STORIES from SULLIVAN

How a Rural Community Addresses the Opioid Crisis

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In rural communities like upstate New York’s Sullivan County, where the bus runs twice a week and cab fare is expensive, people who need substance abuse treatment often have a hard time getting to it.

A few years ago, one public official in the county wanted to show state officials how vital transportation is to addressing access, especially in a county the size of Rhode Island. She started by inviting them to Sullivan County. Instead of meeting in a conference room, she took them for a drive.

“I tried to really give them a visual,” she said. “They were shocked that it took an hour to get from one end of the county to the other, and that’s just straight.”

It’s clear that America has an opioid problem. In conversations with people on the front-lines of the epidemic, however, it is not so clear that lawmakers in Albany or Washington, DC, understand the realities of the crisis — like the challenges of accessing services in remote rural communities.

This disconnect between the communities fighting opioids on a day-to-day basis and lawmakers devising solutions in the state’s Capitol weakens the response to the opioid crisis. How can we expect state and federal officials to craft relevant solutions to a problem we don’t fully understand?

In an effort to bridge this disconnect between local communities and lawmakers, the Rockefeller Institute of Government is conducting an in-depth study of the opioid crisis in Sullivan County, a rural community located 100 miles northwest of New York City.

Readers will follow the project as it happens — what we call “research in real-time.”

By talking to community members, public officials, medical experts, and activists, we seek a better understanding of the causes and effects of the opioid epidemic not just in Sullivan County, but in similar communities across the country.

In short, we ask:

+ What does the opioid problem look like in a small, rural community?
+ How has the community responded?
+ What do people on the ground need from government to address it?

In essence, this project looks at how government works by examining its response to a public health crisis. How do different levels of government — state, federal, and local — work together to address the situation? Are the policy solutions really addressing needs on the ground? How are governmental agencies and departments working or not working together in response?

Our work combines aggregate data analysis with on-the-ground research in affected communities to provide insight into what the opioid problem looks like, how communities respond, and what kinds of policies have the best chances of making a difference.
PART 1

Pathways to Addiction

How the US Developed an Opioid Problem

How did opioids become a problem in the United States? It’s a question that many people are asking and that most newspapers purport to know the answer to, at least if you read the headlines. Opioids became a problem in the early 1990s when big pharmaceutical companies tried to boost profits by pushing the sale of painkillers. People eventually got hooked, but when they lost access to prescription medications they turned to heroin as a cheaper, more accessible alternative.

This is a common story told about the origins of America’s opioid epidemic, and it is probably a story you’ve heard once or twice before. But does it really tell the whole story?

In an effort to answer that question, we traveled to Sullivan County, which has one of the highest opioid death rates of any county in New York State, to consult with community members, public health officials, and the families of people struggling with addiction. Although many people agreed that prescription drugs and the pharmaceutical companies are largely to blame for the current crisis, this narrow focus on painkillers ultimately obscures other parts of the story we heard about legitimate injuries, recreation, and self-medication. In short, it misses the broader sociocultural and economic changes that have coalesced alongside a shift in physicians’ prescribing
practices to lead America down the road to addiction. In this blog, we unpack the national narrative surrounding the opioid crisis in the United States, and then adjust it to account for what we heard on the ground in Sullivan County.

How Did Opioids Become a Problem?

The National Narrative

Americans moved from prescription opioids to heroin and now fentanyl.

Nearly every account of the opioid crisis in America begins in the early 1990s, when large pharmaceutical companies sought to boost profits by increasing the sale of prescription opioids. Indeed, while many doctors feared the addictive properties of drugs designed to minimize pain, companies like Purdue Pharma set out to change physicians’ prescribing habits by aggressively marketing and promoting their drugs. As early as 1995, the Food and Drug Administration approved Purdue Pharma’s pain reliever OxyContin, and other opioids like it, for the purpose of treating moderate-to-severe pain lasting over extended periods of time.¹ Although organizations like the Agency for Health Care Policy and Research believed that such drugs could be used to improve long-term treatment of cancer pain, companies like Purdue hired hundreds, if not thousands, of sales representatives to push the drug on primary care physicians — physicians who treated conditions other than cancer including arthritis, injuries, and chronic back pain.² Their efforts paid off. By 2001, sales of OxyContin exceeded $1 billion annually, and the drug became “the most frequently prescribed brand-name narcotic medication for treating moderate-to-severe pain in the United States.”³


