties and analysis of data related to sociodemographic factors, perinatal health, oral health, behavioral health, and home health care. Some key findings are:

- **About 2 in 5 households in rural CNY have people struggling to afford basic needs.** Service providers are working hard to connect people with food, transportation, housing, and health care. While each county does have pockets of affluence, they also have towns and small cities where people live in extreme poverty.
- **Many health outcomes are worse in rural CNY than in NYS overall or in urban areas.** Infant mortality rates, tooth loss, and binge drinking are just a few of the indicators that are worse in rural CNY compared to Onondaga County and/or New York State.
- **Health disparities exist for people who are low-income and people from marginalized identity groups.** Economic disparities are well-known, but data also reveal extreme disparities in health outcomes for rural CNYers identifying as Black, Hispanic, multiracial, LGBTQ+, and disabled.
- **People have limited choices for health care providers, and access to care is further limited by workforce challenges and low reimbursement rates.** Agencies have a hard time hiring and retaining people to work many of the jobs that are most needed to provide care to people. Safety net providers lose money on some services because reimbursement rates are so low, and this impacts their ability to build capacity to better meet patient needs.
- **Funding for rural health is unstable and insufficient.** In recent decades funding for many agencies and programs has remained flat, declined, or disappeared altogether. Local partners do a good job filling gaps and meeting local needs with few resources, but they are constantly challenged to find ways to sustain programs and to provide services at the level that the community deserves.
- **Organizations need more flexible funding for capacity building, infrastructure, and coordination.** Agencies want and need stable funding streams that strengthen their ability to respond to the complex, challenging, whole-person needs that they see in their communities.

This report discusses many findings that collectively indicate that there is an urgent need to invest more in improving the health of rural communities. In addition, it highlights some examples of promising strategies for improving health outcomes and equity in rural CNY.

# Introduction

Central New York (CNY) is a mostly rural region of New York State (NYS) that includes the City of Syracuse. There is little consensus about the region's exact footprint, but it almost always includes the four counties surrounding Onondaga County. Reports about the CNY region often focus on the urban center and fail to acknowledge the region's rural areas sufficiently. This report will shift that focus, shining a light on the health and social issues in Cayuga, Cortland, Madison, and Oswego counties – a region that this report will refer to as rural CNY.

Rural CNY is home to over 310,000 people.<sup>1</sup> The region is known for its lakes, scenic drives, and the small cities of Oswego, Auburn, Cortland, Fulton, and Oneida. While many employers and community resources are located in those cities, most of the population lives in the villages and towns spread throughout 2,800 square miles – an area larger than the State of Delaware.

CNY is a very productive agricultural region, with farms that begin just beyond the Syracuse suburbs and spread throughout the surrounding counties. Altogether there are over 2,600 farms in rural CNY, and farm acreage accounts for about a third of all land in the four-county region.<sup>2</sup> But even though agriculture is a significant part of the region's economy, farming accounts for only a small portion of employment. The USDA's most recent census estimated that there are less than 4,000 workers on rural CNY's farms, although this number does not include the temporary undocumented workers who increasingly make up the farm workforce.<sup>3,4</sup>

The region's farmers, like the population as a whole, are increasingly likely to be older adults. Between 2010 and 2020, the number of adults over age 65 in rural CNY increased from about 44,000 to nearly 58,000 people<sup>5</sup>. "Older adults are the fastest-growing population and there are not enough services to meet their needs," said Shari Weiss, PhD, Executive Director of Cayuga Community Health Network.

While the older adult population is growing, the younger population is shrinking, due in part to limited job opportunities leading young people to move away. As farming and manufacturing jobs have disappeared, the service economy has grown, mainly offering low-wage jobs in retail and health care.<sup>6</sup> This low-wage work is precarious, unstable, and physically taxing, but it is sometimes the only work available.

The recent growth of remote work may offer more opportunities for some rural residents, but remote jobs will never be an option for the many people living in areas without broadband or reliable, high-speed internet. Internet access is increasingly essential for everything from attending school to dating, and poor connectivity limits job prospects and is another factor that can influence young people to leave rural areas. It is estimated that about 15 percent of rural CNY households lack internet (see Appendix A).<sup>7</sup>



## RURAL CNY IS MORE RACIALLY DIVERSE THAN PEOPLE THINK

Rural CNY has always been more diverse than U.S. Census Bureau statistics indicate, because it has a long history as home to the Haudenosaunee, who have never participated in the census.<sup>8</sup> The Haudenosaunee, often referred to as the Iroquois Confederacy or Six Nations, includes the Cayuga, Oneida, and Onondaga Nations. The Onondaga Nation, considered the capital of the Haudenosaunee, originally occupied territory that spanned the region from Lake Ontario to Pennsylvania, extending into every rural CNY county.<sup>9</sup> However, it lost the vast majority of its land over 200 years ago and the Onondaga Nation is now based just south of Syracuse.<sup>10</sup> The Cayuga are located to the west, while the Oneidas' land is to the east. All three nations are members of the Haudenosaunee but have separate governance structures and cultures.

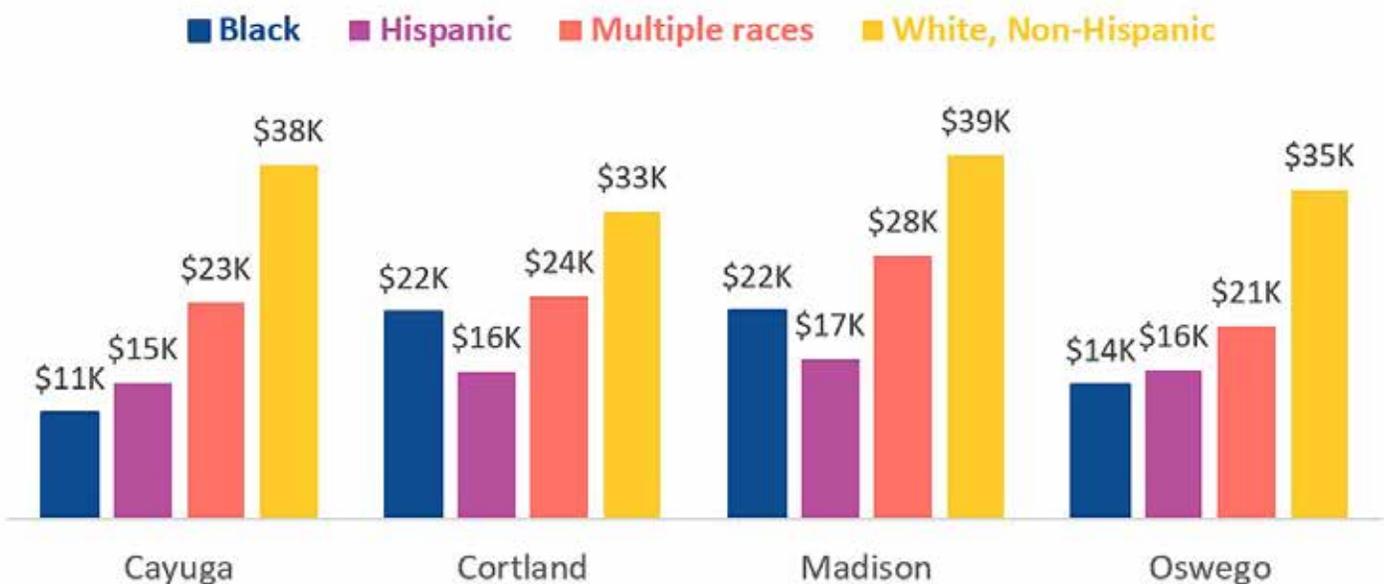
When you ask people in rural CNY about racial diversity, they often say that the population is “mostly white.”

But the most recent census data show that this is not as true as it used to be. Between 2010 and 2020, the population in the four-county region decreased overall, and it lost over 30,000 white people while it gained over 14,000 people who identified as Hispanic, Black, Asian, multiple races, and other racial groups.<sup>11</sup> This resulted in the percentage of people identifying as Hispanic, Black, or another racial minority group growing from 6 percent to 11 percent of the region's total population in just a decade (see Appendix A). This means that over 1 in 10 rural CNY residents are people of color.

Cayuga and Cortland counties have the most racial diversity among the four rural CNY counties (~13 percent of people in each county are from marginalized racial groups), but Madison and Oswego counties are not far behind (~10 percent). New Americans and farmworkers, many of whom do not speak English, account for some of this population and are living in every rural county. These populations may account for some of the differences in per capita income among racial groups, which is shown in the following chart.

### Income varies by race/ethnicity in rural CNY

In 2022 the per capita income of Black, Hispanic, and multiracial residents was significantly lower than that of White, Non-Hispanic residents in every CNY county



Source: U.S. Census Bureau, American Community Survey 5-Year estimates (2022)

## EACH RURAL CNY COUNTY HAS ITS OWN UNIQUE IDENTITY AND CHALLENGES.

Although the four rural CNY counties in this report are explored as one region, each county has its own identity. From the vantage point of Onondaga County, it is natural to consider the surrounding counties as closely tied to Syracuse, but each county borders other regions in which residents may have even stronger connections.

- **Cayuga County** is considered part of the Finger Lakes region, and many people know it by the long lakes that cut through the county lengthwise and fuel local tourism. People in the southern part of the county may be more likely to seek health care in Ithaca or Cortland than Auburn or Syracuse due to proximity, whereas residents of the county's northern towns may travel to Oswego. Most county services are located in Auburn, which is also home to the largest employers: Auburn Community Hospital, Auburn Correctional Facility (rural CNY's only federal prison), and county government.<sup>12</sup> Cayuga County has the largest share of the region's farmland and is the no. 2 county in NYS for agricultural sales.<sup>13</sup>
- **Cortland County**, the most southern county in rural CNY, is one of the northernmost counties in Appalachia and is often tied to the Southern Tier region. Organizations in Tompkins County are partners for some programs and services, such as the call center for 211-Cortland, and people in the southern part of the county may live closer to Ithaca or Binghamton than Syracuse. The population is concentrated in the City of Cortland, home to SUNY Cortland and Guthrie Cortland Medical Center. Of the four rural CNY counties, it is the smallest in both area and population.
- **Madison County** shares a border with six different counties, including Oneida County to the northeast and Chenango County to the south. It is often considered part of the Mohawk Valley region, and it shares many services with nearby Oneida and Herkimer counties. Many residents living around Route 5 are close to Oneida Hospital but may travel to either Syracuse or Utica for specialists and other providers. The towns in the southern part of the county are the most rural and may seek care at Community Memorial Hospital, a 25-bed critical access hospital in Hamilton, or travel farther to Bassett Medical



**In looking at rural CNY as a region, the intent is not to erase or minimize the diversity of experiences throughout the four counties.**

Center in Cooperstown. Turning Stone Casino and Resort, a business owned by the Oneida Indian Nation that is located just beyond the county border, employs more people than Madison County's ten largest private employers combined.<sup>14</sup>

- **Oswego County** is adjacent to Lake Ontario and the North Country region, which leads to collaborations with Jefferson and Lewis counties. Residents of Pulaski, Sandy Creek, and northern towns may travel to Samaritan Hospital in Watertown rather than the hospital in Oswego. Major employers include Oswego Health, SUNY Oswego, and county government. Oswego County is the largest of the four counties in population and area. It is home to 38 percent of the region's residents and has the region's highest overall poverty rate.<sup>15</sup> However, Oswego County is well-positioned to benefit from the arrival of Micron Technology, a semiconductor manufacturing company that recently committed to building a new plant in the town just south of the Oswego County border.

In looking at rural CNY as a region, the intent is not to erase or minimize the diversity of experiences throughout the four counties. Rather, the aim is to highlight shared challenges and opportunities for addressing health and social needs.

## SHARED ASSETS

Relative to more remote rural areas of NYS, rural CNY counties have many advantages. Each county has at least one hospital and colleges/universities that serve as major employers and valued community resources. Each county has outdoor recreation destinations and tourist destinations which benefit the local economy. The “central” location of rural CNY within the state also lends itself to opportunities to host convenings of statewide organizations, which strengthens regional and state networks.

CNY is home to several statewide organizations dedicated to serving rural communities. The NYS Association for Rural Health and the NYS Legislative Commission on Rural Resources both have staff based in CNY. The Rural Health Institute (formerly known as Cortland Area Communities That Care) is based in Cortland County. FarmNet and Cornell Cooperative Extension are located nearby in Ithaca, NY.

Nearly all of the region’s residents live within an hour’s drive of Syracuse, which greatly expands access to jobs, health care providers, and grocery stores for people who own vehicles. Rural CNY residents living near the Onondaga County border and a highway may be able to reach the city in 20-30 minutes. Many farms and businesses based in rural counties take advantage of Syracuse as a market and distribution hub. Many rural CNY residents are also within an hour of a second urbanized area (Rochester, Utica, Binghamton, Ithaca, or Watertown), which further expands options for people who are able to travel.

