

Reaching the Five Percent

A Profile of Western and Central New Yorkers Without Health Coverage

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April 2019







Based in Buffalo, NY with a second office in Syracuse, NY, the Health Foundation for Western & Central New York is an independent private foundation that serves 16 counties, including Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans and Wyoming counties in western New York, as well as Cayuga, Cortland, Herkimer, Madison, Oneida, Onondaga, Oswego and Tompkins counties in central New York.

Our vision is that older adults lead a dignified, independent, high-quality life in their community; all young children impacted by poverty are physically, socially and emotionally healthy as they enter kindergarten; and our communities are able to plan for and meet the health needs of the most vulnerable.

To achieve outcomes that last, we work together with our community partners to develop, implement and evaluate sustainable programs that make a positive difference in the lives of thousands of young children and older adults in our regions.



United Hospital Fund works to build a more effective health care system for every New Yorker. An independent, nonprofit organization, we analyze public policy to inform decision-makers, find common ground among diverse stakeholders, and develop and support innovative programs that improve the quality, accessibility, affordability, and experience of patient care.

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With the ninth anniversary of the passage of the Affordable Care Act just behind us, it is a pleasure to present a new issue brief, *Reaching the Five Percent*, a timely study of residents who still lack coverage (despite qualifying for financial assistance in some cases), and the reasons why. The report begins with a statistical analysis on coverage rates by age and income and concludes with a series of compelling real-life stories from the uninsured, or those who recently gained coverage, in four upstate communities.

Reaching the Five Percent is the first project in a new partnership between the Health Foundation for Western & Central New York and United Hospital Fund, about which we're very excited. For UHF, the collaboration allowed us to hear firsthand about the health care needs of upstate New Yorkers, to be educated by local experts, and to learn more about the insurance markets and institutions in diverse communities such as Gowanda and Syracuse. For the HFWCNY, the partnership gives us a chance to join forces with a leading nonprofit with similar priorities—children, older adults, and universal coverage—and to channel UHF's history of health services research and policy analysis.

Although our partnership is new, we are in complete agreement that though much progress has been made in expanding coverage in New York, much more remains to be done. Some of the voices captured here—representing the more than 1 million New Yorkers who still lack coverage—remind us that there are far too many New Yorkers who live each day with the uncertainty and worry that comes from lacking coverage, and the consequences to their health and well-being. We can do better.

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Acronyms

ACA Affordable Care Act, the landmark federal health reform legislation passed in 2010 and implemented beginning in 2014.

ACS American Community Survey, one of a number of annual, ongoing surveys performed by the United States Census Bureau on Americans' income, housing, health coverage, employment, and other areas.

APTCs Advanced Premium Tax Credits, the income-based, federal subsidy mechanism implemented as part of the ACA to reduce premium costs for individuals and families with household incomes of between 200% and 400% of the federal poverty level.

CHP Child Health Plus, New York's low-cost, comprehensive health insurance coverage program for children under the age of 19, which receives federal matching funds.

The Essential Plan, low-cost or no-cost comprehensive coverage for adults earning less than 200% of the federal poverty level, authorized by the ACA's Basic Health Program options for states.

ESI Employer-sponsored insurance for employees.

FPL Federal Poverty Level, a measure of income promulgated annually that is used to determine eligibility for financial assistance for health, nutrition, and other programs.

NYSOH New York State of Health, New York's ACA health benefit marketplace or "exchange," a one-stop shop for all public and private coverage.

QHP Qualified Health Plan, a benefit package, provider network, and premium developed by a health insurance company and approved for sale by the NYSOH marketplace through its certification process.

Executive Summary

The federal Affordable Care Act, enacted in 2010, provided New York with important new health coverage tools and resources that have helped the State reduce the uninsured rate by half from 2013 to 2017, to just 5.7%. Yet about 1.1 million New Yorkers still lack coverage, and many of them are eligible for free or low-cost coverage through public programs like Medicaid, Child Health Plus, and the Essential Plan—or for tax credits to reduce premiums and cost-sharing for the Qualified Health Plans available from New York State of Health, the State's health insurance marketplace. This category of uninsured is known as "eligible but uninsured," or EBU.

In this report, census data for 16 western and central New York counties—the service area for the Health Foundation for Western & Central New York, the sponsor of this project—were used to group the uninsured based by age and income categories corresponding to eligibility for financial help for coverage. In addition, discussion groups were conducted with residents of these regions to solicit their insights on barriers to coverage. Together, these two approaches shed light on several factors contributing to the numbers of eligible but uninsured, despite the progress New York has made:

- Many currently uninsured appear to be eligible for financial help for coverage, and the rate of insurance varies among counties for different income levels.
- Barriers to obtaining coverage include complexities in the health system generally, lack of knowledge about the availability of free enrollment assistance from trained counselors, and some lingering stigma about public programs.
- Enrollees in Medicaid, Child Health Plus, and the Essential Plan were very satisfied with those programs' affordability, benefits, and providers. For those seeking Qualified Health Plans from the Marketplace, however, even with tax credits and cost-sharing reductions, premiums were unaffordable for many, and deductibles unacceptable.
- Premiums and deductibles for Qualified Health Plans were incompatible
 with many consumers' sense of value—particularly in light of and compared
 to other household expenses—and many viewed paying premiums without
 receiving medical treatment to be a waste.
- Educational and outreach campaigns that reinforced the value of coverage, reduced the stigma associated with public programs, and alerted consumers to free enrollment assistance would help more western and central New Yorkers gain coverage.

Introduction

New York's successful implementation of the federal Affordable Care Act (ACA) reduced the number of uninsured by half from 2013 to 2017, to just 5.69%. Still, about 1.1 million New Yorkers lack coverage, which has policymakers focused on how best to reach the remaining uninsured, now known as "The Five Percent."

Policymakers are particularly focused on those eligible to enroll in public programs like Medicaid, the Essential Plan (EP), or Child Health Plus (CHP)—and those eligible to receive premium assistance for the qualified health plans (QHPs) available through New York State of Health (NYSOH), the state's ACA Marketplace. These individuals are known as the "eligible but uninsured."

This report examines the uninsured in 16 counties in western and central New York, reflecting the service area of the Health Foundation for Western & Central New York, which supported this project.² In Part I, an analysis from the most recent U.S. Census Bureau data available is used to construct statewide and county-level profiles highlighting those who may be eligible for financial help with coverage (based on age and income) but are uninsured, along with general information to facilitate comparisons. In Part II, stories from 36 participants in four recent discussion groups held in western and central New York are presented, organized by common themes and insights. This approach helped to put a human face on the uninsured and to dig deeper into the reasons central and western New Yorkers may lack coverage, through their own words.

Part I. The Numbers

This section presents estimates for New York State and 16 counties on total population, population living in poverty (below 100% of the federal poverty level or FPL, \$12,060 for an individual in 2017, and \$24,600 for a family of four), the uninsured rate, the uninsured rate for children, and the uninsured rate at various multiples of the FPL, which correspond to income eligibility for public programs. (See inset box.)