³ Prescription Drugs: OxyContin Abuse and Diversion and Efforts to Address the Problem.
Consistent with what has been described as a “coordinated, sophisticated, and highly deceptive marketing campaign,” designed to convince “doctors, patients, and others that the benefits of using opioids to treat chronic pain outweighed the risks,” the sale of prescription opioids skyrocketed in the United States.4 Between 1999 and 2010, sales of opioid pain relievers nearly quadrupled, fueling an increase in the number of opioid-related deaths.5 During the same eleven-year period, opioid-related deaths climbed steadily from 8,050 in 1999 to 21,089 in 2010 and beyond. By 2016, estimates from the Centers for Disease Control and Prevention indicate that between 1999 and 2016 opioids claimed the lives of more than 350,000 Americans.6

Alarmed by the growing number of deaths, state and federal officials sought to restrict access to painkillers, or so the narrative continues. In 2016, Massachusetts became one of the first states to limit the duration of first-time opioid prescriptions to seven days.7 In little over a year, the National Conference of State Legislatures found that twenty-three states enacted similar legislation, with prescribing limits ranging anywhere from three to fourteen days. Prescription drug monitoring programs (which seek to improve opioid prescribing) and dosage limits (which penalize healthcare providers who prescribe patients more than a certain amount of opiates) are two additional examples of state-level interventions designed to control the supply of opiates. For its part, the federal Drug Enforcement Administration (DEA) announced in October 2016 that it would reduce the manufacture of almost every opioid pain medication in the United States.

According to research published in Addictive Behaviors, an increasing number of people are experimenting with heroin as their first opioid, rather than transitioning from painkillers to heroin, as the dominant narrative would suggest.

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States by a minimum of 25 percent. Although many people celebrated these supply-reduction efforts as a necessary first step in the war against opioids, others warned about their effects on people already struggling with addiction. Indeed, for the men, women, and teenagers already dependent on prescription opiates, limited access to painkillers created a new problem — finding more money to buy more expensive pain pills on the street, or tracking down a cheaper, more accessible alternative. For many, the solution was heroin.

A rise in the use of heroin seems to bear this out. According to The National Survey on Drug Use and Health, heroin use in the United States has steadily increased since 2007, with only a few exceptions. Because heroin consumption is not as common as the use of other illicit drugs, the survey includes estimates for both current (past month) and past year use. Throughout 2016, an estimated 948,000 people aged twelve or older used heroin (see figure below). Although this figure was comparable to the estimates reported in 2014 and 2015, it was still higher than the estimates reported each year between 2002 and 2013. Not surprisingly, the number of heroin-related deaths has also climbed. “Between 2002 and 2013, the rate of heroin-related overdose deaths nearly quadrupled,” with more than 15,000 deaths occurring in 2016 alone.

Although heroin claimed the lives of more people in 2016 than in any of the previous fifteen years, fentanyl — which is a powerful synthetic opioid that is “fifty to one hundred times more potent than morphine” — proved even more deadly. Over the past several years, the rate of overdose deaths involving fentanyl and other synthetic opioids doubled from 9,580 deaths in 2015 to roughly 19,400 in 2016, making fentanyl the deadliest opioid now available in the United States (see “Number of Drug Overdose Deaths in the United States, 1999 - 2016” on page 5).

So what explains this move from prescription painkillers to heroin and now fentanyl? The common explanation

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outlined above is that cracking down on prescription opiates has shifted the market to more dangerous drugs like fentanyl. As one senior Vox news reporter put it: "If you go after opioid painkillers, people will eventually go to heroin. If you go after heroin, they’ll eventually go to fentanyl. And if you go after fentanyl, they might resort to some of its analogs, like carfentanil." Admittedly, this logic makes sense. It assumes that whenever individuals lose access to prescription painkillers they are forced into the streets to buy stronger, cheaper alternatives. However, this explanation is too simplistic for understanding the complexities of the current opioid crisis. Although the increasing number of deaths does raise questions about the utility of supply-reduction efforts, this common narrative concerning the transition from painkillers to heroin and now fentanyl fails to account for a variety of other factors that have contributed to the current opioid crisis. These include rapid increases in heroin production; changes in the distribution strategies of drug traffickers; and broader patterns of drug addiction throughout the United States.