## SHARED CHALLENGES

In rural communities, everything costs more because people generally need to travel farther than they do in cities. People pay in both lost hours spent on travel time and fuel costs, which are also added on to the cost of goods in rural stores. Rural CNYers are more likely to own than rent their homes, and the homes are generally older and need costly repairs over time to stay habitable. For all these reasons and many more, transportation, food, and housing make up a large share of household budgets. Transportation has been a well-known pressing need for a long time, but in recent years inflation has squeezed many already-tight budgets even further, leading more people to become food and housing insecure for the first time in their lives.

Statistics on the percent of people living “below poverty”

often underestimate how many people are struggling to meet basic needs, and this is particularly true in rural communities. The United Way’s measure of people who are “ALICE: Asset Limited, Income-Constrained, Employed” gives us a way to estimate how many people are working and earning a wage above the federal poverty level, but earning too little to meet basic costs of living. These data show that the percentage of households that are below the ALICE threshold or in poverty ranges from 37-41 percent in rural CNY counties. Looking at the region as a whole, this means that nearly 2 in 5 (39 percent) households in rural CNY struggle to afford basic necessities like food, transportation, and health care.<sup>16</sup>

Many agencies are doing tremendous work to address community needs, but they share the challenge of reaching people living in remote places. There are still pockets of the region without broadband access and many people without computers or internet.<sup>17</sup> Just as it costs more for individuals to access food, it often costs service providers more to get people what they need. But rural organizations are often provided less funding – not more – because their population size is small compared to the more urban counties. And when funding is limited, many funders and statewide organizations regionalize programs, causing rural communities to lose local staff and resources.

### DATA SNAPSHOT: POVERTY IN RURAL CNY

- Percent of households below the ALICE threshold is even higher in some cities and towns:
  - 60% in the Town of Eaton (Madison County)
  - 52% in the city of Auburn (Cayuga County)
- Households with older adults and people under age 25 have the highest poverty rates.
- CNY’s highest child poverty rates are found in Oswego County, where more than 2 in 3 children in some schools are considered economically disadvantaged.<sup>18</sup>
- 37% of older adults in Oswego County earn below \$30,000 per year.<sup>19</sup>
- In Cortland County, over half (53%) of all households owned by people over age 65 are below the ALICE threshold.

## THE APPROACH

To understand the health and social needs of the region, we interviewed dozens of CNY service providers and subject matter experts between August and December 2023. We reviewed local reports, attended meetings and events, and analyzed data from numerous sources. A full list of individuals who provided information is at the end of this report.

In talking with people throughout the region, issues related to transportation, food, housing, poverty, and other social determinants of health came up repeatedly. Many interviewees spoke about challenges related to workforce and limited resources available to serve rural communities. They also spoke to the inequities experienced by specific populations such as low-income people, people with disabilities, older adults, BIPOC, and LGBTQ people. While acknowledging all these issues are interrelated, and many are root causes of other health and social issues, evidence of need compelled us to focus on the following areas:

- Perinatal health
- Oral health
- Mental health and substance use
- Home health care



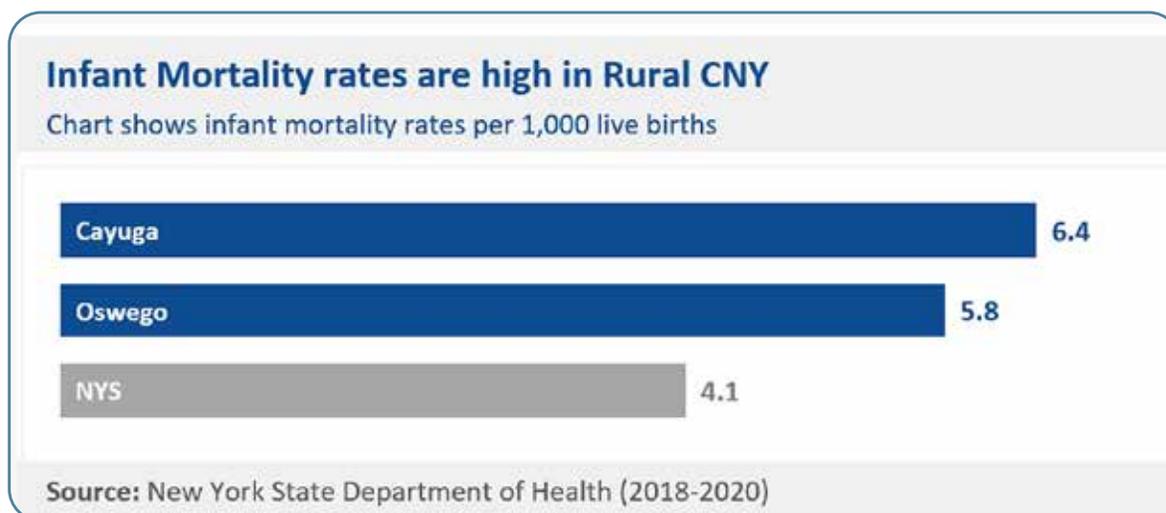
Each topic is large and complex, and we do not claim to offer a comprehensive overview of all the issues related to any particular one in this report. Instead, we aim to summarize the perspectives and data shared by the many people who contributed to this report in hopes of helping others to better understand the local landscape and needs, including some of the known disparities related to each topic. In addition, we highlight some of the successful programs and promising strategies that might be scaled up, implemented, or sustained through further investment by those interested in seeing rural CNY thrive.



## CNY RURAL HEALTH ISSUE:

# Perinatal Health

Infant mortality rates are often cited as one of the key indicators of overall health in a population. Judging by this measure, rural CNY does not fare well. In Cayuga and Oswego, the only two counties for which we have stable estimates, the rates are higher than the statewide rate and considered to be of “high concern.”<sup>20</sup>



From statewide data, we know that Black non-Hispanic babies have an infant mortality rate nearly three times as high as white non-Hispanic babies.<sup>21</sup> Local data on the racial disparity are unavailable for most rural CNY counties due to small numbers of births in specific racial groups. However, the unstable data that are available show alarming disparities in which the region’s Black babies have a much higher risk of dying compared to white babies.<sup>22</sup>

Many factors contribute to high infant mortality. Pregnant people who are low-income have a hard time paying for basic needs and accessing prenatal care, which is key to good birth outcomes. After giving birth, they are unlikely to be able to take leave from their job or afford childcare – if they are fortunate enough to have any available where

they live. Extra expenses like diapers and formula can all add to the strain on new parents. Research on policies that support families during this time, such as paid parental leave, consistently show reductions in risk of infant mortality and numerous other health benefits for both babies and parents.<sup>23</sup>

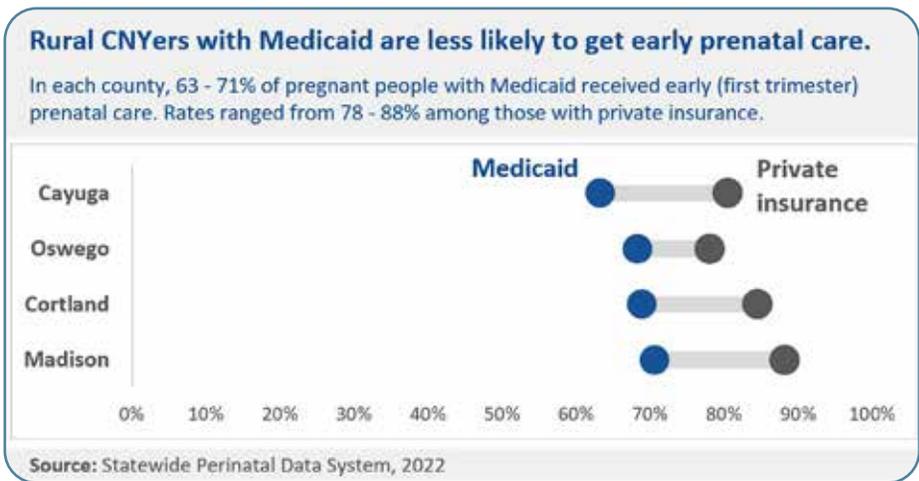
In rural CNY, the vast majority of pregnant people with late or no prenatal care are those with Medicaid for health insurance.<sup>24</sup> According to data provided by the CNY Perinatal Data System, pregnant people who identify as Black, Hispanic, or multiple races are also much less likely to get prenatal care in the first trimester than those who are white. This is likely related in part to economic disparity, since marginalized racial groups in rural CNY earn significantly less compared to their white counterparts.<sup>25</sup>

Low-income people are more likely to be covered by Medicaid, and local health assessments show people are concerned that there are not enough doctors who accept patients with Medicaid.<sup>26, 27</sup> Across NYS, people are less likely to have a regular health care provider if they are low-income or BIPOC (Black, Indigenous, and other People of Color), so the disparity may be due to the time it takes to find a new provider.<sup>28</sup>

Transportation barriers contribute to the challenge of making it to prenatal appointments and pediatrician visits. Cayuga and Oswego are both geographically large counties where many people live far from the only health care providers. Cayuga County has the region's highest rate of households without a vehicle (10 percent), and the rate is nearly as high in Oswego County.<sup>29</sup> There are very few bus routes and Medicaid transportation is notoriously unreliable. If there is an urgent need to see a doctor, many people depend on Emergency Medical Services (EMS) – providers that have been critically underfunded and understaffed in rural areas of NYS for years.

## BIRTHING PEOPLE IN RURAL CNY HAVE FEW PROVIDER OPTIONS

Rural CNY parents and babies are fortunate in that each county still has a hospital with an obstetrics (OB) service. Across the country, many rural hospitals have had to close their OB units due to financial challenges that were worsened by the COVID-19 pandemic.<sup>30</sup> Since 2020, at least seven NYS hospitals have lost their labor and delivery

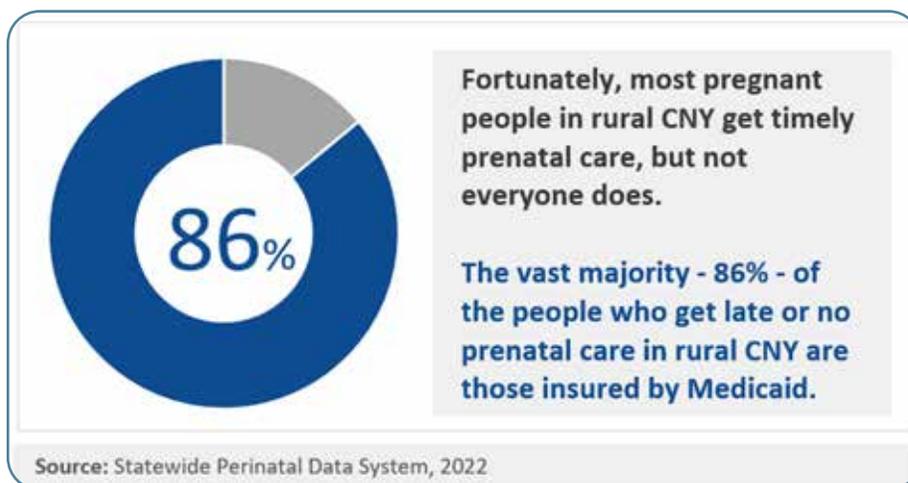


units, including those in rural St. Lawrence and Wyoming counties.<sup>31, 32</sup> Seneca County, located immediately west of Cayuga County, has no access to providers and is considered a maternity care desert.<sup>33</sup>

In rural CNY, each county is considered to have “full access” to maternity care because there is one birthing hospital. However, many pregnant people – especially those in the most remote areas of the region – still have to drive long distances to get there. These counties often rely on only one OB/GYN or midwife, which makes their access to care tenuous. Cortland County recently found itself without any providers after losing its only OB/GYNs.

“It’s been rough,” said Gabrielle DiDomenico, Coordinator of the Doula Partnership at Seven Valleys Health Coalition. “Moms were hearing that they needed to go to Syracuse or Ithaca because there’s no good care here.”

Fortunately for Cortland, Guthrie Cortland Medical Center was able to respond to the local need. They opened a new OB/GYN clinic in 2022 and hired a doctor specializing in OB/GYN and multiple certified nurse-midwives. They are working in collaboration with community partners to let people know that Cortland has new high-quality resources that can serve most birthing people. “Now we’re looking to wipe the slate clean and rebuild people’s understanding of what maternal health care in the area could look like,” said DiDomenico.