Though income is a strong indicator of potential eligibility, those whose incomes meet standards for public programs may still not be entitled to coverage or assistance, since citizenship status, household composition, and other factors can affect eligibility as well. Finally, data is also presented on the number of tax returns filed in 2016 that included ACA individual responsibility payments, required for those who did not purchase coverage deemed to be affordable.³

The estimates in this section for larger counties are derived from the U.S. Census Bureau's American Community Survey (ACS) one-year estimates for 2017, and estimates for counties with less than 65,000 residents are based on the ACS five-year estimates for 2013–2017.⁴ For each profile, a short narrative and a table highlight key findings, and a figure provides a graphic illustration of the uninsured by income level. This format facilitates county-to-state comparisons and comparisons between counties.

ncome Eligibility Re	
Medicaid	138% FPL, or \$16,040 for an individual/\$32,718 for a family of four
Essential Plan	200% FPL, or \$24,120 for an individual
Advanced Premium	Sliding scale: 201% to 400% FPL, or \$24,120 to \$48,240 for an individual, and \$49,200 to \$98,400
Tax Credits (APTCs)	for family of four (for QHPs purchased through the Marketplace)
CHP, for children	Free to families below 160% FPL, or \$40,160 for a family of four (with sliding-scale premiums
under age 19	ranging from \$9 per child at 160% FPL to \$60 per child at 400% FPL).
	Note that cost-sharing is not permitted for CHP enrollees at any income level, and coverage for
	children is also available through the Marketplace, with the same APTC schedule noted above.

New York State

About 14% of New York State's 19,338,000 residents lived in poverty in 2017. New York's uninsured rate stood at 5.69% in 2017; only seven states had appreciably lower rates.⁵ Just over 110,000 children lacked coverage (2.59%), better than all but seven other states.⁶ Almost two-thirds of New York's 1.1 million uninsured appeared to be income-eligible for either Medicaid or Marketplace subsidies. One recent study⁷ found that almost 640,000 of New York's uninsured in 2016 were eligible for premium tax credits (264,000) or Medicaid (374,000). One factor that can prevent low-income New Yorkers from enrolling in public programs is their citizenship status. While some noncitizens are eligible for public programs and Marketplace assistance because of their immigration status, many others lack the authorization to participate in public programs.⁸ About 309,500 uninsured noncitizens lived within New York City in 2017, out of a total of roughly 410,000 statewide.⁹

Category	Number	Percent	Uninsured by Income Category**
Population	19,321,141		
In poverty	2,722,257	14.08%	
Uninsured	1,098,446	5.69%	242,008, 334,017,
Uninsured less than age 19*	110,745	2.60%	22% 334,017,
Uninsured less than 138% FPL*	334,017	8.42%	
Uninsured 138-199% FPL*	165,903	8.88%	357,808, 165,903,
Uninsured 200-399% FPL*	357,808	4.44%	33% 15%
Uninsured more than 400% FPL*	242,008	2.85%	
ACA individual penalties paid	280,620		

^{*} Percentage uninsured within that age/income category.

Western New York

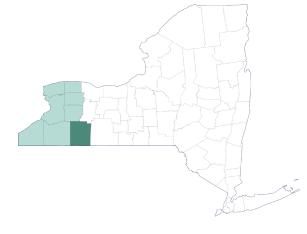
The eight counties that make up the western New York region are home to 1,479,230 residents, about 8% of New York's total population, with about 14% of residents there living at or below the federal poverty level. In the region, there were about 59,500 uninsured individuals, 4.03% of the total population in western New York. All but two counties had uninsured rates at or below the statewide average, but five counties had higher uninsured rates among children than the statewide average. In 2016, about 16,640

^{**}Percentage of all uninsured in state.

tax filings from western New York included individual responsibility payments required by the ACA for those not purchasing affordable coverage. One important group with a religious exemption from the individual responsibility provisions is the Amish community, which is large and growing in New York. According to one estimate, the Amish population in New York grew from 10,125 in 2009 to nearly 20,000 in 2018. Uninsured estimates in counties such as Allegany and Cattaraugus in western New York, and some counties in central New York, may reflect the presence of large Amish communities. Following are more detailed profiles of all the counties in the region. Smaller counties have headings in italics.

Allegany County

Three counties have higher poverty rates than Allegany County, the third smallest county in the region, but the county has the highest rate of uninsured (8.70%) of all western counties, with about 60% of its uninsured income-eligible for Medicaid or the EP. Almost 1,200 residents are uninsured but income-eligible for APTCs for QHPs as well. The county leads western New York in most categories, including the highest percentage of uninsured children—more than a third higher than



the next highest county, and over 25% of its total uninsured—and the highest percentage of residents who are income-eligible for Medicaid, the EP, and APTCs for coverage.

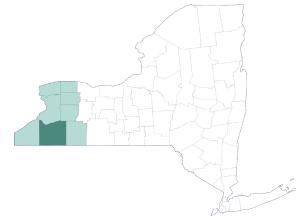
Category	Number	Percent	Uninsured by Income Category*
Population	42,351		101
In poverty	6,553	15.64%	191, 5%
Uninsured	3,683	8.70%	
Uninsured less than age 19*	1,074	10.96%	1,205,
Uninsured less than 138% FPL*	1,788	16.31%	33% 48%
Uninsured 138-199% FPL*	499	8.32%	100
Uninsured 200-399% FPL*	1,205	7.95%	499, 14%
Uninsured more than 400% FPL*	191	1.87%	
ACA individual penalties paid	560		

^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Cattaraugus County

Cattaraugus County has about the same percentage of residents living below the poverty level as Allegany, but its overall uninsured rate (5.43%) is much lower, about the same as the statewide average. As in Allegany County, almost two-thirds of uninsured residents were income-eligible for Medicaid or the EP, and another 25% would qualify for APTCs based on their incomes, but a much lower percentage of residents in these categories was uninsured. For example, about 11% of Cattarauguans earning less



than 138% of the FPL were uninsured, compared to 17% of Alleganians. Cattaraugus's rate of uninsured children (4.64%) was still higher than the statewide average, as just over 800 kids were uninsured.

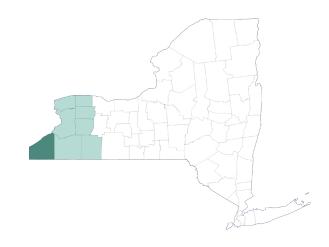
Category	Number	Percent	Uninsured by Income Category**
Population	74,743		
In poverty	11,757	15.70%	361,
Uninsured	4,055	5.43%	9%
Uninsured less than age 19*	815	4.64%	1,060,
Uninsured less than 138% FPL*	1,925	11.15%	26% 47%
Uninsured 138-199% FPL*	709	7.94%	
Uninsured 200-399% FPL*	1,060	3.87%	709, 18%
Uninsured more than 400% FPL*	361	1.71%	10 70
ACA individual penalties paid	1,040		

^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Chautauqua County

Chautauqua County is the poorest county in western New York, measured by the percentage of the county population living below the federal poverty level. Even so, the county's uninsured rate (4.56%) is lower than the state average. Many uninsured Chautauquans appear to be eligible for free or very low-cost health coverage through the Medicaid or the EP; nearly 75% of the currently uninsured meet income standards for these programs. Also, the uninsured rate for



children under age 19 (4.74%) is higher than the state average, leaving nearly 1,300 kids uninsured.