Cheap Heroin Floods the Market

With respect to the supply-side economics of addiction, a substantial increase in the availability of heroin has created new opportunities to abuse it. As the DEA observed in its 2017 National Drug Threat Assessment: “Rapid increases in heroin production in Mexico since 2015 have ensured a reliable supply of low-cost heroin, even in the face of significant increases in user numbers.... This increase was driven in part by reduced poppy eradication in Mexico and Mexican organizations’ shift to increased heroin trafficking.” What this means in the context of the United States is that more people have access to heroin than ever before. According to research published in Addictive Behaviors, an increasing

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number of people are experimenting with heroin as their first opioid, rather than transitioning from painkillers to heroin, as the dominant narrative would suggest. In 2005, less than 10 percent of people who were dependent on opioids used heroin first. However, a decade later, that number increased to a third, making heroin “the leading drug for new opioid initiates.” As one observed, a dealer-driven increase in supply “gave more people new opportunities to try heroin even if they weren’t addicted to painkillers.”

Changes in the way drug traffickers are doing business have also contributed to the rising number of deaths, particularly with respect to the sale of fentanyl. While prescription fentanyl — which takes the form of patches or lozenges — is sometimes diverted from healthcare facilities, it is more common for powdered forms of the drug to be illicitly manufactured in China and Mexico and then smuggled into the United States. Once here, powdered fentanyl is mixed into heroin, oftentimes without the buyer’s knowledge, or pressed into counterfeit pills resembling Xanax, Oxycodone, and other opioid medications. When used as a cutting agent in heroin, fentanyl “looks like heroin, is packaged in the same baggies or wax envelopes as heroin, and displays similar stamps or brands as heroin.”


16 2017 National Drug Threat Assessment.

17 Ibid.
perspective, the logic is simple. By mixing fentanyl with other adulterants including sugar, dealers can sell less heroin for the same price and oftentimes with the same effect. In fact, the DEA has observed that an increasingly large amount of fentanyl is being sold as heroin, even when there is no heroin in the product.

Although most people who are exposed to fentanyl are unaware that it was used to cut heroin, there is some anecdotal evidence to suggest that others actively seek the drug. When we asked folks in Sullivan County about whether people know they are being sold fentanyl, one retired probation officer told us that some people go looking for it. When a death occurs, rather than alert people to avoid a particular dealer, it signifies to buyers the drug’s potential potency. “If it does kill somebody they run down the road and get more,” he explained. The DEA alluded to a similar phenomenon in its 2017 National Drug Threat Assessment. According to the federal government’s leading drug agency, public health warnings intended to notify “the community that a particular heroin stamp is known to contain fentanyl” can actually cause “some users to go in search of it.” Still, the DEA believes that the vast majority of heroin users who are exposed to fentanyl actually have no desire to take the drug.\(^\text{18}\)

Beyond the supply-side economics of drug addiction outlined by the DEA, we spoke to folks in Sullivan County about what they believed was driving the epidemic. Surprisingly, their answers didn’t revolve around drug cartels in Mexico or the profits to be made by selling fentanyl. Instead, their responses were rooted in the small, rural community in which they lived. In fact, the only person to mention illegal drug markets in Mexico or China was a county-level official who told us that the federal government was failing in its responsibility to stop drugs at the border. In describing the federal government’s “lackluster response” to the opioid epidemic, he pointed out that opioids — unlike marijuana — cannot be grown legally in the United States. “The great poppy fields of Sullivan County aren’t fueling this issue,” he reassured us. Still, the vast majority of people we spoke to talked less about foreign drug markets than about the realities of why people in rural communities turn to opioids in the first place.