## WHEN RURAL CNY BABIES NEED A NICU, THEY GO TO SYRACUSE

Rural hospitals are able to support the vast majority of births, but when a baby needs a Neonatal Intensive Care Unit (NICU), the family usually goes to Syracuse. Crouse Health and St. Joseph's Health are the region's only hospitals with NICUs, so parents of the smallest and sickest babies often have to travel to Onondaga County with their newborns.<sup>34</sup> In 2022, there were 254 babies from rural CNY admitted to the NICU. Over half of them had mothers with health insurance through Medicaid, meaning that they likely had the most limited financial resources to travel and stay in Syracuse.

Having a baby in the NICU can be a traumatic experience, but it's also really hard when families need to leave the hospital. Christine Kowaleski, a nurse practitioner who has worked in Crouse's NICU for 25 years, said, "I know the fear of taking any baby, much less a preemie to a rural area, sometimes with medical equipment and the lack of support due to limiting visitation, particularly in the winter months."

Kowaleski and Kathleen Miller Murphy both work at Crouse Health and co-chair Postpartum Support International's

## DATA SNAPSHOT: PERINATAL HEALTH

- Among rural CNY counties, Oswego County had the highest rates of mothers receiving late/no prenatal care (5%) and low birth weight babies (10%) in 2022.<sup>35</sup>
- There are racial disparities in CNY for many metrics, including mothers receiving early prenatal care, preterm births, and low-birth-weight babies. County-level data may provide unreliable estimates because they are based on low numbers of births among specific racial groups each year, but there are clear disparities seen at the regional level.

*For example:*

- In CNY in 2022, only 3.6% of white pregnant people receive late or no prenatal care, whereas the rate ranges between 6.4% and 7.6% among Black, Hispanic, multiracial, and other marginalized racial groups.<sup>36</sup>
- Maternal mortality rates in rural CNY are low. The only death in 2018-2020 was in Madison County.<sup>37</sup>
- Most areas of rural CNY are considered childcare deserts, meaning that there are not enough childcare providers to meet local need.<sup>38</sup>



New York Chapter (PSI-NY). They spoke of how they see many new parents – especially those who've had a baby in the NICU – struggle with recovery from the trauma of their experience. It is a lot to handle on top of adjustment to life with a newborn, which usually entails sleep deprivation and physical exhaustion, and it's especially hard for those people isolated at home in rural areas.

"I know it's probably worsened since COVID, but I feel like it's a chronic problem," said Amanda Barbera, Program Coordinator of the Perinatal and Infant Community Health Collaborative (PICHC) Program serving Oswego County through REACH CNY. "People are isolated and just don't have the supports that they need."

CNY is fortunate that Crouse Health offers free perinatal family support groups and resources that help parents who are struggling with depression and anxiety. Crouse has also led the effort to ensure screening for perinatal mood and anxiety disorders at prenatal visits, while in

the hospital for delivery, and postpartum. During the COVID-19 pandemic they began offering support groups online through Zoom, and this made it much easier for parents in rural areas to connect.

## FUNDING FOR PERINATAL PROGRAMS VARIES

Many different providers take part in perinatal service delivery. There are OB/GYNs, pediatricians, childcare providers, and the agencies that provide WIC, Healthy Families, Early Head Start, breastfeeding/chestfeeding education, and many other services designed to support infants and their families from pregnancy through the first year of life. Funding for specific programs often fluctuates with the state budget, building up resources when money is available, but more often placing agencies in rural counties in competition for limited grant dollars to get or sustain programs. The history of NYS's Perinatal Networks offers an illuminating example of how this impacts rural CNY.

REACH CNY historically (1990-2013) served Madison, Onondaga, Cayuga, and Oswego counties as the NYS-funded regional Perinatal Network. Funding allowed the agency to convene Perinatal Councils in each county and facilitate coordination between clinical and community-based providers. However, their work shifted in 2013 after the NYS Department of Health reconfigured its grant programs, combining several funding streams into a new initiative called the Maternal and Infant Community Health Collaboratives (MICHC). MICHC was designed to focus limited public health resources on areas with known racial and economic disparities and the greatest need.



However, the RFP placed counties in tiers based on the size of the population in need and the three smallest rural CNY counties (Cayuga, Madison, and Cortland) were in the lowest tier and not covered by MICHC funding.

In its most recent round of funding, NYS modified the MICHC program by eliminating direct services to people in the preconception period (prior to pregnancy), requiring more engagement of program participants in Community Advisory Boards and changing the name slightly to the Perinatal and Infant Community Health Collaboratives (PICHC), to reflect the fact that not all birthing people identify as women. Fortunately, both Oswego and Cayuga counties were awarded PICHC funding. Oswego County is served by REACH CNY, which contracts with Oswego County Opportunities to provide the Community Health Worker (CHW) services. The Cayuga Community Health Network implements PICHC in Cayuga County.

PICHC connects new parents with CHWs who work to improve the health of whole families by creating person-centered goals. They provide education and link families to everything from health insurance to parenting classes. But more importantly, the funding is flexible and allows them to serve as a local champion for perinatal health while building partnerships and collaborations that respond to local needs.

Madison and Cortland counties do not have PICHC funding, but there are still active coalitions supporting collaboration among clinical and community providers to improve perinatal health. Years ago, Madison County Public Health decided to take on the work of convening local partners, after maternal and child health needs were





identified through their Community Health Assessment. They've managed to continue hosting quarterly meetings for the many people who serve young families through the Madison County Healthy Beginnings Provider Network, but this work is entirely unfunded. Without dedicated funding and this work coming under an agency focused on perinatal health, there is a gap in what they can do. Partners would like to offer childbirth and breastfeeding classes, more mental health resources for mothers, better dental education and care for prenatal patients, and more supports for low-income families, but current resources don't support these activities.

In Cortland County, local partners have also continued to do some local work without funding because they know it addresses an important need. For example, their Breastfeeding Partnership has met for years and tries to be creative, doing high-visibility low-cost activities like arranging for breastfeeding book displays at the local libraries. Some partners participate in meetings of the Perinatal Network that covers the Southern Tier, which is based in Binghamton, but there is no funding for coordination of local perinatal partners.

### **HIGHLIGHT: OSWEGO COUNTY EARLY CHILDHOOD ALLIANCE**

For several years Oswego County agencies have been working on a new approach to improve outcomes for babies and young children. It emerged in part from local anti-poverty initiatives where lack of childcare was identified as one of the major barriers holding people back from getting jobs and getting out of poverty. Community leaders recognized there was a need for a more comprehensive

approach to early childhood efforts, given its importance in shaping the course of people's lives in the long term.

"We talk a lot in our meetings about the need for a universal touchpoint," said Brandy Koproski, Executive Director of Integrated Community Planning of Oswego County. "Where are all of the kids before they hit kindergarten? The truth is we don't really know. We have a limited supply of childcare... Until children enter school, we don't know who's falling through the gaps." For example, young children experiencing neglect or showing signs of developmental disabilities may not have contact with any professionals who could recognize those signs and connect families to services that could help.

Koproski and partners at Oswego County Opportunities and Center for Instruction, Technology, and Innovation (CiTi) BOCES were the initial group that convened to form the Oswego County Early Childhood Alliance (ECA), but that group expanded in 2022 to include the Richard S. Shineman Foundation, Oswego County Administration, and the NYS Office of Children and Family Services Regional Office. Oswego County ECA has designed a structure that will allow for better coordination across the dozens of programs and agencies that serve children ages zero to 5 and their families. It is a model that has been successful in Onondaga



**"We talk a lot ...about the need for a universal touchpoint. Where are all of the kids before they hit kindergarten? The truth is we don't really know."  
Brandy Koproski, Executive Director, Integrated Community Planning of Oswego County**



County, leading to substantial public and private investment in initiatives to build systems that work.

Oswego County ECA recently brought together partners in a forum to review local data and discuss needs and opportunities. They shared that Oswego County has nearly 6,000 children under age 5 and has the highest rate in NYS for drug-addicted babies.<sup>39</sup> The county also has one of the state's highest rates of child abuse, a shortage of childcare providers, and very long waiting lists for services such as Early Intervention. Early Intervention is a program serving children under 3 that provides free screenings and connections to a wide range of services such as family counseling, home visits, and speech therapy.

"There are not enough providers, and it's causing great delays," Koproski said. "A daycare provider from a center was recently talking about how they have kids being sent to kindergarten without being toilet trained. We're also seeing social emotional needs and behavioral problems that are much higher than they ever used to be."

Through Oswego County ECA, they are planning to bring service providers and families together to find new ways to improve coordination and referral. Their first big initiative will be implementing Help Me Grow in Oswego County. Help Me Grow is not a program, but rather an evidence-based "system model that utilizes and builds on existing resources in order to develop and enhance

a comprehensive approach to early childhood system-building in any given community."<sup>40</sup>

Through Help Me Grow, they hope to create a central access point for families, leveraging the 211 resource directory to help families better navigate a very fragmented system. Although much work remains to be done to shore up childcare and other community services, the new system will help more families connect to the resources that do exist. Through the initiative, staff will conduct outreach to health care providers, families, and the community at large to help improve people's understanding of the importance of early child development and local resources. Help Me Grow will also collect and analyze data that should help in efforts to address local needs and evaluate progress over time.

Partners coming together to form the Oswego County ECA are close to seeing their plans move forward. Koproski recently hired the first Oswego County ECA employee and is aiming to launch Help Me Grow in 2024.

### **HIGHLIGHT: THE DOULA PARTNERSHIP**

Rural health networks in Cayuga, Cortland, and Madison counties are all working together on a very different initiative to improve birth outcomes: the Doula Partnership. It started in 2018 as a program of the Cayuga Community Health Network (CCHN), which saw a need to better



**“We see low-income moms who don’t have partners or any family living nearby who can help them take care of themselves during pregnancy. Doulas fill that gap.”  
Holly Beauchine, Program Coordinator at CCHN**

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support birthing people – especially those who are low-income and without resources to advocate for themselves when they deliver a baby.

“Doulas bring a sense of ease to moms,” said Holly Beauchine, Program Coordinator at CCHN. “We see low-income moms who don’t have partners or any family living nearby who can help them take care of themselves during pregnancy. Doulas fill that gap.”

“Birth doula” is not a term that people were widely familiar with when CCHN began its program, but they have done a lot of work to spread the word and educate people about the growing body of evidence that shows that doulas are effective in improving birth outcomes. Birth doulas do not provide medical care, but take care of the many other physical, emotional, and informational support needs that people have before, during, and shortly after childbirth. Their goal is “to help the birthing individual achieve the healthiest, most satisfying experience possible.”<sup>41</sup>

Birth doulas are an important strategy for reducing inequities in birth outcomes for Black birthing people that have slowly gained acceptance in public health. In 2023, NYS passed legislation making doula services reimbursable through NYS Medicaid, which many hope will enable doulas

to help more low-income moms and other birthing people.

Since starting the Doula Partnership program, CCHN has trained over 80 doulas. Grant funding from the Health Foundation for Western & Central New York has supported the training and enabled them to offer doula services to people free of charge. Over the years, CCHN has continued to receive testimonials from parents about how valuable it was to have a support person through their birthing process.

Due to the success of the Cayuga County program, the Rural Health Networks in Madison and Cortland counties began talking about partnering with CCHN to expand the program. They engaged in a planning process in 2021 where they looked at the data, explored potential for reaching different populations, and connected with local maternal and child health partners. What they found was considerable need, especially among low-income populations who could not otherwise afford a doula, and a lot of enthusiasm to start a birth doula program. As a result, the agencies applied for funding and were able to start a program in 2023.

So far Madison and Cortland counties have trained 23 birth doulas who are looking forward to serving the community in the coming years. To date, they have only had a few people deliver babies with the assistance of a doula, but those births were very successful and there are more on the way. One client, who has not yet given birth, is a younger family with a lot of need. “This has been interesting because the doula has actually spent most of her time connecting the client to local supports like parenting classes,” said DiDomenico.

Although rural counties like Cortland have a smaller group of service providers than you’d find in the larger cities, an advantage is that it’s possible for everyone to know each other at a closer level. Cortland’s doulas recently attended a “meet and greet” event with the new midwives at the local hospital and local agencies who serve birthing people.

“I think that one of the sweet things for our area is that it’s condensed – especially in the City of Cortland where all these organizations exist – and we really can get to know each other and really support each other’s work,” said DiDomenico.

As more health care and community partners in Madison, Cortland, and Cayuga counties become aware of how birth doulas can help, the Doula Partnership will undoubtedly be able to help more low-income birthing people find more support in pregnancy and in their baby’s first months.

## CNY RURAL HEALTH ISSUE:

# Oral Health

High rates of tooth decay in young children, tooth loss among adults, and people experiencing dental pain are not new issues, but getting treatment has become a lot harder since the COVID-19 pandemic.