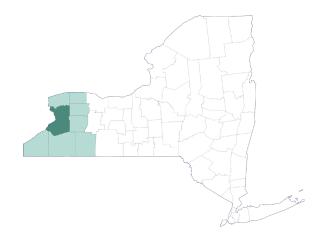
Category	Number	Percent	Uninsured by Income Category**
Population	123,442		
In poverty	21,866	17.71%	634,
Uninsured	5,629	4.56%	11%
Uninsured less than age 19*	1,295	4.74%	929, 16% 2 957
Uninsured less than 138% FPL*	2,957	8.92%	2,957, 53%
Uninsured 138-199% FPL*	1,109	6.73%	1,109,
Uninsured 200-399% FPL*	929	3.39%	20%
Uninsured more than 400% FPL*	634	1.81%	
ACA individual penalties paid	1,630		

^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Erie County

With nearly 900,000 residents, Erie is western New York's largest county; it encompasses Buffalo as well as rural areas in the southern portion of the county. Erie was at the median in terms of residents living under the federal poverty level, but it had the region's lowest uninsured rate (3.31%) and the lowest uninsured rate for children (1.92%), both below the statewide average. Although nearly half (47%) the county's uninsured were income-eligible for Medicaid or the EP, the programs reached all



but about 5% to 6% of those eligible by income, and the largest group of uninsured (37%) were income-eligible for APTCs through the Marketplace. Erie's rate of uninsured living above 400% FPL (1.31%) was the lowest in the region. A more diverse county than other counties in the region, Erie has an estimated 1,500 noncitizens who were uninsured. Black/African Americans made up about 22% of the uninsured, and Latinos about 6%.

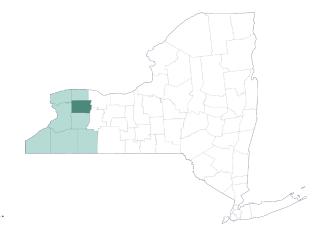
Category	Number	Percent	Uninsured by Income Category**
Population	897,954		
In poverty	131,546	14.64%	4,729,
Uninsured	29,749	3.31%	16% 9,241,
Uninsured less than age 19*	3,720	1.92%	31%
Uninsured less than 138% FPL*	9,241	5.04%	
Uninsured 138-199% FPL*	4,874	5.80%	10,905,
Uninsured 200-399% FPL*	10,905	4.06%	37% (4,074,
Uninsured more than 400% FPL*	4,729	1.31%	
ACA individual penalties paid	9,080		

^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Genesee County

Genesee, at about the median among western counties in terms of size, had the lowest percentage of residents living in poverty in the region (10.93%) and the second-lowest percentage of children under the age of 19 who were uninsured (1.93%), but the third-highest overall uninsured rate (5.10%). Twenty percent of its uninsured (over 2,900 in total) had incomes meeting the income eligibility standards for the EP; another one-third were eligible for Medicaid.



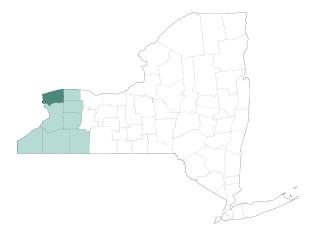
Category	Number	Percent	Uninsured by Income Category**
Population	57,705		
In poverty	6,248	10.93%	264, 9%
Uninsured	2,941	5.10%	970
Uninsured less than age 19*	241	1.93%	941,
Uninsured less than 138% FPL*	1,143	10.91%	32% 39%
Uninsured 138-199% FPL*	593	9.71%	
Uninsured 200-399% FPL*	941	4.44%	593, 20%
Uninsured more than 400% FPL*	264	1.32%	20%
ACA individual penalties paid	760		

^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Niagara County

Niagara, western New York's second-largest county, also had the second-lowest uninsured rate (4.46%) and a lower uninsured rate for children than all but two other counties. One of three uninsured were income-eligible for Medicaid, and about one out of four were income-eligible for APTCs for Marketplace coverage. Nearly a quarter of the uninsured (over 2,000 individuals) had incomes over 400% of the FPL, which made them likely ineligible for any type of assistance (including Marketplace APTCs), the highest rate in the region.



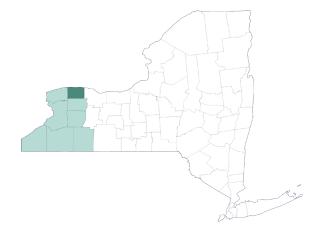
Category	Number	Percent	Uninsured by Income Category**
Population	207,387		
In poverty	25,144	12.12%	0.004
Uninsured	9,243	4.46%	2,094, 23% 3,002,
Uninsured less than age 19*	1,097	2.53%	32%
Uninsured less than 138% FPL*	3,002	8.17%	
Uninsured 138-199% FPL*	1,621	6.83%	2,526, 1,621,
Uninsured 200-399% FPL*	2,526	3.86%	27% 18%
Uninsured more than 400% FPL*	2,094	2.57%	
ACA individual penalties paid	2,510		

^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Orleans County

Orleans, western New York's second-poorest and second-smallest county, had both the second-highest overall uninsured rate (6.45%) and the second-highest uninsured rate for kids (7.15%). Over 80% of the county's uninsured were income eligible for Medicaid (49%), or APTCs (33%). Only 6% of the county's uninsured had income which made them ineligible for any financial assistance, the lowest rate in the region.



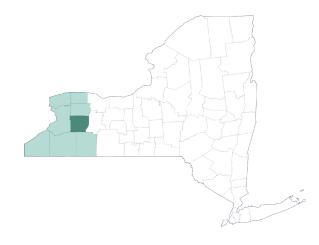
Category	Number	Percent	Uninsured by Income Category**
Population	38,820		148,
In poverty	6,188	16.25%	6%
Uninsured	2,505	6.45%	
Uninsured less than age 19*	614	7.15%	825,
Uninsured less than 138% FPL*	1,233	12.77%	33% 49%
Uninsured 138-199% FPL*	299	5.93%	
Uninsured 200-399% FPL*	825	6.37%	299, 12%
Uninsured more than 400% FPL*	148	1.33%	12 /0
ACA individual penalties paid	570		

^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Wyoming County

Western New York's smallest county, Wyoming, is also the second-least impoverished county in the region. The largest percentage of the roughly 1,800 total uninsured residents fell into the income group eligible for APTCs for Marketplace coverage (50%). The county's small size illustrates the challenges of census data analysis for small regions. Although less than 300 children were uninsured, that added up to an overall uninsured rate for kids of 3.57%. Similarly, almost half of the uninsured were income-



eligible for Medicaid or the EP, but that amounts to less than 800 county residents in total.

Category	Number	Percent	Uninsured by Income Category**
Population	37,356		
In poverty	4,368	11.39%	172, 420,
Uninsured	1,843	4.93%	9% 23%
Uninsured less than age 19*	296	3.57%	
Uninsured less than 138% FPL*	420	6.22%	919, 332,
Uninsured 138-199% FPL*	332	7.51%	50% 18%
Uninsured 200-399% FPL*	919	6.41%	
Uninsured more than 400% FPL*	172	1.45%	
ACA individual penalties paid	490		

^{*} Percentage uninsured within that age/income category.

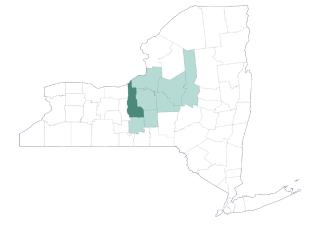
^{**}Percentage of all uninsured in county.

Central New York

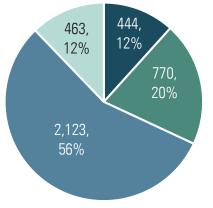
The eight counties making up the central New York region are home to about 1,113,000 residents, roughly 5.7% of the state's total population; about 15% live in poverty. Some 49,000 residents were uninsured (about 4.4%), below the statewide average. Only two counties had uninsured rates above the statewide average, and five counties had uninsured rates for children above the statewide average. In 2016, central New Yorkers filed a total of 13,710 income tax returns that included ACA penalties for not maintaining coverage. Following are more detailed profiles, with small counties denoted with italics.