From a Bird’s-Eye View to a Worm’s-Eye View: Pathways to Addiction in Sullivan County

Although we spoke to a variety of people in the fields of public health, law enforcement, and even families struggling with addiction, they pointed us in the direction of three main pathways to addiction — legitimate injuries, recreational use, and self-medication.

\(^{18}\) Ibid.
Legitimate Injuries

When asked about the different pathways to addiction, several people told us that friends and family members were prescribed opiates following a physical injury at school or work — for example, a high school student who was prescribed painkillers after suffering a football injury; a young woman who had her wisdom teeth removed; or a middle-aged man who slipped and fell at work. Because men and women of all ages are susceptible to these types of injuries, the sentiment in Sullivan County is that opioid addiction “does not discriminate” — that it threatens young and old, rich and poor, urban and rural communities alike. However, some respondents, many of them public health officials, expressed concern that middle-aged people and the elderly are at a particularly high risk for opioid abuse. “It’s not just young people,” one official told us. “A lot of people think that it’s the eighteen-to-twenty-four-year-olds. What we’re really finding is it’s predominantly more in the thirty-and-forty-year-olds.”

National statistics bear these findings out. Between 1999 and 2014, the CDC found that prescription overdose rates were highest among people aged twenty-five to fifty-four years old. Listening to the folks in Sullivan County, many people feel that prescribing practices themselves obscure the dangers of taking prescription medications to manage pain-related injuries. In the paraphrased words of one respondent — it starts off with a prescription, then leads to a problem. It’s not cocaine, which you buy from the street. It’s not marijuana, which comes from an illegal source. The rationalization is that it’s from a doctor. People don’t realize its impact. Once you’re hooked, you’re hooked.

Recreational Use

Despite growing concern over opioid abuse among middle-aged Americans, there was considerable speculation regarding the pathways to addiction among those who use drugs recreationally. Oftentimes, though not always, these discussions focused on teenagers who are allegedly stealing painkillers from their parents’ medicine cabinets. According to Aleta Lymon, former director of prevention and training at the old Recovery Center in Monticello, young people are gaining access to prescription drugs by going to pharm parties in Sullivan County. “They’re taking the medicine from their medicine cabinets at home, and they’re going to parties, and they’re dumping all these meds into bowls,” she told the Times Herald Record. After talking with several people about opioid abuse in Sullivan County, such concerns appear rooted in the belief that drugs have increasingly come to define youth culture in the United States. Thus, one parent and community organizer told us about songs like “Rockstar,” which glamorize “poppin’ pillies” and other forms of drug use. Kids, she explained, are looking for more ways than ever to get high, whether that’s by huffing glue or mixing prescription cough syrup with soda and Jolly Ranchers (the so-called purple drank or sizzurp, named after the ingredient used to make it). Still, the notion that kids are doing what they’ve always been doing, namely partying...
with drugs to have fun, was prevalent in many of the conversations we had about young people. While it remains to be seen whether, and to what extent, changes in American youth culture precipitated the current opioid crisis, one thing is certain — the drugs available to young people are becoming both increasingly deadly and available.

**Self-Medication**

While pill parties and the purple drank conjure up images of teens acting irresponsibly and out of control, it is clear that young people turn to opioids for other reasons. Of the three women we spoke with whose children struggled or are struggling with addiction, two indicated that their daughters were ostracized at school because they didn’t fit in. The use of heroin among these young women was not a form of acting out, or even the result of a dependency on painkillers. Instead, it was a form of self-medication. According to one parent: “My daughter she was bullied in school and I think that’s part of the reason why she started.” For others, opioids helped their children cope with anxiety, depression, and other co-occurring mental health disorders. Thus, another parent indicated that her daughter, now in recovery, was never prescribed painkillers. In fact, she never even smoked cigarettes. Yet once her daughter discovered that marijuana could help reduce her anxiety, it was only a matter of time before she started using alcohol, and eventually heroin, to cope with her mental health issues. This is not to say that all people with mental health disorders use drugs to self-medicate their symptoms, or vice versa. Indeed, the causal relationship between mental health and substance abuse disorders is still unclear.