“Dental is a public health crisis right now,” said Patty McMahon, Executive Director of Forward Leading Independent Provider Association (FLIPA). “Folks continue to struggle to recruit dentists at a rate they can afford to pay them. The wait lists are astronomical – hundreds, thousands of people. In some places they’re doing triage – only seeing people with emergencies – and it’s really hard for adults to get visits because there’s such a short supply.”

## THERE ARE NOT ENOUGH DENTAL CARE PROVIDERS IN RURAL CNY

Every rural CNY county is partly or fully designated as a Health Professional Shortage Area (HPSA) for Dental Care.<sup>42</sup> The providers that are in the region struggle to find and retain enough dentists, hygienists, and dental assistants to serve all their patients. Practicing dentistry during the pandemic meant working in close proximity to unmasked patients when COVID-19 was at its most deadly and untreatable, and it pushed a lot of people to leave this essential workforce.<sup>43</sup> The result was that the already inadequate provider pool shrank even more, making it harder for people to get appointments and access routine care.

When people are trying to find a provider, dental insurance limits their options even further. In 2023, a Madison County Public Health survey found that 54 percent of caregivers of young children (ages zero to 5) reported concern over not finding a dentist that accepts their child’s insurance or their child not having dental insurance. Across the entire rural CNY region, there are only nine dental providers who accept Medicaid.<sup>44</sup>



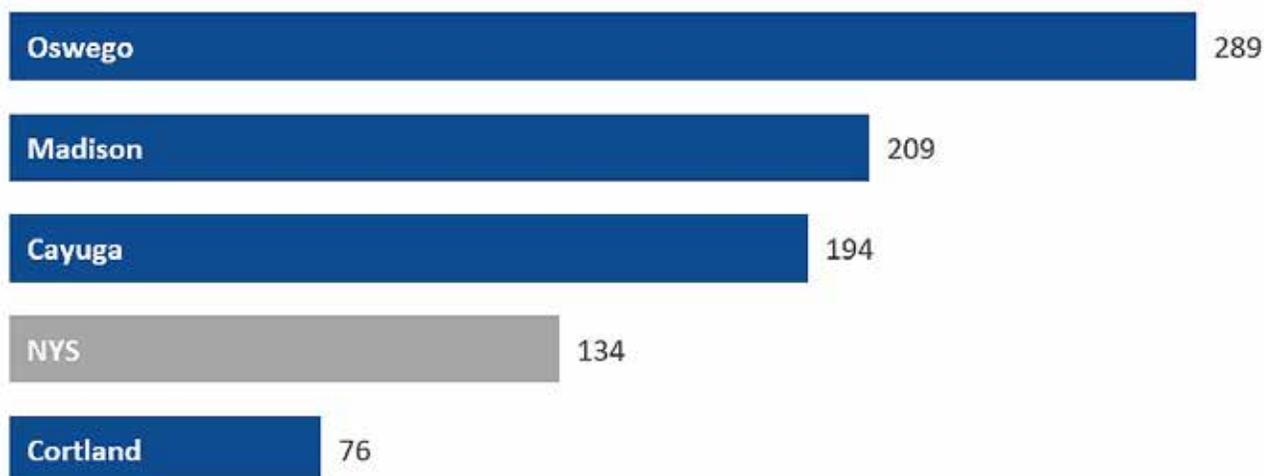
The long waitlists provide evidence that these providers do not currently have the capacity to meet local needs.

## THE COST OF DENTAL CARE IS A BARRIER FOR MANY PEOPLE – EVEN THOSE WITH INSURANCE

For older adults, we know inadequate dental insurance is a major concern.<sup>45</sup> Medicare largely does not cover dental care sufficiently, despite some improvements to coverage in recent years.<sup>46, 47</sup> CNY is fortunate to have several Federally Qualified Health Centers (FQHCs) that provide dental care to everyone, regardless of their insurance or ability to pay, but many low-income people still forgo care due to fear of the cost.

## Rural CNY children have lots of ER visits due to tooth decay

Chart shows caries outpatient rate per 10,000 children aged 3-5



Source: New York State Department of Health (2018-2020)

NY StateWide Senior Action Council's CNY Health Task Force conducted a survey in 2021 that found 40 percent of respondents avoided dental care due to cost – even when they have insurance. Many people do not visit the dentist because they know that insurance will not cover the care they need, and they can't risk a large bill. As a result, they endure dental pain until it becomes an emergency.

High rates of people seeking emergency treatment for dental issues is reflected in one of the few oral health statistics we have for CNY counties: the rate of 3 to 5-year-olds going to the hospital (outpatient) for untreated tooth decay. As the chart above shows, the rates are much higher in most rural CNY counties than in NYS overall.<sup>48</sup>

Bridget Walsh, Senior Policy Analyst with the Schuyler Center for Analysis and Advocacy, said, "Instead of asking 'how can we get more dentists in rural areas?', the question should be 'why are so many 4-year-olds in need of tooth extraction? And how can we help families access the care they need to maintain good oral health?'"

Tooth decay is a highly preventable disease, yet we treat it differently than we would treat disease in any other part of the body. Oral health issues are addressed through

prevention programs and provider networks that are still largely separate from those used to address other health issues. This is especially frustrating to people who study oral health and know that periodontal disease has been linked with overall health and many specific diseases such as diabetes, heart disease, cancers, and dementia.<sup>49</sup> Research also shows there are disparities in oral health for populations who are rural, poor, and from historically marginalized racial and ethnic groups. Focusing on prevention could go a long way toward health equity, yet it is continually sidelined.

We don't know the full extent of the problem in CNY because oral health is so under-resourced. While most of the NYS Department of Health (DOH) data sources are updated annually, the most recent data on the rate of tooth decay among children is over a decade old.<sup>50</sup> In 2014, NY published its *Oral Health Plan for New York State*, which noted that almost 80 percent of all children experience tooth decay by the time they graduate high school.<sup>51</sup> The plan outlined goals and objectives to address this problem, but the plan has not been updated and there's no evidence that things have improved for NY's youth.

## TOO MANY CHILDREN HAVE TOOTH DECAY – A PAINFUL AND ENTIRELY PREVENTABLE DISEASE

Providers in rural CNY know that rates of tooth decay are far too high because they see the issues show up in their patients every day. In 2023, 38 percent of the children visiting East Hill Medical Center’s dental clinic in Auburn had signs of decay or dental caries.<sup>52</sup> That means more than 1 in 3 children visiting the clinic have a preventable disease that may impact their ability to learn, lead to a lifetime of need for further dental treatment, and increase the likelihood of developing many other diseases.<sup>53, 54</sup>

“Dental care is the biggest need in the community,” said Jessica Soule, Chief Operations Officer at East Hill Medical Center. “It’s just really heartbreaking that people don’t see how important this is, and how central it is to people’s lives, and how underrated and underfunded and underappreciated dental and oral care is. It’s a basic human need.”

Sadly, rural CNY has many children who do not brush their teeth or have dental checkups. Several interviewees mentioned low-income households where the whole family shares one toothbrush. Besides leading to dental disease, this allows viruses to quickly spread through the family and

creates cycles of illness – which also means more sick days and less income for those families that need it the most.

Many factors put young children in poor families in rural areas at especially high risk. Sugary foods and drinks are cheap and widely available, but dentists are not. Families may know that it’s important to visit the dentist and change toothbrushes regularly, but those aren’t easy things to do in practice. Giving children consistent support and guidance in good oral hygiene is especially challenging in homes where adults are working multiple jobs, stressed about money, or struggling with their own health issues.

## MANY RURAL CNYERS ARE AT HIGH RISK FOR DENTAL DISEASE DUE TO LACK OF FLUORIDATED WATER

Community water fluoridation is one of the most effective ways to prevent dental caries, also known as tooth decay, but it’s not available to most people in rural CNY. Many people, especially those living outside the small cities and villages in the most rural areas, use private well water, which almost always lacks fluoride. When Madison County tested the fluoride level of 74 private wells, they found that only four had sufficient fluoride to be protective.<sup>55</sup>



Many people in rural CNY are served by public water systems, but most of these systems do not provide fluoridated water (see the table on page 19) Many of the region's poorest residents live in the cities of Auburn, Cortland, and Oneida – and none have fluoridated water on tap.

“We don’t have fluoridated water [in Cayuga County]. From the perspective of someone in public health, that means everyone in this community is at risk,” said Soule.

Over the years, health advocates in many rural CNY counties have tried multiple times to advocate for adding fluoride to the public water systems, with no success. “Every few years we’ve taken up the cause and we keep getting beaten down,” said Jackie Leaf, Executive Director of Seven Valleys Health Coalition, the rural health network in Cortland County. Madison and Cayuga County have also discussed fluoridation at times over the years, but it is politically untenable because there are vocal activists who come out to hearings to oppose it.

Fluoridating municipal water supplies could be helpful in some parts of rural CNY, but people reliant on private well water need other solutions. It is recommended that people who don’t have fluoridated water – especially children – protect their teeth by taking fluoride tablets regularly. However, this solution is more difficult because it requires children to get to a provider who prescribes the tablets. In Madison County’s recent survey of caregivers, only 32 percent said that their children take supplemental fluoride. Fluoride varnish is another preventive solution, but it is challenging for providers to reach all the children who could benefit.

## TOTAL TOOTH LOSS IS HIGH AMONG OLDER ADULTS IN RURAL CNY

In rural communities without good access to dental care, dental problems often begin in childhood and worsen as people age, leading to numerous other physical and mental health problems and sometimes leading to tooth loss. In rural CNY, it’s estimated that between 10 percent and 13 percent of adults age 65+ have lost all their teeth.<sup>56</sup> The rate is even higher (18-19 percent) in the cities of Auburn, Oswego, Fulton, and Cortland, where many of the region’s lowest-income residents are concentrated.

Tooth loss impacts older adults in many ways. It can cause people to self-isolate and avoid social situations because

they are embarrassed about people seeing their missing teeth or poor-fitting dentures.<sup>57</sup> They may live with dentures that cause them pain for long periods of time, since insurance companies only cover replacements every eight years. Tooth loss also limits people to soft foods, which sometimes means that people can’t eat balanced meals.

“I have had a particular concern about the elderly, especially those living in institutions, and even those living at home, because of the pain associated with dental disease and their inability to eat the right foods,” said Walsh. She noted that the pain of dental disease is one of the leading causes of people needing to move into institutionalized care.

As the average lifespan increases and the older adult population grows, it will be more important than ever to address oral health needs in older adults. The true extent of dental pain and its health impacts among the oldest and most vulnerable older adults is unknown and largely unaddressed, representing a major opportunity to address disparities.<sup>58</sup>

### HIGHLIGHT: FEDERALLY QUALIFIED HEALTH CENTERS MEETING DENTAL NEEDS

In rural CNY, many low-income people find the dental care they need at the region’s FQHCs. East Hill Medical Center in Cayuga County, Family Health Network Dental Office in Moravia, Port Byron Community Health (part of Finger Lakes Community Health), and ConnexCare in Oswego County all receive federal funding that allows them to provide care to everyone, regardless of their ability to pay. All FQHCs provide at least some dental care services, but those services vary depending on funding and capacity.

Dental care is expensive to provide, and FQHCs often lose money when they provide dental services. For example, East Hill Medical Center offers dentures to people below cost because of the high need. They see a lot of patients needing dentures at younger ages, and these dentures need to be replaced over time as people’s mouths change and they stop fitting as well. One of East Hill’s challenges is that the current process of getting dentures requires five separate visits, and many patients have a hard time getting to all these appointments.

“If I could do anything I wanted, I’d get a 3D printer [to make dentures], to reduce that hassle of people needing to come to the office five times,” said Soule. It would also save them

NY County	Percent of county residents served by community water systems with optimally fluoridated water (2021) <sup>59</sup>
Cayuga	0.3%
Cortland	3.2%
Madison	22.4%
Oswego	78.2%

the cost of sending dentures out to labs for adjustments and mean that their many patients with no teeth get the relief they need sooner. When people don't make it through the process, the patients suffer and East Hill is left with a half-made set of useless dentures – and bears the cost.

Even though they lose money on dental care every month, East Hill is always working to improve its processes and dental services because they are committed to meeting the community need. In 2020, when the pandemic restrictions forced them to stop offering routine services, they used that time to outfit their offices with brand new equipment. They added air filters to every room and implemented many additional infection control systems to minimize risk to patients and staff.

Private dental offices were not required to implement the same control measures and meet all the same requirements as FQHCs to reopen during the COVID-19 pandemic. This meant that when FQHCs reopened, their patients had gone much longer without preventative care and were much worse off. FQHCs had so many overdue patient appointments to schedule that some clinics had to stop accepting new patients.