Cayuga County

Cayuga is at the median in terms of both poverty and size for western New York counties, with an overall uninsured rate (5.00%) slightly less than the statewide rate, but a children's uninsured rate (7.23%) well above the statewide mark and the second highest in the region. Children made up nearly a third of the total uninsured in Cayuga, and the residents in the APTC eligibility range of 200% to 400% FPL made up over half of the county's 3,650 uninsured residents.



Category	Number	Percent	Uninsured by Income Category**
Population	73,024		
In poverty	8,289	11.35%	463, 444,
Uninsured	3,650	5.00%	12%
Uninsured less than age 19*	1,142	7.23%	770, 20%
Uninsured less than 138% FPL*	444	3.26%	20 /0
Uninsured 138-199% FPL*	770	8.86%	2,123,
Uninsured 200-399% FPL*	2,123	6.65%	56%
Uninsured more than 400% FPL*	463	1.68%	
ACA individual penalties paid	1,030		

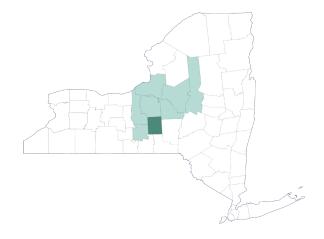


^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Cortland County

Cortland is central New York's smallest county, with a median level poverty rate, the region's third-highest uninsured rate (5.08%), and the fifth-highest rate for uninsured children (4.49%). Almost half of Cortland County's uninsured were income-eligible for Medicaid or the EP, but once again, the biggest segment of uninsured (35%) fell within APTC income eligibility levels.



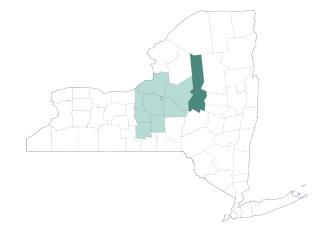
Category	Number	Percent	Uninsured by Income Category**
Population	44,718		
In poverty	6,719	15.23%	405, 511,
Uninsured	2,270	5.08%	18%
Uninsured less than age 19*	440	4.49%	
Uninsured less than 138% FPL*	511	5.62%	
Uninsured 138-199% FPL*	549	9.13%	805, 549,
Uninsured 200-399% FPL*	805	5.63%	35% 24%
Uninsured more than 400% FPL*	405	2.65%	
ACA individual penalties paid	620		

^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Herkimer County

Next to Cortland, Herkimer is the region's second-smallest county, with a lower poverty rate than all but one county, but the highest uninsured rate (6.63%), and a rate of uninsured children (5.36%) about double the state average. Individuals who are income-eligible for Medicaid or the EP account for about 50% of the uninsured, in addition to the more than a third who are eligible for APTCs through the Marketplace.



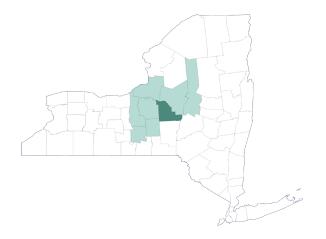
Category	Number	Percent	Uninsured by Income Category**
Population	61,708		
In poverty	8,306	13.59%	660,
Uninsured	4,089	6.63%	16% 1,132,
Uninsured less than age 19*	733	5.36%	28%
Uninsured less than 138% FPL*	1,132	7.99%	1 404
Uninsured 138-199% FPL*	813	10.42%	1,484, 813,
Uninsured 200-399% FPL*	1,484	7.12%	20%
Uninsured more than 400% FPL*	660	3.50%	
ACA individual penalties paid	840		

^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Madison County

The region's "smallest big county," Madison also has the lowest percentage of residents below the poverty level (9.58%). With an overall uninsured rate of 5.0%, nearly 30% of the uninsured in Madison County are eligible for Medicaid or the EP, but more than half are eligible for APTCs and another 20% earn more than 400% FPL.



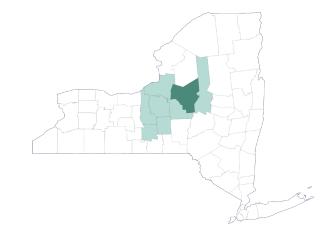
Category	Number	Percent	Uninsured by Income Category**
Population	66,086		
In poverty	6,332	9.58%	678, 685,
Uninsured	3,320	5.00%	19%
Uninsured less than age 19*	779	5.35%	
Uninsured less than 138% FPL*	685	6.39%	301, 9%
Uninsured 138-199% FPL*	301	5.14%	1,865,
Uninsured 200-399% FPL*	1,865	6.02%	53%
Uninsured more than 400% FPL*	678	2.78%	
ACA individual penalties paid	860		

^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Oneida County

With population centers such as Utica and Rome, Oneida is central New York's second-largest county. Oneida's overall uninsured rate (4.7%) is below the state average, but its uninsured rate for children is above the state average, and the region's fourth highest (4.82%). The county's roughly 10,200 uninsured are closely grouped among the four income categories, ranging from 28% for those eligible for APTCs to 16% for individuals eligible for the EP. About 16% of Oneida's uninsured are Latinos, and another 8% are noncitizens.



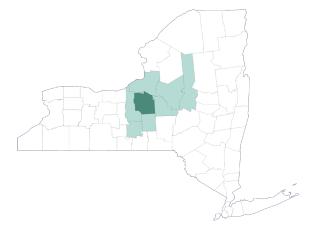
Category	Number	Percent	Uninsured by Income Category**
Population	218,641		
In poverty	35,242	16.12%	
Uninsured	10,273	4.70%	3,986, 3,797,
Uninsured less than age 19*	2,432	4.82%	28% 27%
Uninsured less than 138% FPL*	3,797	7.52%	
Uninsured 138-199% FPL*	2,325	10.02%	4,048, 2,325,
Uninsured 200-399% FPL*	4,048	4.51%	29%
Uninsured more than 400% FPL*	3,986	5.08%	
ACA individual penalties paid	2,410		

^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Onondaga County

Home to Syracuse, New York's fifth-largest city, Onondaga is the region's largest county, with the fourth-highest poverty rate (13.89%), an uninsured rate (3.90%) below the statewide average, and a child uninsured rate (2.81%) at about the same level. About half (46%) the county's 17,300 uninsured fall into the group income-eligible for Medicaid or the EP, with about a quarter income-eligible for APTCs, and a quarter (5,582) with incomes too high for subsidies. A more diverse county, Onondaga's



uninsured include 10% Black/African American, 14% noncitizens, 12% Latino, and 6% Asian American.

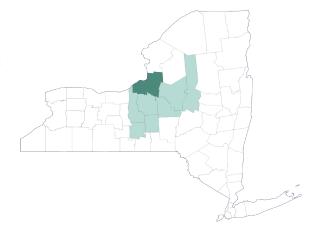
Category	Number	Percent	Uninsured by Income Category**
Population	444,382		
In poverty	61,820	13.89%	
Uninsured	17,321	3.90%	5,582, 5,787,
Uninsured less than age 19*	2,800	2.81%	26% 27%
Uninsured less than 138% FPL*	5,787	6.28%	
Uninsured 138-199% FPL*	4,089	8.66%	5,909, 4,089,
Uninsured 200-399% FPL*	5,909	3.42%	28% 19%
Uninsured more than 400% FPL*	5,582	3.11%	
ACA individual penalties paid	5,260		

^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Oswego County

Despite having the second-highest poverty rate in the region (16.97%), Oswego County had an uninsured rate (4.22%) below the statewide average, and the second-lowest uninsured rate for children (1.27%). About one-third of the county's 4,800 uninsured were income-eligible for Medicaid or APTCs for the Marketplace, but a higher percentage of individuals eligible for the EP (7.08%) were uninsured.