However, the number of people with co-occurring disorders is significant. In 2016, an estimated 8.2 million adults aged eighteen or older (3.4 percent of all adults) experienced co-occurring mental health and substance abuse disorders, even though only about half received either mental health care or substance abuse treatment.21

Research on the rising morbidity and mortality of middle-aged white Americans indicates that teenagers are not alone in using opioids to self-medicate. In a now-famous study, researchers Anne Case and Angus Deaton found a surprising increase in midlife mortality among non-Hispanic whites living in the United States due to drug overdoses, suicides, and chronic liver diseases. In interpreting their data, Case and Deaton have argued that these so-called “deaths of despair” may be linked to declining wages, limited job opportunities, and fewer marriages.22 In other words, failure to fulfill societal expectations has led to higher rates of suicide, drug abuse, and other risky behaviors, particularly among middle-aged white Americans. In Sullivan County, which is 73 percent white, the effects of joblessness and other “collateral issues,” as they were described to us, can be seen driving through town.23

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If you were to drive over Route 52 to go to ShopRite, it’s not uncommon — if you keep your eyes open — to see people walking over that overpass with a baby carriage, holding the baby in their arms, with everything they own in the carriage.... Now put it this way. I’m going to be brutally honest with you. If I was in that position, I’d probably shoot dope too. I would boot up and bang off in a heartbeat if I felt that hopeless.

In Sullivan County, like many other rural communities throughout the United States, townspeople have watched as industries died, wages diminished, and jobs evaporated. Yet many people remain. In this setting, people don’t just abuse drugs because they want to experiment or have fun, although some of them do. In this setting, people depend on drugs to numb the reality of an otherwise painful existence. Absent an understanding of how these broader, socioeconomic forces feed into the cycle of addiction, any response to the opioid crisis will be inadequate at best.

**Conclusion**

Sullivan County isn’t much different from other communities ravaged by the opioid epidemic. An increasing number of people are dying but there’s very little anybody can do to stop it, or at least that’s what most people told us. Thus, when researchers, journalists, and politicians ask the question about how opioids became a problem, it is imperative that we speak to the people who face down this epidemic every day in their communities. Indeed, a national narrative that begins and ends with pharmaceutical companies and aggregate data misses the human element of addiction and the multitude of pathways to get there.
Nestled in the Catskills, Sullivan County has a striking natural topography: beautiful mountains and houses dotting picturesque lakes. It’s no wonder why, in its heyday, New York City’s residents flocked to Sullivan to escape the summer heat.

Like many upstate communities, however, major industries have left. The agriculture and tourism industries that drove Sullivan’s economy have declined substantially, and the prevalence of drugs has increased. Today, like many places, opioids are common. Even though Sullivan is a relatively small county of 78,000 people, it has one of the highest opioid death rates of any county in New York.¹

A 2017 Rockefeller Institute report found that more than 3,000 New Yorkers died from drug overdoses in 2015, a number that has steadily grown over time.² Although no part of the state is left untouched by the opioid problem, the effects are most stark in upstate communities. For example, between 2010

² Ibid.

Sullivan County, New York
and 2015, the Bronx saw a 57 percent increase in drug-related deaths, while Onondaga County saw a 145 percent increase, and Erie County a more than 250 percent increase.

State policymakers have shined a light on the opioid problem with both executive and legislative task forces and a broad package of reforms — reducing the amount of opioids a doctor can prescribe, eliminating insurance barriers for treatment, and increasing the number of treatment beds in New York.

Even with good intentions, statewide reforms mandating particular kinds of behavior can still have a disparate impact on the state’s very different regions. What works in New York City — with its extensive infrastructure and robust economy — may not work in upstate areas without these advantages. Or, what works in urban centers like New York City, Albany, or Buffalo, may not work in rural counties like Sullivan because rural areas face a different set of challenges than urban or even suburban areas.

**Why Are Opioids So Hard to Combat?**

In our discussions with policymakers, health officials, community activists, and providers in Sullivan, we heard common themes, likely similar in many other places: it’s hard to get appropriate treatment; there is little or no support for housing and jobs; and wraparound services are nonexistent. But we also heard of problems distinct to rural places like Sullivan: All of the above problems are exacerbated by a lack of services and a lack of transportation.