## DENTAL THERAPISTS COULD HELP WITH WORKFORCE CHALLENGES

Tricia Peter-Clark, President and Chief Executive Officer of ConnexCare, explains that part of the challenge is that they haven't increased their capacity in dentists. So long as they have a backlog of patients needing dental exams, they have limited ability to take on new hygiene patients. She sees dental therapists as one solution that could really help FQHCs.

"The concept of the dental therapist is similar to the model between a physician and a physician assistant," Peter-Clark explains, "They would be able to work under the supervision of a dentist to do some basic things like dental sealants, which leaves the harder work like root canals to be handled by a dentist."

Many FQHCs and the Community Health Care Association of New York State (CHCANYS) are pushing for New York to license dental therapists so that they can better meet the critical need for dental care.<sup>60</sup> There are currently at least 14 other states that have authorized dental therapists in some or all settings in order to increase access to care.<sup>61</sup> In some areas dental therapists work with dental hygienists under the supervision of a dentists to go out to community settings to do things like apply dental sealants. If this role was approved, dental therapists could treat small cavities in children so that those cavities don't become big and painful while that child waits six months to see a dentist.

Bridget Walsh from the Schuyler Center also noted that dental therapists are something that New York should be looking at. "I can't tell you how many meetings I've been to in the past 20 years about how to get more dentists to move to rural areas," said Walsh. "The problem isn't new, and workforce issues aren't unique to dental. But we do know from the data that dental therapists tend to be from the communities they serve, and they stay in those communities."

## DATA SNAPSHOT: ORAL HEALTH

- The cost of dental care was the no. 1 concern of seniors in a recent survey from Madison County Area Agency on Aging.<sup>62</sup>
- The most recent available data show that Madison County has the highest rate in NYS of third grade children with dental caries (74%).<sup>63</sup>
- Only 1 in 3 (32.8%) of NYS children enrolled in Medicaid received a preventive dental visit in 2020, which was lower than the national median (41.5%)<sup>64</sup>



## HIGHLIGHT: ADDRESSING TRANSPORTATION BARRIERS IN MADISON COUNTY

Lack of transportation is one of the biggest challenges to accessing health care in rural areas. People needing to see a dentist may not have a car or enough gas money to get them there, even when they have insurance. For many people in rural CNY, mobility management services like those offered by the Madison County Rural Health Council (MCRHC) fill a critical need.

MCRHC's program, called GoMadisonNY ([gomadisonny.com](http://gomadisonny.com)), receives a lot of calls from people needing to access health care – including people needing to get to the dentist in Oneida, Hamilton, and Cazenovia. Donny Ybarra, Mobility Manager at MCRHC, explained the many ways their program can help people with transportation dilemmas. For one, they teach people about their travel options and work with individuals to make trip plans. They connect people to resources such as bus tokens and travel vouchers, or help people understand how to request transportation through Medicaid if they have that insurance.

Travel training is also a big piece of their work. Ybarra said that if people need to get to Oneida Dental, GoMadisonNY can help them to set up a “route deviation” on the bus route between Oneida and Canastota, meaning that they arrange for the driver to make an extra stop that is not part of the regular route. If people are unfamiliar with the bus system or worried about being stranded, their staff can meet people at their homes or at other public places and ride the bus with them until they get comfortable riding the bus independently.

In addition to providing much-needed services to individuals, MCRHC staff have worked with local partners to expand the transportation options in the county. The Madison Transit System has enhanced existing bus routes to offer more connections to health care and groceries, and created a new route between Hamilton, Morrisville, Nelson, and Cazenovia. MCRHC also has a growing volunteer driver program and partners with Madison County Office of the Aging and ITNAmerica to offer adults age 60+ transportation to health care appointments.<sup>67</sup> With grant support and donations, MCRHC has been able to sustain and grow their transportation initiatives since 2018, helping many people access the care they need.

**“I can’t tell you how many meetings I’ve been to in the past 20 years about how to get more dentists to move to rural areas.”** Bridget Walsh, Senior Policy Analyst, Schuyler Center

In 2024 NYS Assemblywoman Carrie Woerner, a Democrat, introduced a bill to allow for licensing of dental therapists, but it has a long road ahead before potential adoption.<sup>65</sup> It does not yet have a companion bill in the NYS Senate, and it will likely face the same opposition from state and national dental associations that was seen in other states that introduced dental therapists. Dental associations believe it will compromise patient care to allow mid-level providers to perform procedures, and in a recent article about the movement from dental therapists the New York State Dental Association (NYSDA) raised doubts about the evidence that dental therapists will solve the provider shortages.<sup>66</sup> NYSDA is more focused on increasing reimbursement rates as a strategy to get more providers to accept patients with Medicaid.

It is unclear if the effort to bring dental therapists to New York State will succeed, but one thing is clear: researching, approving, and training a new type of health care provider is a long-term strategy. Just like prevention work, it will take years for rural communities to reap the benefits. But it’s clear that rural CNY needs more sustained work to prevent and treat dental disease.

## CNY RURAL HEALTH ISSUE:

# Mental Health and Substance Use

In 2022 Oswego County lost 14 people to suicide and 35 people to drug overdoses.<sup>68</sup> Dozens more were lost to the same causes in Cayuga, Cortland, and Madison counties. Each one of these premature deaths is a tragic loss borne by families and friends and felt across the community. But deaths are also only the most visible consequences of mental health and substance abuse issues that are widespread across the region, causing quiet suffering and leading to issues like preterm birth, child neglect, abuse, unemployment, homelessness, and incarceration.



“Many people think of substance abuse as an urban problem, which we know is not accurate,” said Alex Milkowski, Executive Director of Access to Independence (ATI) of Cortland County. Milkowski used to run a substance use outreach program, helping distribute Narcan and train people to use it. She’s also done mobile crisis throughout the region, responding to calls whenever mental health issues were suspected.

“The issues are spread out. More [crisis] calls may come in from the city because [Cortland] has more police covering

a concentrated area, whereas the sheriff’s department may have one person covering a wide area,” said Milkowski. “City police are more likely to notice they’ve been to the same house ten times in a week and make a referral – but we see the issues all over. And many parts of the county don’t have cell coverage, so you can’t call for help if you see someone pulled over on the side of the road and don’t know what’s going on.”

Following its most recent Community Health Assessment, every rural CNY county made the data-driven, community-informed decision to prioritize the focus area of mental health and substance use. These are two large, complex topics that are distinct in many ways. Many people struggling with anxiety, depression, and other mental health issues do not drink or use drugs, just as people often have substance use disorder (SUD) alone. But the issues are related, and local agencies often see them go hand in hand.

## MENTAL HEALTH AND SUBSTANCE USE NEEDS HAVE WORSENERD IN RECENT YEARS

Rates of “deaths of despair,” defined as deaths due to suicide, drug overdose, and alcohol abuse, have been increasing among rural Americans since the early 2000s.<sup>69</sup> Since COVID, the national suicide rate reached a historic



high and the Surgeon General has been sounding the alarm about the impact of loneliness and isolation.<sup>70,71</sup> Locally, service providers see evidence of the problems all the time. “The issues that people are calling with are more complex than ever before,” said Julie Harney, Executive Director of Madison County Office for the Aging. “There are a lot of people struggling with anxiety and depression. When they call, they’re in distress.”

During the pandemic, when many people were cut off from activities outside the home, some already dysfunctional family dynamics deteriorated even further. Rural families are often private, self-reliant, and inclined to hold things together for a long time before they get bad enough to seek help, and some providers say that they are seeing the effects of problems that have been building for years and finally reached a breaking point.

## **MANY GROUPS ARE AT RISK, AND ACCESS TO TREATMENT VARIES**

People interviewed for this report talked about mental health and substance use issues in many groups including

youth, low-income people, single moms, people with disabilities, LGBTQ people, farmers, and isolated older adults. They noted the impacts of parents’ substance use on children, such as drug-addicted babies and child abuse or neglect, and many referenced data showing that these issues are more common in Oswego County than nearly everywhere else in NYS.<sup>72,73</sup> Several people talked about the increased risks for people working taxing physical jobs who experience injury and face barriers accessing medical care.

“There’s a pain-to-addiction pipeline,” said Julie Sorenson, Director of the New York Center for Agricultural Medicine and Health (NYCAMH). “These industries can lead to repetitive-use injuries in the agricultural community. Prescriptions for painkillers can then lead to addiction without careful monitoring by clinical staff.” NYCAMH staff offer outreach services to farms throughout rural NYS as well as health care screenings, but they often have trouble connecting people to follow-up care. Migrant farmworkers lack insurance, so they have few options when it comes to providers. The providers that do exist may not accept new patients, often lack translators, and are rarely accessible to those working long hours with few breaks and no car.

The many people in rural areas who are isolated, underpaid, and working long hours are at risk for depression and suicide as well. Stigma around mental health issues often makes people reluctant to seek treatment. Managing mental illness or substance use addiction is a difficult, long-term struggle that requires repeated visits to providers.

In rural CNY, counseling is usually available without a long wait, but it takes longer to meet with a psychiatrist. Access to treatment will always be more challenging for people who lack transportation or internet access, but local directors of community services in every county work hard to coordinate among providers and manage caseloads. In addition, local agencies and regional organizations such as Liberty Resources, Helio Health, and Crouse Health have worked to expand inpatient and outpatient treatment in recent years.

One workforce challenge is that patients – especially those without private health insurance – are often resigned to see many different providers during the course of treatment because there is so much turnover among the low-paid behavioral health workforce. The work of treating mental illness and addiction is highly complex and challenging, but low reimbursement rates make it hard to retain the many counselors, peer specialists, and social workers who do this essential work.

### **HIGHLIGHT:** **COLLABORATIONS IN CAYUGA COUNTY**

Addressing the region's behavioral health issues entails collaboration across many different partners. There are federal, state, and regional agency partners, and in each county the Department of Mental Health, law enforcement, health care providers, community-based organizations, and others coordinate a complex array of services. Together they troubleshoot, navigate the ever-changing regulations and funding streams, and work to ensure people get access to treatment when they need it.

One example of these partnerships is found in Cayuga County's work to address the high rates of substance use disorders among employees of Auburn Correctional Facility (ACF). These employees found it difficult to seek treatment at local agencies that also serve many people who were previously incarcerated. To address this barrier, agencies collaborated to create a program where corrections officers

and other ACF employees can receive treatment remotely and confidentially, rather than in-person.

"We're really quite proud in Cayuga County of the partnerships that we've created here with all our agencies working together to serve our populations," said Caroline Dixon, Executive Director of C.H.A.D (Confidential Help for Alcohol & Drugs), an agency that provides a wide range of substance use prevention services in Cayuga County.

Like most rural areas, Cayuga County has been hit hard by the opioid epidemic, so many collaborations have emerged specifically to reduce opioid overdoses. Based on high need, Cayuga County was selected for the national HEALing Communities Study, and received federal grant money in 2020.<sup>74</sup> This funding allowed them to create a dashboard to better understand where opioid overdoses are happening and implement initiatives that resulted in a 22 percent reduction in overdoses and 94 lives saved through Narcan in 2021. Funding for HEALing Cayuga ended in June 2022, but local partners continue the hard work they started.

To people in recovery from opioid use disorder (OUD), staying sober is a daily battle. Evidence shows that methadone treatment is an effective way to reduce opioid use, but until recently, this treatment wasn't available in Cayuga County. People had to travel to Syracuse, Rochester, or some other county to get methadone treatment, and the drive added another barrier to continuing treatment – especially for people who rely on Medicaid cabs or rides from family.

Recognizing this gap, in 2021 Dixon and Kevin Hares, the previous Executive Director of C.H.A.D., began

### **DATA SNAPSHOT: BEHAVIORAL HEALTH**

- For many years, Oswego County has had one of the highest rates of drug-addicted babies in New York State. In 2020, its rate was 5 times higher than the NYS rate. Cortland County's rate was nearly as high, and the 3rd highest rate in NYS.<sup>75</sup>
- In rural CNY counties it is estimated 18-20% of adults engage in binge drinking.<sup>76</sup>

conversations with the late Eric Bresee, Executive Director of Farnham Family Services, about the possibility of creating an opioid treatment program in Auburn. Farnham is Oswego County's only treatment provider funded by the NYS Office of Addiction Services and Supports (OASAS) and it operates a growing number of clinics with methadone throughout Oswego County. The agency had experience managing all the compliance issues that running these clinics entails and was willing to open a clinic in Cayuga County. However, OASAS regulations were a hurdle to overcome, because they would not have allowed patients to receive methadone from one provider and substance use counseling at another.

"The rules didn't allow for patient choice," said Dixon. The regulations also would have placed the small agencies like C.H.A.D. that provide treatment services at risk of losing their patients – and the associated reimbursement – if those patients received methadone from another provider, because they would have been considered dually enrolled. Fortunately for patients, OASAS changed the rules and in September 2023 Farnham's new Opioid Treatment Program opened in Auburn. Thanks to these efforts, people in Cayuga County with OUD now have a local option for methadone treatment.