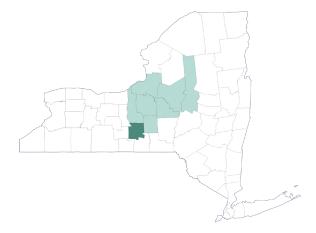
Category	Number	Percent	Uninsured by Income Category**
Population	112,583		
In poverty	19,121	16.97%	876,
Uninsured	4,793	4.26%	1,716,
Uninsured less than age 19*	318	1.27%	34%
Uninsured less than 138% FPL*	1,716	6.04%	1 001
Uninsured 138-199% FPL*	852	7.08%	1,661, 32% 852,
Uninsured 200-399% FPL*	1,661	3.78%	17%
Uninsured more than 400% FPL*	876	2.18%	
ACA individual penalties paid	1,690		

^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Tompkins County

Like Oswego County, Tompkins posted a high poverty rate (20.52%), but its overall uninsured rate (3.46%) and children's uninsured rate (0.94%) were the lowest in the region. Of roughly 3,200 uninsured, those ineligible for any assistance accounted for the highest number of uninsured (45%, the highest in the region), and about 40% were income eligible for either Medicaid or the EP. But nearly 20% of Tompkins' uninsured residents were noncitizens.



Category	Number	Percent	Uninsured by Income Category**
Population	91,475		
In poverty	18,772	20.52%	
Uninsured	3,166	3.46%	1,132, 26%
Uninsured less than age 19*	142	0.94%	1,909,
Uninsured less than 138% FPL*	1,132	4.95%	45%
Uninsured 138-199% FPL*	661	6.85%	661, 15%
Uninsured 200-399% FPL*	577	1.84%	577,
Uninsured more than 400% FPL*	1,909	5.13%	14%
ACA individual penalties paid	1,000		

^{*} Percentage uninsured within that age/income category.

^{**}Percentage of all uninsured in county.

Part II. The Stories

To put a human face on the data analysis and gain additional insights into the reasons many New Yorkers eligible for financial help for health coverage still lack insurance, four discussion groups were conducted with a total of 36 central and western New Yorkers, 11 in four counties: Cortland, Onondaga, Chautauqua, and Allegany. During the roughly 90-minute sessions, participants vividly and painfully described the consequences of not having insurance. Two participants had extracted their own teeth. A single mother of two fighting thyroid cancer made sure her kids had coverage, but financed cancer screenings out of pocket, as well as the medication she needed "because I don't have a thyroid anymore." Participants also described their strategies for getting needed care and managing without medications they had to forgo, many for mental health disorders.

All participants were highly aware of the growing costs of health care, and they wondered why national and state officials allowed it to happen. Two participants said insurance company profits and administrative expenses were part of the problem, but many more cited skyrocketing costs for emergency room visits and prescription drugs. For example, when a panelist with Medicaid coverage described how her son needed growth hormone medication every 24 days at a cost of "\$7,000 a pen" because he was born without a stem to his pituitary gland, another participant said, "See, there should be a law against that. That anything could cost \$7,000 a pen? That's crazy." Following is a summary of the themes and highlight of the sessions. When participants are quoted, fictitious names are used to protect their privacy.

Employer-Sponsored Insurance

For many participants, periods without insurance—often extended ones—usually began with the loss of employer-sponsored insurance (ESI), due to layoffs, a business closing, or the employer discontinuing the coverage or changing the contributions to unaffordable levels. Roger (62) felt "pretty lucky" to have affordable, comprehensive ESI at his job "until the day nine years ago when they said, 'we're closing the doors." A new job brought coverage briefly, but new owners changed the terms, making it unaffordable to him, triggering another period without insurance, until he found his way to the EP.

Toni (57) saw the changing ESI pattern coming. "And the thing is, everywhere I worked for years and years, everybody gave you coverage, everybody gave you Blue Cross because it was affordable, affordable for the employer to purchase as a benefit, and for the employees," she said. "But in the past probably 10 years, maybe 12—I watched because I had access to all those files at work—premiums went up and up and up. Coverage never went up, coverage became less. And then employers didn't give you coverage. And I'm sorry, when your employer gives you coverage and

it's \$18 a week with a \$5,000 deductible, I might as well put the \$18 in my pocket and save it and take the fine. I'm sorry, I'm never going to be able to come up with a \$5,000 deductible."

For many participants in the discussion, ESI simply wasn't an option, because they were independent contractors (many driving trucks); owned their own home repair, carpentry, construction, or other business; had seasonal jobs; or worked in areas in which employers typically don't offer ESI, such as restaurants or agriculture. "I'm a chef," said Katya, who was uninsured for a four-year span while battling cancer. "Been doing it for 22 years, and I've never once worked at a place that had

"Everywhere I worked for years and years, everybody gave you Blue Cross because it was affordable, affordable for the employer to purchase as a benefit, and for the employees. But in the past 10 years, premiums went up and up and up. Coverage never went up, coverage became less. And then employers didn't give you coverage. And I'm sorry, when your employer gives you coverage and it's \$18 a week with a \$5,000 deductible, I might as well put the \$18 in my pocket and save it and pay the fine. I'm never going to be able to come up with \$5,000 for a deductible."

-Toni (57)

lost ESI eligibility
but found coverage through EP

insurance." Harriet (58) and Christine (50) had worked as servers (waitresses) for 28 and 20 years respectively, never with ESI. Joseph (40) has a well-paying union job, but the seasonal nature of the work leaves him without coverage from September 1 to January 1 of each year.

For two participants, however, ESI was a godsend. Kaley, 25, was covered under her mother's policy until she lost her job, and her new job had prohibitive premiums for employee/child coverage. Uninsured for a year, her coverage will start next month: "I got a job at the college, with all kinds of benefits, and there's no real waiting period for coverage. It's a stable job, year-round, four weeks' paid vacation. So when they called me, I was like, 'OK, I'll take it." Other participants congratulated her for her good news, as if she had won the lottery.

For Steve, ESI solved a different problem. Because of a deep philosophical objection to "sending all that money to for-profit insurance companies," Steve paid for medical care out of pocket when needed, even when a mugging left him with thousands of dollars in hospital bills

that took years to pay off. "I paid at my own pace, ended up saving money, but it was an ordeal. Then the penalties [ACA individual responsibility payments] started going up, so I said, 'nuts to this.' I stopped applying for the better jobs and hunted out a company that's known for taking care of its employees. I have coverage now, with a low deductible and a fair premium."

A Lingering Stigma for Public Coverage

Many changes have accompanied the implementation of the ACA in New York, including the establishment of the Marketplace as a one-stop shop for public and private coverage, replacing for the most part county social service districts' responsibility for enrolling eligible residents. While some participants had good things to say about county workers, far more viewed that change as a positive one. Many expressed the sentiment that county officials "acted like it was coming out their own pockets." In fact, most participants, when asked about their current coverage, would reply with "Fidelis" or "Blue Cross" or "Your Care," rather than the name of a public program such as Medicaid, the EP, or CHP. Alice, who had recently relocated to the area from another state, said, "This was something

"I have never, never taken anything from anybody. I've never taken any handouts. Anxiety medicine, checkups, I took care of myself. I've been working since I was 15 years old. I paid my dues, I guess. Now, I don't want to take [public insurance], but I'll take what I can. I guess it gets a bad rap. There's so many people that take advantage of something."