**Access to Appropriate Treatment**

In New York City, lack of access to treatment services might mean plenty of doctors and facilities, but none that will take a patient unable to pay. In rural areas like Sullivan, some services are just not available: There are no detox beds in the county’s premier hospital and service providers rely heavily on outpatient treatment. We heard over and over again about a lack of both treatment beds in qualified medical facilities and even just beds to sleep in at night. Getting a bed of any kind requires a wait.
Families, providers, health officials, and activists noted that the model of care has shifted and long-term treatment facilities are closing. As one county health official told us: “There is no long-term treatment programs anymore, the eighteen to twenty-four months do not exist. Do I understand it? Yes,... I do understand the six to nine month, and so on and so forth. There’s just no ifs, ands, or buts about it.” Treatment was most often at outpatient facilities, but outpatient rehabilitation is especially hard in rural counties that lack public transportation.

**Housing and Jobs**

We heard over and over again how people addicted to opioids had difficulty finding housing and jobs, even after they completed treatment. For all of the empty resorts peppering the county, there are few housing options for addicts who have completed recovery programs. They go back to the same environments that maintained or even fed their addictions. Low-income individuals, for example, are housed in motels known for cockroaches and drug deals. As a lawyer explained to us, once people with addictions finish a program, they are forced back to the place that got them started and they relapse: “Aftercare treatment is homelessness.”

People who have addictions or who have criminal records (often because of their addictions) have a difficult time finding and maintaining steady employment. Although many of the best resort jobs dried up when the tourism industry died down, the county did bring in a new casino to the area, which opened in February. But even here, local residents wondered how many local people would be hired, especially given constraints on the skills they have, the addictions they are combating, and the criminal records that follow them.

**Wraparound Services**

For people who have successfully completed treatment programs, there are no wraparound services to help them find housing and jobs and to navigate the complex healthcare system. Instead, they are left to fend for themselves. For example, we heard about a senior citizen who suffered a stroke and applied for Medicaid, but the process of applying for Medicaid can take up to three months. “He has a beat-up car, can’t afford an inspection,” but his only option was to drive to Poughkeepsie for rehabilitation “because not a single provider between here and there will take his insurance.”

**Why Is It Hard in Rural Areas?**

Rural areas, like Sullivan, have a small population spread out over a large geographic area. The very basic services that urban and suburban residents take for granted, like transportation and communication infrastructure, are missing in rural areas. Other essential services, like education and emergency medical services, are spread out over a large area, making them more expensive to provide. When combined with poverty, the problem can feel insurmountable.
Almost every person we spoke with said that transportation is an issue. According to one community member, “transportation and poverty are powerful.” They create a barrier to just about everything from buying fresh food to seeking out appropriate medical care to finding and maintaining a job. The county — a thousand square miles, roughly the same size as Rhode Island — runs just two bus routes and only on Thursdays and Fridays. Lack of transportation makes it difficult for people who suffer from addiction to get the services they need.

People suffering from substance abuse disorders may not have access to cars. Medicaid will pay for taxis to medical appointments, but it does not pay for transportation for other necessities, like trips to the pharmacy or grocery store. Even if they do have cars, lack of transportation means that someone who is on drugs and wants or needs to get somewhere may drive while under the influence.

A health official explained that there are not enough treatment facilities in the county and, with no real public transportation, a traditional system does not work. There aren’t enough beds, certainly. But there aren’t enough doctors (only two psychiatrists in the county), not enough dentists, and not enough social workers. For people who live outside the center of the county — the triangle composed of Monticello, Liberty, and Fallsburg — it’s three times as hard. Health officials and providers are well aware of the problem, but not as sure about the solutions, such as telemedicine or mobile clinics. Although they need a presence in the far reaches of the county, doing so takes resources from the already stressed services provided in Liberty and Monticello.

Because of the large geographic size of the county and the lack of meaningful transportation, many services in Sullivan become, like healthcare, hard to get: basic necessities, work, or even daycare. According to one education official: “Transportation has a big impact on workforce…. I know there are people who have, they have to take a cab to work and they will pay $15 to go two and a half miles, but it’s [snowing] ... and they might only be making $9 an hour or $8 an hour.
or something.... And I think that’s harder here.... Even within Monticello, people take cabs and it’s really expensive.”