A big issue Cayuga County is facing right now is homelessness. There is a shortage of affordable housing in rural areas of NYS that has worsened in recent years, and it's especially challenging to house the many people coming out of inpatient treatment or jail. In towns and villages with a limited number of apartments, people may emerge from treatment only to find that they've burned a bridge with the only landlords in town. To respond to the need, Cayuga County agencies have created and expanded supportive housing programs, and a few years ago Cayuga Community Health Network (CCHN) created a Street Outreach Program which has helped over 100 individuals and families so far.

"Helping people doesn't just mean finding a homeless person housing," said Shari Weiss, PhD, Executive

Director of CCHN. "It means helping people with food security, transportation, primary health care, behavioral health care, and connection to all the services and supports they need." The work is resource-intensive and involves case management and providing supportive referrals to providers offering mental health and drug and alcohol treatment. Hopefully, continued collaboration and changes in the regulatory environment that silos mental health and substance use treatment providers will keep more people in the community, safely housed and able to achieve long-term recovery.

## SELF-HARM AND SUICIDE ARE ISSUES ACROSS RURAL CNY

A 2023 report found that rural New York had a suicide rate over twice as high as that in the state's cities and urban areas.<sup>77</sup> The disparity in rural areas is attributed to many factors, including social isolation, barriers accessing mental health services, and high gun ownership. Although the most recent data available for all four counties (from 2019) show that rural





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**Suicide Prevention Coalition work varies throughout the region, but partners in multiple counties spoke of one common challenge: more funding is needed to support this vital work.**

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CNY's suicide death rates are not as high as those in some of the more rural counties of NYS, the region does have some of the highest rates in the state for hospitalizations due to self-harm.<sup>78</sup> "Self-harm" statistics include people who intentionally overdose on drugs, but also those who cut themselves or try to harm themselves in other ways. Recent assessments from local health departments indicate that the situation has worsened since then.

*For example:*

- In Madison County, the hospitalization rate for self-harm and attempted suicide nearly doubled between 2018 and 2021.<sup>79</sup>
- In Cortland, there were 59 emergency department (ED) visits due to self-harm in 2019, but a more recent report showed that this number increased from 210 visits in 2021 to 252 visits in 2022.<sup>80, 81</sup> The report also notes that Cortland County had the worst rate for ED visits due to self-harm when compared to seven neighboring counties.

In an *Auburn Citizen* article from 2023, Dr. Adam Duckett, the Cayuga County Coroner, said that suicide and addressing the mental health issues that lead to it, are his biggest concerns as a primary care physician.<sup>82</sup> Unfortunately, Cayuga County is the only county in rural CNY without an active coalition of partners working on suicide prevention. In Cortland, Madison, and Oswego counties, staff from local government, behavioral health care providers, law enforcement, schools, and many other agencies collaborate so they can share resources, educate

the community, and implement evidence-based prevention strategies to prevent suicide.

"Suicide, suicidal ideation, and self-harm remain public health crises in Madison County," said

Maureen Campanie, Executive Director of BRiDGES, the community-based organization that facilitates the Suicide Prevention Coalition of Madison County. Campanie shared that their coalition "continues to provide a forum for local organizations and community members to work together to identify gaps in resources, and implement strategies to reduce suicide, increase social connectedness of Madison County residents, and create an environment which provides support for those impacted by suicide loss, risk, or self-harm."

## **HELP IS AVAILABLE THROUGH THE 988 SUICIDE & CRISIS LIFELINE**

In rural CNY, people in crisis who call for help often find themselves on the phone with someone at Contact Community Services (CCS). CCS is a non-profit based in Syracuse that operated the National Suicide Prevention Lifeline and a local hotline for decades. In recent years, the Lifeline went through a transition and became part of the 988 Suicide & Crisis Lifeline – a new national service that allows people to connect to help by dialing three digits (9-8-8) from anywhere in the United States. Text/chat services and specialized services for LGBTQI+ youth and young adults are also available.

CCS currently answers calls from throughout the region and coordinates with other organizations to seamlessly take calls from other regions of the state when their call centers are busy. Between January and mid-November 2023, CCS had

received 864 calls to 988 from people in rural CNY.<sup>83</sup> This number underestimates the true number of calls because some calls from Cayuga County are routed first to the crisis center based at Goodwill of the Finger Lakes, and some calls from Cortland, Madison, and Oswego counties may be answered by other centers if CCS is busy. The Lifeline is available 24 hours a day, 7 days a week, and has translation services, making it an important resource for anyone needing to connect with a crisis counselor.

## TELEHEALTH HAS INCREASED ACCESS TO CARE

If you seek treatment locally in rural areas, you're likely to run into someone who knows you or your family. Some people may drive out of town to visit providers, but this isn't an option for people without cars or living on tight budgets. For many, the easing of regulations during the COVID-19 pandemic enabled them to access therapists, substance use counselors, and other mental health service providers via telehealth for the first time.

To make telehealth more available to people without good broadband access or a private place in their home, the CNY Health Task Force of Statewide Senior Action Council helped to set up Community Telehealth Access sites throughout the region. Their website lists 35 sites in rural CNY counties; 31 are at libraries, but they are also at community organizations such as Access to Independence of Cortland County and Oswego County Opportunities.<sup>84</sup>

Telehealth expansion has made a big difference for the many low-income people in rural communities struggling with mental health and disability. Prior to the pandemic, regulations required people to meet with a provider in-person every 30 days in order to get a script for controlled medications to treat their mental health issues. This presented a significant challenge because it required people to have the organizational skills and flexibility to arrange one's work schedule, transportation, childcare, and other caregiving needs to accommodate the limited availability of health care providers. People who were struggling and had reached the point where they knew they needed treatment spent years on wait lists before the easing of rules allowed them to meet with providers remotely.

The end of the federal public health emergency in 2023 brought new concerns about rollbacks and changes

to telehealth expansion. Due to concerns about potential abuse and misuse of certain drugs prescribed by telehealth, the federal government proposed implementing rules that would require people to meet with providers in-person before getting prescribed medications. There was immediate pushback from providers who feared their patients – especially those in rural areas – would lose access to medications, and the telemedicine flexibilities have been extended into 2024.<sup>85</sup> However, the battles over policies that support telehealth access are ongoing and have many fronts.

One issue of concern for FQHCs in NYS is a policy that reduced reimbursement rates for behavioral health visits that happen via telehealth, effective May 2023.<sup>86</sup> "I can't think about expanding psychiatry, even though the need is there," said Tricia Peter-Clark of ConnexCare. "The reimbursement doesn't support the costs I have to pay for a psychiatric nurse practitioner, and I don't have space in the health center if visits need to be in person." The Community Health Care Association of New York State, an organization representing CHCs throughout NYS, is leading the charge for "full reimbursement parity" so that health centers that serve the most vulnerable New Yorkers will continue to have access to behavioral health care.

### HIGHLIGHT: ADDRESSING DISPARITIES IN CORTLAND COUNTY

Among rural CNY counties, Cortland County is unique in how it collects and shares data about populations experiencing disparities. For its 2022 Community Health Assessment (CHA) survey, the Cortland County Health Department and its local partners were intentional about collecting data on demographic factors such as sexual orientation and gender identity, and then disaggregating survey results to show differences in responses for various groups. In addition to sharing their data in the county's CHA report, they published a dashboard which allows users to explore the data on their own.<sup>87</sup> The data reveal many disparities – especially for the LGBTQ+ population (see chart on page 27). For example, 21 percent of Cortland County residents identifying as LGBTQ+ reported that they had attempted suicide – a rate much higher than that among straight residents (5 percent).

The disparity among Cortland County's transgender residents was even more extreme. Three out of four

## Data show mental health disparities for the LGBTQ+ population

A Cortland County survey found higher rates of poor well-being, suicidal ideation, and suicide attempts among people identifying as LGBTQ+ compared to those identifying as Straight.



**Source:** Cortland County Health Department, Community Health Assessment Survey Results 2022

*Data on transgender individuals is not reflected in this chart.*

transgender residents reported that they experience poor well-being, 67 percent reported suicidal ideation, and 50 percent had attempted suicide. Although we do not yet have data on the LGBTQ+ population in other rural CNY counties, they very likely have the same disparities. National studies consistently show that the LGBTQ+ population experiences worse mental health outcomes and has higher rates of substance use as well.<sup>88, 89</sup>

“None of these data were surprising because we had been looking at these priorities and focus areas for a while,” said Margaret Broderick, Epidemiology Manager at the Cortland County Health Department. “Cortland was very lucky to have a strong data set in the community which had shown disparities for the youth LGBTQ population for several years. Our Community Health Assessment was able to add a second data source showing the same trend among adults.” Broderick is referring to the Youth Development Survey, which Cortland Area Communities That Care (CACTC) has administered in every school in Cortland County for over 20 years.

“We intentionally added many demographic questions so we can identify disparities among youth and make sure our strategies are targeted to addressing the greatest need,” said Matthew Whitman, Executive Director of CACTC. “We have also added questions like the ACES scale, to learn how

many students experience Adverse Childhood Experiences, and questions about sleep habits and loneliness, so we can create data sets that otherwise don’t exist.”

CACTC’s approach has succeeded both in shining a light on disparities and in helping local agencies find funding to address local needs. Cortland County now has local initiatives to address mental health among LGBTQ youth and substance use among people with disabilities.

“When local surveys finally asked the question, it turned out that people in Cortland who identify as having a disability are using substances at a higher rate and have more serious impacts of alcohol use,” said Milkowski. Through a new initiative, ATI and CACTC are collaborating to focus their prevention efforts on addressing this problem.

Going forward, CACTC is interested in using its expertise in data collection to help other organizations in rural communities. In 2023 they announced their intention to formally adopt the Public Health Institute model, joining a national network of organizations who support community partners by building capacity in many ways, including through better use of data and epidemiology. Renaming the organization as the Rural Health Institute, they aim to be a resource throughout the largely rural Upstate New York region.

## CNY RURAL HEALTH ISSUE:

# Home Care

In every rural CNY county, people spoke of challenges related to home care. The systems for providing care to the many older adults, people with disabilities, and others who have serious, long-term health issues who prefer or need that care at home have never functioned well for everyone. But now, as the first Baby Boomers reach their late 70s and the number of people needing care grows exponentially every year, we're seeing increasing numbers of people who can't get the care they need.

"Home care" is a broad term that can encompass a wide range of services provided in the home, medical and non-medical. Some people need assistance with activities of daily living (e.g., bathing, dressing, cleaning, eating), while others may need specialized health care (e.g., post-acute care after surgery, physical therapy, dementia-specific care). Some home care recipients may only require occasional visits, while others need 24/7 in-home support. Most home care recipients are older adults (age 65+), but people can need care at any age due to a medical condition or disability – and they often need it for the long term.

Most people prefer to live in their homes rather than in institutions or skilled nursing facilities, and home care makes this possible. In rural communities where most people live far away from health care providers and transportation is often a challenge, home care saves people many long, onerous trips. Home care is also less costly, and it allows people to live with more independence and privacy than is possible in congregate settings.

Home care has long been recognized as critical to ensuring people can age in place, and the exponential growth in need has been anticipated for decades. Yet we have collectively failed to build systems and a workforce that can meet that need for people with limited resources.

## FAMILY CAREGIVERS ARE PROVIDING MUCH OF THE CARE

It's hard to know exactly how many people could use home care, because so many people rely on family caregivers rather than a home care aide or other providers whose services might be covered partly or fully by insurance. It is estimated that unpaid caregivers – most of whom are female family members or friends – provide about 80 percent of home care for people needing long-term care services in the U.S.<sup>90</sup> A 2023 AARP survey of NYS voters age 40+ found that women are twice as likely as men to be caregivers, and "at least seven in ten of the women caregivers perform medical or nursing tasks and manage medications and finances."<sup>91</sup> Many survey respondents indicated that caretaking impacted their ability to maintain paid employment, and most indicated that they could use more financial assistance from NYS.

Brenda Wiemann, Director of Cayuga County Office for the Aging, says their office gets many calls from people who've been doing the work a long time and reach a point where they can't manage it any longer. "It's really tough," said Wiemann. "It's hard for people to find aides and to coordinate care. A lot of times when people call, they're feeling desperate. They have tried to get hospice to come in, but they're told they need to have aides. It tends to be very near the end, when people are in crisis, and somehow they



get by until the end without really having what they need.”

Informal caregivers are the norm, in part because people know that they can't afford care or fear that the costs of long-term care could bankrupt them. These fears are not unfounded. A recent report found that 9 percent of people who need long-term care died broke compared to 2 percent of people who did not need long-term care.<sup>92</sup> Among people who had paid help, 18 percent depleted their savings.