-Harriet (58)

enrolled in Medicaid after work-related disability

I definitely noted when we first got up here and were getting ourselves established, and first got ourselves on Medicaid. Technically, it was Medicaid, but I don't think I ever heard it referred to as Medicaid."

But many other participants, particularly older ones, were very reluctant to enroll in coverage. Harriet, working but eligible for assistance, didn't seek public coverage until she was seriously injured at work and had to take a leave of absence; disability payments made her incomeeligible for Medicaid. "I have never, never taken anything from anybody," she said. "I've never taken any handouts. Anxiety medicine, checkups, I took care of myself. I've been working since I was 15 years old. I paid my dues, I guess. Now, I don't want to take [public insurance], but I'll take what I can. I guess it gets a bad rap. There's

so many people that take advantage of something." "I'm with her on that," another participant said. "I've been working nonstop and never took anything, that's the way I was brought up." Another participant offered a different point of view: "But you've been paying into that. There's a huge stigma around all of it because there are people out there that are only getting Medicaid because they can abuse the system—and they are in the minority."

Young (and Old) Invincibles

Many young people questioned the need for insurance when they were young and healthy. Daniel (27), recently married and expecting his first child this spring, has been uninsured since aging off his parent's policy in August. His wife (and the new baby, when it arrives), have ESI through her job. "To be honest with you, [coverage] is the least of my concerns," he said. "The payments are not really an issue with me. Between all the day-to-day stuff with starting my new business, and getting the house ready for the kid, I barely have time to relace my boots. I guess you could say

"I'm sitting here as the poster child for 'there but for the grace of God go all the rest of us.' I always had companyprovided insurance, never went to the doctor. Then I had an accident on the Thruway, crashed my truck and lost my job and the insurance... Never in my life did I think I would need any services, need anybody to help me out, not having insurance, not have a job."

-Tim (62)

enrollment in EP pending for himself and his spouse

it's something I'm being ignorant about. But I have some coverage through my business, and there's the urgent care thing. Down the road I will probably look into insurance, but it doesn't seem like the most important thing for me to worry about. If I bust myself up that bad, I'll make ends meet somehow."

The availability of services from urgent care centers has changed the equation. Many young people, especially those ineligible for less-costly Medicaid or EP coverage, didn't see the point of paying premiums. Alice said, "I don't see the health insurance system that we have in place is viable for most young, healthy Americans. It makes no sense to pay for something you're never going to use, and you can always go to urgent care when you need something." Shirley (33), became uninsured when she lost her job, and couldn't afford COBRA. "When it came to the end of the year and they were going to fine me,

they said I didn't make enough to be fined, but I made too much for any subsidies. I got sick one time, urgent care was \$100. They paid for my X-rays and they paid for my medication. So it was way cheaper than paying two or three hundred bucks for insurance."

An older invincible, Tim (62), offered a different perspective. "I'm sitting here as the poster child for 'there but for the grace of God go all the rest of us," he said. "I always had company-provided insurance and I was an insurance company dream, never went to the doctor. In August, I had an accident on the Thruway, crashed my truck and lost my job and the insurance. And with my age, and injuries from the accident, it was really difficult finding or getting another job." Tim's main expense was prescription drugs for his spouse; thanks to help from a local pharmacist, they found ways to manage those expenses through the GoodRx drug discount plan, lower cost generic drugs from Walmart, and a referral to a local navigator, where they

have begun the enrollment process, and hope to join the EP next month. "Never in my life did I think I would need any services, need anybody to help me out, not have insurance, not have a job."

Comments by Joseph echoed a similar theme: "It used to be, you get hurt, stick a Band-Aid on it. I'm 40. It's not liked it used to be. Stuff hurts now."

Affordability and Value

Most of the participants in the discussion groups who had recently gained coverage had enrolled in Medicaid or the EP, and they were very pleased with the benefits (particularly dental coverage) and the affordability. Many of those above the EP income limit—even those eligible for APTCs—found coverage to be unaffordable and the deductibles unreasonable. "When we went to apply," said Louanne, "they

"My daughter's friend figured it out for me, and it was a \$3,000 deductible plus your copays, and they wanted \$461 and I cannot afford that... I have a good doctor. She knows I don't have insurance, so she'll work with me. I'll be 61 in January. That's a joke between me and her, 'you'll have insurance in four years, I'll do everything I can to get you there,' she says."

-Rebecca (61)

lost ESI when her spouse retired, now waiting for Medicare

wanted \$1,500 a month in premiums, and I said, 'I can go to the ER for \$1,000 and be done with it.' Plus a \$5,000 deductible, \$50, \$75 copay." Her family does incur medical expenses, which they manage with a very helpful family physician, but "I'd rather pay those than that \$1,500 every month. It just does not compute."

Rebecca (61), with a household income of about \$50,000, lost her ESI when her husband retired, but a QHP with APTC subsidies was not the answer. "I went to my daughter's friend's house, and she sat there and figured it out for me, and it was a \$3,000 deductible plus your copays, and they wanted \$461 a month and I cannot afford that." Instead, her committed family physician helps her manage her medical expenses to treat heart disease and diabetes, supplying her insulin for free, and switching her to generic medications

available at Walmart for \$10/\$4 copays. "I have a good doctor. She knows I don't have insurance, so she'll work with me. I'll be 61 in January. That's a joke between me and her, 'you'll have insurance in four years, I'll do everything I can to get you there,' she says." Toni was uninsured and on the "don't ask, don't tell" coverage, "but some things came up and I had to get coverage. So I had to go the Marketplace and scrape up all my money to get the best plan I could, a silver plan. I did that for a while, and it was extremely painful, because my payment was over \$300 a month. Fortunately, the owner of the new company I worked for was semi-retiring, so my hours got cut," which led her to enroll in the EP at a \$47 premium, because of her

now part-time income. "This is the only country I know of where you are rewarded for working less."

When queried, many participants thought that \$200 per month was "the max" they could spend on health insurance. Many expressed frustration at different elements of the income-based subsidy calculations. Several encountered difficulties with the "cliff" where small increments in income resulted in much higher premiums. "I'm a single mom and I work two full-time jobs and I'm still broke an hour after I get my paycheck. And I make \$3 a week more, too much to get any assistance. Period. Three dollars." Self-employed individuals complained that the calculation didn't properly measure income. "What's on paper and what you actually pull in is different." Others singled out different expenses, equating a \$400-per-month premium to a car payment, noting housing rental payments in high-cost areas, citing

"When we went to apply, they wanted \$1,500 a month in premiums, and I said 'I can go to the ER for \$1,000 and be done with it." Plus, a \$5,000 deductible, \$50, \$75 copay... I'd rather pay for [ongoing medical expenses] than that \$1,500 every month. It just does not compute."

-Louanne (50)

no ESI from her employer, spouse self-employed

student loan expenses that exceeded \$1,000 per month for one young couple, high weekly child care expenses, or alimony and child support payments. Louanne's monthly expenses included a \$300 monthly payment to a medical credit card company, from a \$10,000 loan she took out for urgent dental work, at a 24% interest rate. She has been paying it off for three years, with no end in sight, even though she pays \$75 more each month than the minimum payment.

One final element in the affordability equation was the perceived value of coverage: many participants saw little value in the protection against catastrophic expenses that insurance coverage provided. They instead described premium payments, when no medical expenses

were being incurred, as "wasteful" even when those payments were made by employers. Similarly, the broad, fundamental premise that premiums from individuals without immediate medical claims help stabilize the cost of coverage for those utilizing benefits, was not something most participants considered. The availability of premium tax credits is one tool that helps stabilize risk pools, and ACA individual responsibility payments (reduced to \$0 for 2019) have been another inducement to purchase coverage. The ACA individual responsibility payments were not popular with many participants—viewed as a penalty for not buying something you can't afford—but several participants said the penalties, after the 2016 increase, influenced their decision to purchase coverage.

The Value of Enrollment Assistance

While discussion group participants, depending on their circumstances, had varying views on the value of coverage, there was universal agreement that finding an enrollment counselor for help was the most important step in finding coverage. Danielle (20) said young people in particular would benefit from assistance, because, despite the fact that many young people stand to lose the coverage they get through their parents, none had ever discussed how coverage works or how to find it. Even accounting for a degree of "selection bias"—local assistors helped organize the discussion groups for this project—participants heaped praise on them, using terms like "lifesaver" to describe their role.

Assistors recently helped Santa (37) enroll in the EP, ending a period without insurance that coincided with her decision to leave her job to go back to school, a divorce that ended coverage through a spouse, and a diagnosis of Bell's palsy. "When my navigator said I was approved, I was literally in tears, and I hugged every single person here," she said. "In this whirlwind of everything that's been going on in the

"It's not as easy [to sign up for coverage] as people said it was. I'm a pharmacy technician, so all the time at work I'm dealing with the people that don't have insurance to pay for their prescriptions. So I tell them, 'Well, you could go on the Marketplace. Have you done that? Yeah, it's super easy.'

So, there I was, a bald-faced liar."

-Kelly (26)

enrolled her child in CHP and found a job with ESI

last few months, this is the one thing that went right." Kelly, a recently divorced single parent who lost Tri-Care coverage when her ex-husband left the military, and then was laid off from a job with coverage, found out that signing up on her own "is not as easy as people said it was. I'm a pharmacy technician, so all the time at work I'm dealing with people that don't have insurance to pay for their prescriptions. So I tell them, 'Well, you could go on the Marketplace. Have you done that? Yeah, it's super easy.' So there I was, a bald-faced liar."

According to a 2018 NYSOH report, ¹³ about 17% of enrollees signed up for coverage directly through the website. The rest obtained coverage with the help of in-person assistors: brokers; certified application counselors working for providers, nonprofits, or health plans; navigators;

and NYSOH customer service representatives. For the population enrolling in CHP, Medicaid, or the EP, 74% to 84% of enrollees received in-person assistance. According to a 2018 NYSOH directory, there are about 90 in-person assistor sites in central New York and 110 in western New York. ¹⁴ Discussion group participants described many types of situations where their assistors helped them overcome glitches or difficult transitions that threatened their coverage.

One participant, enrolled in Medicaid, cited her navigator's help when prescription drugs for her newborn were denied and she received a bill from the hospital for the birth, because she had been "switched" from traditional Medicaid to a managed care plan providing Medicaid coverage without her knowledge. Another participant was enrolled in the much more affordable EP instead of a QHP with the help of his navigator, who figured out that the Marketplace had treated the two paystubs for episodic employment as two separate full-time jobs. In another incident, a young mother praised her assistor for reinstating her infant son's CHP coverage, which was cancelled when the Marketplace mistakenly required income verification for her 1-year old son—not working yet, but named after his father, whose income information was needed instead. Others described how navigators intervened because Marketplace customer service officials "are not allowed to call you back," or when the one "account holder" permitted was unavailable to address a mistake and a spouse could not intervene, or to sort through the multiple letters enrollees received in a single day.

Many participants also praised navigators' assistance when they cycled through transitions that involved switching from Medicaid to the EP or a QHP, and perhaps back again. These transitions, triggered by changing family situations, family caregiving, or minor changes in income, were very common.

The Need for Education and Outreach

Discussion group participants also agreed that more education and outreach would help uninsured connect with health benefits. One priority was combatting the

"Education about these programs and their whereabouts [should be a priority]. To do this whole [enrollment process] is free. And they do it all for you. You just sit in a chair and answer a few questions and they listen. I have been volunteering for a sandwich program across the street for years, and I never knew this place was here."

-Tim

stigma associated with public programs and the ACA. "The stigma [should be addressed], getting people to think it's a right, and you need to keep yourself healthy. Because in the long run with the essential health benefits, if you are not taking care of what you need, then you're going to have more issues. And if you think now that other people are paying for it, it's going to get paid for worse if you let it get too far." Another participant thought a name change would help: "Well just listening here, I hate the fact that they call them entitlements. Because I hear people saying I don't want a handout, I don't want people to think I'm entitled to these things, and I think some people have a hard time I guess swallowing their pride and asking for help. So they should

be called you-earned-its or something." Another saw the need to combat the negative image of the ACA generally and navigator programs: "There's just a bunch

of disinformation out there and overcoming that is really difficult. A lot of people want programs like this to fail, so they put out bad information about it, and people then just don't get the help they need from these organizations, only because there's someone out there trying to get a political end out of it, smear campaigns."

All of the participants thought navigators had made a large difference in their lives, but nearly all of them connected through word of mouth from friends or family members. They all wished there was some better way to get the word out: "Education and giving people knowledge about these programs and the whereabouts" was at the top of one participant's list of things that could ease coverage barriers. "This is free. To do this whole process is free. And they do it all for you. You just sit in a chair and answer a few questions and they listen... I have come down to volunteer at the sandwich program across the street most Saturdays for years, and I never knew this place was here." The cornerstone of the participants' relationship with their enrollment assistors was trust, often developed from that first session, when navigators and customers huddled in front of a computer screen, building an application question by question. As one participant noted: "I got that letter that says coverage is gonna die, and I just call [my navigator] and I got coverage again."

Conclusion

New York State has made great strides in reducing the number of uninsured throughout the state, including in western and central New York. For example, analysis of 2009 federal data on an upstate region that included Tompkins and Cortland counties estimated an overall uninsured rate of 13.2%;¹⁵ that rate has dropped to 3.5% for Tompkins County and to 6.3% for Cortland County. But based on the numbers, over 150,000 uninsured in western and central New York had income that may have made them eligible for assistance, and over 95,000 of them met the income standards for free or very low-cost coverage through Medicaid, CHP, or the EP. Reducing the uninsured rate for children could be a priority, for a lot of reasons: the impact good health coverage and primary care can have on a child's later development is unquestioned,¹⁶ New York's CHP program provides more generous subsidies than any state in the nation, and citizenship is not a condition for eligibility.

Discussion group participants agreed that stronger education and outreach about enrollment assistance, along with messages that combat the stigma associated with public programs, could help. NYSOH launched such an effort for the 2019 open enrollment period for QHPs on New York's Marketplace, which concluded on January 31, 2019 (Medicaid, CHP, and the EP are open for business year-round).