Some people in rural CNY rely on informal caregivers because they are reluctant to enroll in Medicaid, which is the main payer for long-term care. People worry that their families will lose their home after they die, which is possible if they own a house and have not done estate planning. Many people interviewed spoke about how families choose to avoid enrolling in government insurance programs and manage

on their own, despite the many difficulties this entails.

Across NYS, it is estimated that 4.1 million people are caregivers, providing unpaid care to family members, friends, or neighbors.<sup>93</sup> This includes more than 1 in 4 adult children, most of whom are in their 60s or 70s, who are caring for their parents. This caregiving takes its toll physically, emotionally, and financially, often impacting people's ability to work, earn, and save for retirement.

There are respite programs to ease the burden on caregivers, but these services are often unavailable due to homecare workforce issues. For example, the Alzheimer's Association offers free respite services to caregivers throughout CNY, but the county Offices for the Aging that administer the program find the shortage of home health aides to be a barrier to connecting people with respite

## Population of Older Adults in Rural CNY Counties (2020)<sup>94</sup>

### Adults Aged 65+ in Rural CNY

AGE GROUP	Cayuga	Cortland	Madison	Oswego	Rural CNY
65-69	5,069	2,587	4,591	6,923	19,170
70-74	4,081	2,160	3,544	5,452	15,237
75-79	2,656	1,445	2,527	3,609	10,237
80-84	1,775	955	1,602	2,209	6,541
85+	2,019	997	1,538	2,166	6,720
<b>TOTAL (65+)</b>	<b>15,600</b>	<b>8,144</b>	<b>13,802</b>	<b>20,359</b>	<b>57,905</b>

Source: U.S. Census Bureau (2020 Decennial Census)

services. Jessica DesRosiers, Senior Director of Programs and Services of the CNY Chapter of the Alzheimer’s Association, said, “the funding is available, but the staffing shortages make it impossible to deliver the services.”

A 2018 report from AARP NY described family caregivers as “the backbone of New York’s long-term care system.”<sup>95</sup> It detailed the many challenges this unofficial workforce faces, such as the stress of coordinating care for loved ones, financial strains, and the lack of respite. The report warned that demographic changes are not only increasing the number of people who need care, but they are reducing the numbers of potential family caregivers. Many people in rural CNY do not have adult children or a support

network living nearby, so they often rely on the “formal” home care workforce.

### WHEN INFORMAL CAREGIVERS ARE UNAVAILABLE, PEOPLE TURN TO HOME CARE PROGRAMS

It can be confusing for people to understand how to get the care they need. NY Connects, a program that is available through each rural CNY county’s Office for the Aging and Independent Living Center, provides a much-needed service by helping people navigate home care options. For example, people with Medicaid may find home care through one of three different Medicaid programs:<sup>96</sup>

- Managed Long Term Care Program
- Consumer Directed Personal Assistance
- Community First Choice Option

Each program covers different services, has different eligibility criteria, and will lead to more choices about specific providers. People enrolled in both Medicaid and Medicare may suspect that they are eligible for the Program of All-Inclusive Care for the Elderly (PACE) offered through PACE CNY, but this program, which provides comprehensive services to help people age in place, is only available to Onondaga County residents – not people living in rural CNY.<sup>97</sup>

There are also statewide programs administered by the



NYS Office for the Aging (NYSOFA) that cover non-medical in-home services. For example, rural CNYers may be eligible for the following programs:

- **Expanded In-Home Services for the Elderly (EISEP)** – a program for older adults who are ineligible for Medicaid
- **Community Services for the Elderly (CSE)** – a program for frail, low-income older adults

These programs are carried out through county-based Area Agencies on Aging (AAAs), otherwise known as Offices for Aging, and support older adults by providing services such as home-delivered meals, personal care, and respite. According to a 2023 report from NYSOFA, the average person assessed for services is in their 80s and has multiple chronic conditions.<sup>98</sup>

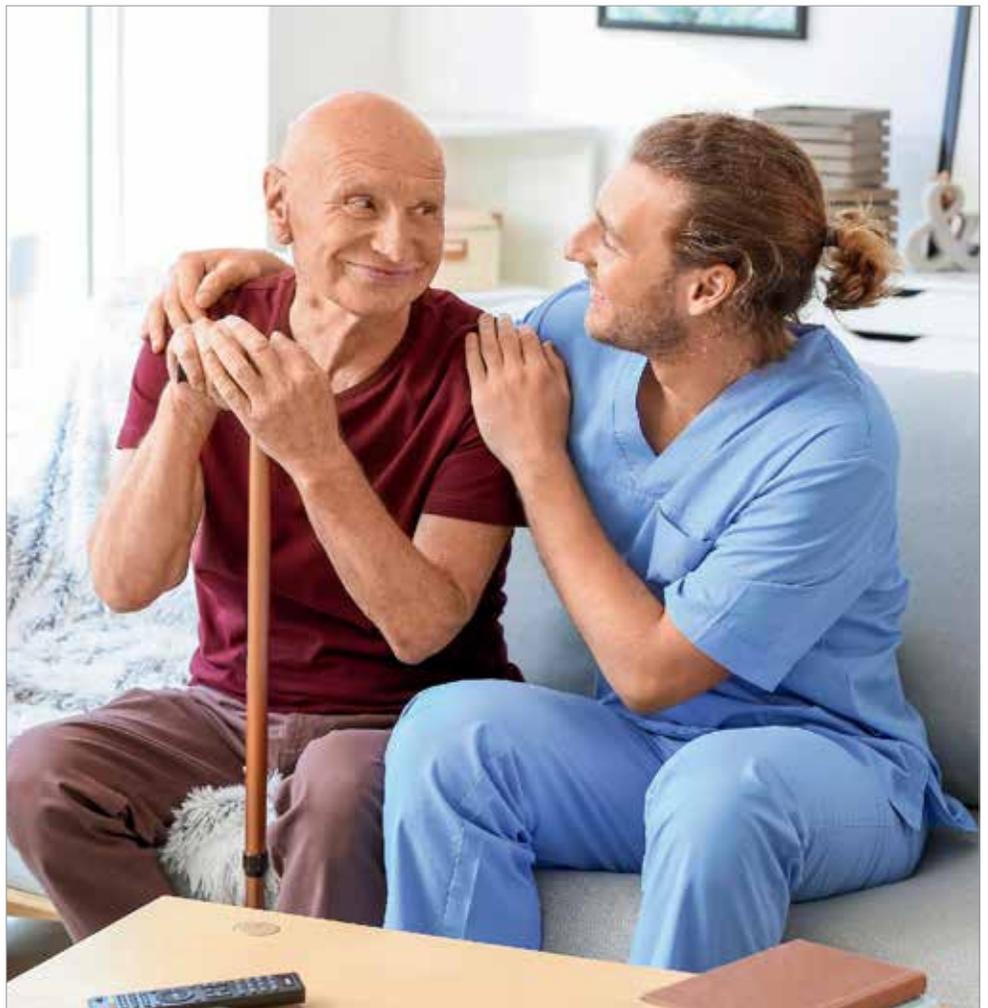
EISEP and CSE are not able to provide services to everyone who needs them, so many older adults end up on waiting lists. NYSOFA analyzed data and found that people waiting for services had many unwanted and costly outcomes, including ER visits, hospitalizations, placement in skilled nursing facilities. To alleviate the problem, many AAAs receive “unmet need” funding. However, AAAs often have a hard time spending their full allocation due to the difficulty finding home care workers to provide the services.

## THE HOME CARE WORKFORCE NEEDS HELP

Even for people with money and willingness to pay, it can be very hard to find a home care aide in rural CNY. There is no local data on the scale of the problem, but the 2022 State of the Industry report from the Home Care Association of NYS found that on average, 31 percent of personal care aide positions and 25 percent of RN positions at home care agencies were unfilled across NY State.<sup>99</sup> The same report presented data

showing that the home care workforce was providing care for nearly 15,000 patients in rural CNY in 2018 (the most recent year for which data were available). Of these patients, over 13,000 received care through Certified Home Health Agencies (CHHA), about 1,400 were served through Licensed Home Care Service Providers (LHCSP), and less than 450 received hospice care.

Access to home care professionals varies throughout the region, based in part on the availability of staff and the capacity of local agencies. For example, in 2018 there were over 13 times more people receiving hospice care in Cortland County than Cayuga County, even though its population is smaller. The difference may be due to fact that 2018 was the year Cayuga County’s Hospice of the Finger Lakes merged with Hospice of Central New York, an agency based just north of Syracuse that now serves Cayuga, Madison, Onondaga, and Oswego counties. Hospice nurses may now need to travel an hour to reach the most remote parts of the region, such as those in the southern part of Cayuga County.





**Even for people with money and willingness to pay, it can be very hard to find a home care aide in rural CNY.**

Many people noted that it's hard to find home care aides and nurses in rural counties because the work is so underpaid and people earn more in cities. Some towns in rural CNY are "bedroom communities," where many people travel to work for agencies based in Syracuse, Utica, or Ithaca if they can get a slightly higher hourly rate or better benefits. Jeanette Zoeckler, PhD, former Director of the Occupational Health Clinical Center based in Syracuse, talked about the difficulty of home care work.

"Home health aides are often working in really dangerous settings," said Zoeckler, who studied issues in this workforce. "They drive all over the place and enter homes that can be very uncontrolled environments. There could be many exposures: dogs that bite; unstable, stressed-out family members, some of whom have substance use issues; environmental hazards like asthmagens; sharps in the beds (such as auto-injectors, needles, syringes, infusion sets, and lancets or fingersticks). They frequently find themselves transferring people – feeding, toileting, and bedding people – in unsafe environments that cannot be regulated in the same way as other workplaces."

Even worse, home care aides are undervalued and not respected as professionals within the care team. For many socially isolated people who are in pain, these workers are meeting essential physical and emotional needs.

Yet despite the critical need to elevate and expand this workforce, which is disproportionately women and people of color, people who provide home care are chronically underpaid. In 2023 NYS successfully passed a budget that included a minimum wage increase for home care workers, but it does not seem to have impacted the workforce shortage in rural CNY counties.

Hundreds of organizations around NYS are engaged in campaigns and initiatives to address the urgent need to address home care and related health care workforce issues. ATI of Cortland County and ARISE, the Independent Living Center for Cayuga, Oswego, Onondaga, and Madison counties, are two of 100+ organizations from around NYS participating in NY Caring Majority – a coalition of seniors, people with disabilities, family caregivers, and domestic and home care workers who are campaigning for better pay for home care and passage of the NY Health Act. The NY Health Act would create a single-payer system that includes coverage of long-term care for everyone.<sup>100</sup>

Fixing home care will help keep the many people who want to stay in their homes out of the hospitals, nursing homes, and other costly institutional settings. As NYS continues work to develop its first Master Plan for Aging, many hope that the needs of both caregivers and care recipients in rural communities will be addressed.

### **HIGHLIGHT:** **STRATEGIES FOR ADDRESSING HOME CARE WORKFORCE SHORTAGES**

Agencies across NYS are experimenting with many strategies to improve the availability of home care. For example, in 2022 Tompkins County Office for the Aging decided to address the workforce shortage by directly offering a Personal Home Care Aide, rather than contracting out.<sup>101</sup> This decision allowed them to regularly serve 15-20 people who needed services in order to continue living independently in their homes that year. They continued the program in 2023, and their success in meeting the needs of people on their waiting list, including those with complex needs, has led them to propose hiring an additional personal home care aide in 2024. According to the NYS Office for the Aging, Tompkins County is now one of 10 NYS counties in which the AAA is directly hiring home care aides to address local need.

The Preliminary Report of the NYS Master Plan for Aging (MPA) lists “increase the opportunities for AAAs to hire personal care aides directly” as one of many potential solutions to the home care workforce needs.<sup>102</sup> Other strategies include better supporting working caregivers and informal caregivers. The MPA also lists strategies that focus on increasing the status of home care workers, such as by incorporating non-medical workers into multidisciplinary care teams and helping people obtain multiple certifications (e.g., Home Health Aide, Certified Nursing Assistant). This last strategy is one that may be advanced in rural CNY through the HealthCARES initiative – a project in which 11 SUNY community colleges, including Cayuga



Community College, are working together to strengthen pathways to health care and social assistance careers to help address NY’s workforce shortages in this sector.<sup>103</sup>

In the short term, given the scarcity of the home care providers available in rural areas, many people believe that the Consumer Directed Personal Assistance Program (CDPAP) is the best option for people in need.<sup>104</sup> CDPAP allows the person receiving care to choose their caregiver, which can allow them to recruit and pay family, friends, or other adults to provide home care services. In this model the burden of responsibility for supervising and managing the caregiver shifts to the care recipient (the “consumer”), rather than an external agency, which gives the recipient more flexibility in directing their care.

In rural CNY, CDPAP is available through regional agencies such as AccessCNY and ARISE, county agencies such as

Cortland County Community Action Program (CAPCO), and private firms. For example, Elite Home Health Care (HHC) is one of the NYS-designated “fiscal intermediaries” that help people throughout NYS connect with CDPAP. Elite HHC works to recruit home care workers who live near care recipients, since so much of the potential workforce lacks access to transportation.

Shelley Skellington, a Community Outreach Representative based in Elite HHC’s Syracuse office, said, “Transportation is a barrier. We recruit personal assistants from Lacona and Pulaski to serve clients in those communities. Some people are able to walk to work.” Skellington also uses social media to find people who may be looking for part-time, flexible work in the rural areas of CNY where people need care.

At least some of the people who become paid caregivers are likely to be those who are already doing caregiving work as family caregivers. Recognizing that the vast majority of home care is currently provided by unpaid caregivers who could use more support, initiatives such as the AmeriCorps Senior Demonstration Program (ASDP) focus on recruiting more people to provide respite. ASDP, led by the NYS Caregiving & Respite Coalition (NYSCRC) and funded in part by the Health Foundation for Western & Central New York, works to identify, train, and place adult volunteers in respite positions throughout a rural 6-county region that includes Cortland County.<sup>105</sup> The program offers stipends to income-eligible volunteers, to financially support people who need it. However, it also aims to encourage and support the volunteers in finding employment as a paid respite provider, to help address the need over the long term.

Given the large and growing need, the many ongoing statewide and local efforts to recruit, bolster, and maintain a high-quality home care workforce are more important than ever.

## DATA SNAPSHOT: HOME CARE

- 65% of people who receive long-term care receive care in their home. On average, the home care lasts for two years.<sup>106</sup>
- Nearly 15,000 people in rural CNY received home care in 2018.<sup>107</sup>

# Conclusion

Community-based organizations, health care providers, county governments, schools, and many other partners are doing important work to address health issues, but systemic inequities continue to create barriers to good health outcomes.

**Funding for rural health has not kept pace with inflation. Many agencies have had their budgets cut or been flat-funded for years.**

For example, Rural Health Networks have seen their funding slashed by 50 percent since 2016. Until 2024, the New York Center for Agricultural Medicine and Health had gone 14 years without a funding increase.

**When funding is provided for agencies to serve the central New York region, it often goes to an organization that does not have an office or staff based in rural CNY.**

For example, the CNY Area Health Education Center, which formerly had an office in Cortland, now has all staff based in Syracuse. Even with the best of intentions, regional funding can result in rural counties struggling to access funds.

**Many funding streams make it hard for rural communities to qualify.** Sometimes RFAs include language that systematically disadvantages rural areas, such as requirements to locate programs nearby public transportation, which often does not exist in rural towns. Funders sometimes create rubrics that prioritize applications based on how many people will be served.



**Rural counties have fewer funding options and often receive smaller awards.** Relative to more populated areas, rural CNY counties have fewer local foundations, large companies, and potential donors to approach. Agencies that rely mostly or fully on government funding frequently find that they are only eligible for small awards due to their county's population. This is frustrating to the many interviewees who noted that it often requires more funding, not less, to adequately serve people who are spread out across large geographic areas.

**Low reimbursement rates for safety-net providers limit their ability to hire more providers and expand access to care.** Family Health Network of CNY, an FQHC with locations in Cayuga, Cortland, and Madison counties,

notes on its website that Medicaid reimbursement rates for Community Health Centers (CHC) in NYS have not changed in 24 years and only cover 70 percent of the costs of providing services.<sup>108</sup>

For all these reasons, agencies are challenged to address the many health and social needs in rural CNY. Better funding for rural health could help advance the many promising strategies that will help the region thrive.

## THE FUTURE OF RURAL HEALTH

Disparities in rural health often mirror the systemic barriers that lead to poor outcomes in urban areas. By addressing these issues head-on, we can create a ripple effect that improves health equity for all.

There are many areas of opportunity in progress that can have a positive impact on rural central New York. For example:

**Digital Equity plans** – NYS’s ConnectALL Office is actively working to expand access to broadband internet in areas where it is lacking;

**2-1-1 infrastructure** – all rural CNY counties have an information and referral system that, with investment, has the potential to do more to connect people to health and social resources; and

**NY’s 1115 Waiver** – the Centers for Medicare & Medicaid Services (CMS) recently approved NYS’s request to implement a program that could help address health care workforce shortages and create successful regional systems for connecting people with Medicaid insurance to social care.

We look forward to continuing to collaborate on opportunities to improve the health of people in all communities we serve.

## LEARN MORE ABOUT TRANSFORM RURAL HEALTH

This report is part of the Health Foundation’s Transform Rural Health campaign, launched in 2022 to raise awareness and influence change in the systems that contribute to rural health outcomes.

The Health Foundation created Transform Rural Health to uplift the voices and stories of the people who live in, work in, and serve the rural communities of western and central New York.

At the heart of this campaign is the belief that every person, regardless of where they live, deserves access to the resources and support necessary to achieve good health.

Scan the QR code with your phone to visit the Transform Rural Health’s webpage and read firsthand stories of rural health.



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*\* It was with deep sadness that we learned of the unexpected death of Eric Bresee, Executive Director of Farnham Family Services, during the writing of this report. Eric was one of the many people who cheerfully responded to a request to be interviewed and shared about issues facing Oswego County and the greater region. He had a career full of work aimed at improving the health of his community, and it is with gratitude that this report is dedicated to Eric.*

# Appendix A. Data Summary

## Data for Rural CNY Counties

POPULATION	Cayuga	Cortland	Madison	Oswego	Rural CNY
Population (2020)	76,029	47,173	70,478	116,346	<b>310,026</b>
Pop. Change (2010-2020)	-5%	-4%	-4%	-5%	<b>-5%</b>
Population (2010)	79,905	49,277	73,442	122,141	<b>324,765</b>
RACE AND ETHNICITY					
White*	87.0%	87.2%	89.6%	89.9%	<b>88.7%</b>
More Than One Race*	4.8%	4.7%	4.4%	4.4%	<b>4.5%</b>
Hispanic or Latino	3.5%	3.5%	2.5%	3.1%	<b>3.1%</b>
Black or African American*	3.6%	1.8%	1.6%	1.2%	<b>1.9%</b>
Asian*	0.5%	2.2%	1.0%	0.7%	<b>0.9%</b>
Amer. Indian/Alaska Nat.*	0.3%	0.2%	0.6%	0.4%	<b>0.4%</b>
Some Other Race*	0.3%	0.4%	0.3%	0.3%	<b>0.3%</b>
Nat. Hawaiian/Pac. Islndr.*	0.1%	0.0%	0.0%	0.0%	<b>0.0%</b>
* Non-Hispanic					
SELECT CHARACTERISTICS					
Civilian veterans	8.0%	6.9%	7.7%	9.2%	<b>8.2%</b>
Foreign born	2.1%	2.6%	2.5%	2.0%	<b>2.2%</b>
With a disability	14.6%	13.1%	12.5%	14.7%	<b>13.9%</b>

Sources: U.S. Census Bureau (2020 Decennial Census and 2021 ACS 5Yr estimates)

## Data for Households in Rural CNY Counties

HOUSEHOLDS (HH)	Cayuga	Cortland	Madison	Oswego	Rural CNY
<b>Total Households</b>	30,604	18,260	24,779	46,749	<b>120,392</b>
<b>BELOW POVERTY OR ALICE</b>					
<b>Below Poverty (#)</b>	4,980	2,422	2,935	7,037	<b>17,374</b>
<b>Below Poverty (%)</b>	15.4%	13.3%	11.6%	15.0%	<b>14.1%</b>
<b>Below Poverty + ALICE (#)</b>	11,923	7,180	10,148	19,098	<b>48,349</b>
<b>Below Poverty + ALICE (%)</b>	36.8%	39.3%	40.1%	40.7%	<b>39.3%</b>
<b>SELECT CHARACTERISTICS</b>					
<b>No vehicle (%)</b>	9.8%	8.1%	6.0%	8.0%	<b>8.1%</b>
<b>No internet (%)</b>	16.8%	19.3%	15.3%	12.2%	<b>15.1%</b>

Source: U.S. Census Bureau (2021 ACS 5Yr estimates); United Way (2021)

## People receiving home care (HC) by provider type in Rural CNY counties

	Cayuga	Cortland	Madison	Oswego	Rural CNY
<b>Certified Home Health Agencies</b>	4,427	1,010	1,190	6,374	<b>13,001</b>
<b>Licensed HC Service Providers</b>	246	129	329	732	<b>1436</b>
<b>Hospice</b>	10	137	62	238	<b>447</b>
<b>TOTAL</b>	<b>4,683</b>	<b>1,276</b>	<b>1,581</b>	<b>7,344</b>	<b>14,884</b>

Sources: Home Care Association of NYS (State of the Industry 2022 report)

## Population of Adults with Independent Living Disabilities in Rural CNY Counties (2021)

### Adults with Independent Living Disabilities in Rural CNY<sup>109</sup>

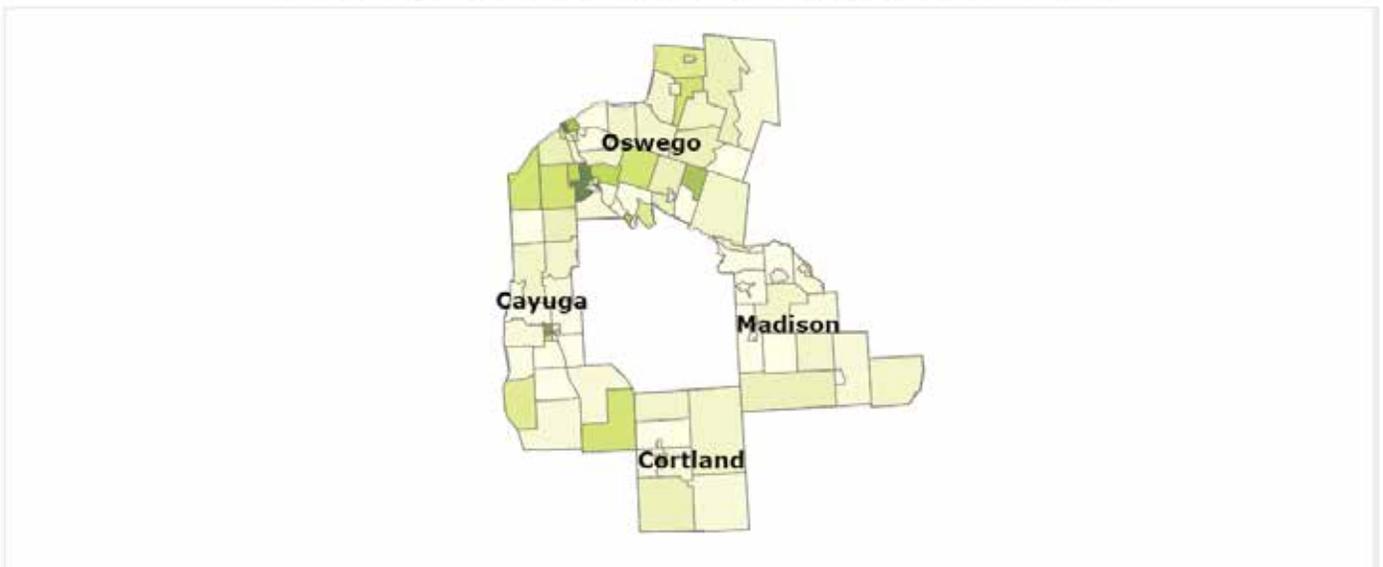
AGE GROUP	Cayuga	Cortland	Madison	Oswego	Rural CNY
18-64	1,623	1,151	2,188	3,318	8,280
65+	1,583	826	1,428	2,419	6,256
<b>TOTAL</b>	<b>3,206</b>	<b>1,977</b>	<b>3,616</b>	<b>5,737</b>	<b>14,536</b>

Source: U.S. Census Bureau (2021 ACS 5Y Estimates)

### Children living below poverty in Rural CNY<sup>110</sup>



Under 18 years Population in Poverty by Tract - 2021



As shown on the New York State Association for Rural Health (NYSARH) Diversity Dashboard

Based on the map above:

- In some Census Tracts, as many as 2 in 3 children live below the Federal Poverty Level
- The child poverty rates are highest in
  - the Town of Granby, just west of Fulton in Oswego County (67%)
  - parts of the City of Oswego (65%)
  - parts of Auburn (56-59%)
  - parts of Cortland (45%)
  - and other tracts throughout Oswego County

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Community  
Health Needs  
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in Rural Central  
New York