Television ads, part of the \$14 million New York spends on advertising,¹⁷ aired widely in upstate New York, featuring consumers and the navigators who helped them.¹⁸ The theme for this year's campaign—You Deserve Affordable Healthcare—sounds just about right. Despite federal cutbacks, New York committed \$23 million for its outreach program, apparently with some success. NYSOH reported increased enrollment in all programs and products—Medicaid, CHP, EP, and QHPs—for 2019,¹⁹ and in all counties.²⁰

The effort to reach those uninsured but eligible for premium tax credits for QHPs may be more challenging, given the large gap between many consumers' perceptions of value and what is available for them to buy, and the fact that many individuals at the higher end of the subsidy scale simply cannot afford premiums. The unlikelihood of another all-out effort by Congress to repeal the ACA—now that a Democratic majority has assumed its role in the U.S. House of Representatives—may give states some space to explore strategies to fine-tune the ACA and reach more households. It may also allow states to make more sweeping changes, such as enacting laws to create single-payer plans, or allowing people with higher incomes to "buy in" to the Medicaid program. At the same time, a new case challenging the constitutionality of the ACA brought by state attorneys general from Texas and other states will work its way through federal appeals courts, after a surprising decision by a Texas judge. Western and central New Yorkers caught in the middle—uninsured but ineligible for deeper subsidies or ESI—will just have to stay the course and hope for the best:

"If it were different, if we were using [insurance coverage], it would make it more reasonable that we were paying out those things. Not at \$1,500 a month in premiums. You never know. But then again, I look at it this way too. If I'm at a point where I have to be hospitalized, obviously I'm not going to be working, so I'm not going to have any income. And same goes for my husband. If he's hospitalized and can't work, our income is totally going to change, and it's going to go from this, to it's going to be nothing. And then hopefully and eventually, we would be eligible for some kind of health insurance help. So that's where we're at right now. You never know. Right now, he's driving on icy roads into New England. You never know. That's a sad way of looking at things."

—Louanne

Methodology

Numbers

Data on insurance by age and income are from the American Community Survey (ACS) 2017 1-year estimates (B27016: Health Insurance Coverage Status and Type by Ratio of Income to Poverty Level in the Past 12 Months By Age) for the larger

counties, and ACS 5-year estimates from 2013 to 2017 for counties with less than 65,000 people (C27016: Health Insurance Coverage Status by Ratio of Income to Poverty Level in the Past 12 Months by Age). Poverty information is based on 2017 American Community Survey 1-Year Supplemental Estimates with a Population Threshold of 20,000 or More (K201702: Ratio of Income to Poverty Level in the Past 12 Months). Citizenship data is from ACS 2017 1-year estimates (B27020: Health Insurance Coverage Status and Type by Citizenship Status). Racial and ethnic data for the smaller counties are from ACS 2017 5-yr. estimates (S2701: Selected Characteristics of Health Insurance Coverage in the United States), and for larger counties, the 2017 ACS 1-year estimates.

Each of the surveys presents estimates with +/- margins of error, which were not included in the tables in this report, for the sake of brevity and the overall presentation. For the smaller counties, the +/- margin can produce comparatively large swings. For example, the estimate for Allegany County for uninsured children under age 19 living in households earning less than 100% FPL is 564, with an upper range of 761 and a lower estimate of 367. There were also small differences in the 1-year and 5-year estimates that had to be reconciled, such as a larger number of income levels in the 1-year estimate than in the 5-year estimates.

Discussion Groups

UHF set the parameters for the discussion groups, and the 36 participants were recruited by local nonprofit organizations in each of four counties. The first discussion group was conducted in Homer, NY (Cortland) on November 7, 2018, with the assistance of Family Health Network; the second in Syracuse, NY (Onondaga) on November 8, 2018, with ACR Health; the third in Gowanda, NY (Cattaraugus) on November 12, 2018, with Healthy Community Alliance; and the final session on November 13, 2018, in Wellsville, NY (Allegany) with Ardent Solutions. Local partners were asked to recruit participants under 65 who were currently uninsured or were without coverage within the preceding two years. All but three of the participants were white, 21 were women, and 15 were men. Participants ranged in age from 20 to 62, with 21 participants under the age of 40, and 14 over 40. In terms of income, 21 participants earned under \$25,000 annually, 11 earned between \$25,000 and \$50,000, and 4 earned more than \$50,000. The sessions typically lasted for 90 minutes. In the first segment, the moderator led a discussion to gauge participants' familiarity with health insurance terms and programs. In the second segment, participants were asked to describe their current status, recent periods of being uninsured, their experience with the health care system generally, the decisions they made and the support they received, and the enrollment process. In the final segment, participants were asked for ideas to address barriers to enrollment and improve the process and access to coverage. At the conclusion of the discussion, each participant received a financial incentive of \$50.

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Endnotes

- 1 Smith J and Medalia C. September 2014. *Health Insurance coverage in the United States: 2013.* United States Census Bureau, Current Population Reports. https://www.census.gov/library/publications/2014/demo/p60-250. html. UHF analysis of 2017 American Community Survey, 1-year estimates.
- 2 For background on the HFWCNY and a map of its service area, see https://hfwcny.org/about/
- **3** For background information on the ACA's individual responsibility payments, see *The Requirement to Buy Coverage Under the Affordable Care Act*. August 2, 2017. Kaiser Family Foundation. https://www.kff.org/infographic/the-requirement-to-buy-coverage-under-the-affordable-care-act/. In 2017, the penalty was the greater of \$695 per adult or 2.5% of family income. The federal Tax Cut and Jobs Act reduced the payment to \$0, effectively repealing the penalty for 2019.
- **4** Five-year surveys were used for the smaller counties because one-year estimates are not available, due to reliability concerns. Although we used the most recent five-year surveys, these may undercount coverage gains from the ACA somewhat when compared to one-year estimates—which can lead to higher uninsured rates, an effect to keep in mind when comparing counties are compared or ranked. More details are available in the Methodology section.
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- **7** Garfield R, Damico A, Orgera K, Claxton G, and Levitt L. June 2018. *Estimates of Eligibility for ACA Coverage among the Uninsured in 2016. Data Note.* Henry J. Kaiser Family Foundation. http://files.kff.org/attachment/Data-Note-Estimates-of-Eligibility-for-ACA-Coverage-among-the-Uninsured-in-2016
- 8 Immigration rules and public benefit eligibility is a very complex matter. For an excellent summary of the eligibility rules and terms for health insurance, see https://empirejustice.org/wp-content/uploads/2018/07/PUB-Health_Coverage_Crosswalk_Eligibility_by_Immigration_Status.pdf

- **9** UHF analysis of ACS 1-year estimate for New York State (B27020) and Bronx, Kings, New York, Queens, and Richmond Counties.
- **10** Young Center for Anabaptist and Pietist Studies, Elizabethtown College. *Amish Population Change 2009-2018*. https://groups.etown.edu/amishstudies/files/2018/08/Population_Change_2009-2018.pdf
- 11 See the Methodology section for detail on the discussion groups.
- **12** NYSOH has special eligibility rules for the self-employed. Navigators in central New York found these rules to be very helpful in signing up tattoo artists, hairdressers, and other self-employed individuals, because the final income figure used for eligibility accounted for their expenses for supplies, rentals, equipment, etc. An instruction guide on the rule is available at https://info.nystateofhealth.ny.gov/sites/default/files/Self%20 Employment%2C%209-30-15.pdf. With so many self-employed central and western New Yorkers, utilization of this rule more broadly could result in more individuals accessing coverage.
- **13** 2018 Open Enrollment Report. May 2018. NY State of Health: The Official Health Plan Marketplace. https://info.nystateofhealth.ny.gov/sites/default/files/NYSOH%202018%20Open%20Enrollment%20Report_0.pdf
- **14** IPA/Navigator Site Locations. November 2018. NY State of Health: The Official Health Plan Marketplace. https://info.nystateofhealth.ny.gov/ipanavigatorsitelocations
- **15** Marcri J, et al. September 2011. *Health Insurance coverage in New York, 2009.* Urban Institute and United Hospital Fund.
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