What Can We Learn from Sullivan County?

Like many counties in New York State and across the nation, Sullivan County has an opioid problem. And, like many counties, the opioid problem is hard to combat when individuals lack access to services they need.

However, unlike urban and suburban areas, rural areas have particular challenges. First, lack of access in rural areas does not mean having services but not being able to afford them; rather, many services are just not available. Second, rural areas have a small population spread out over large geographic areas. Transportation is an issue for meeting basic needs like

As a lawyer explained to us, once people with addictions finish a program, they are forced back to the place that got them started and they relapse: “Aftercare treatment is homelessness.”
healthy food, healthcare, and work. County officials and service providers struggle with how to use limited resources to meet these complex needs, either finding ways to bring people to centralized services or finding ways to get services out to the far reaches of the county. Either way, existing resources are stretched thin as it is, and it is not clear how to expand to meet the growing challenges.

Additionally, rural areas have been hard hit economically. When industry leaves, there are not a lot of alternatives. Two health officials explained in rural areas, “When it’s bad, it’s really bad.” We heard this sentiment often. Rural areas are slower to recover from economic downturns. Even with the new casino, they have fewer people who are qualified and able to work in it.

Although the opioid problem is national news, it is experienced in local communities. Our visits to Sullivan County have showed us how the problem looks on spreadsheets to researchers or policymakers may be very different from how it looks on the ground to upstate communities.
The first time I saw someone smoke pot, it was in the back row of a school bus that had just crossed the line dividing Ulster County from Sullivan.

I was twelve years old. Each day, I took a school bus for forty-five minutes from home to the local high school, weaving through a series of small towns along Route 209 to a slightly bigger town where the school sat. At the end of the day, we did the same ride in reverse, working our way through one-store and no-store towns and along rural roads that followed streams or ran alongside forests with signs for hunters.

This wasn’t the suburbs. No one got dropped off in front of their house. Instead, the bus rode down what passed for the main arteries in towns like Spring Glen or Phillipsport. Schoolkids would disembark in bunches at drop-off points.
and then walk far down gravel roads, the thin capillaries that lead to old farmhouses and simple ranch homes and trailers all over Sullivan County.

I spent ten years of my childhood in Sullivan County, from age seven to high school graduation. The time covered the end of the 1970s and most of the 1980s. The end of the famous Borsht Belt resorts felt inevitable even then, though a few of the old hotels hung on. As a teenager, I worked each summer at the Nevele, just over that county line where the school bus ran. Crowds still came for the belt-busting meals and the summers at the pool, but each summer there were more empty chairs on the lawn and fewer guests to entertain.

The Stardust Lounge rolled the spotlights each night, though the entertainment was far from cutting edge. (One old Catskills comedian, playing to his mostly Jewish crowd, opened each set with a groaner about the then-King of Jordan and enemy of Israel: “King Hussein? They should call him King Whonuts!”)

Back then, Sullivan County felt like two worlds: the mythical past of the Borsht Belt and the day-to-day rural poverty that made up reality for most of the kids who lived in my corner of the county. They were children of men who worked at the tanning factory (which closed), the sawmill (which closed), the local auto mechanic. Or their parents were teachers who tried to educate children up and out of the county.

As the incident in the school bus suggests, Sullivan County was like many places then in regards to drugs: kids smoked pot in parked cars, or in woodsy hideaways, or in abandoned bungalows. Our parents smoked too, downstairs after they thought the kids were asleep, or in their woodshops or tool-scattered garages, or peacefully on their screened-in back porches. They drank, too, and unlike pot that felt like a real danger. Until Mothers Against Drunk Driving made its voice heard in the 1980s and the state police started cracking down on DWIs, being able to steer home after working your elbow at the local bar was considered a basic life skill.

Much has changed in that time, but the fundamental dynamic of too much space and too little money has not. I am lucky that opioids had not arrived to Sullivan County when I was a teenager.

What’s different now? The hotels are gone, definitively, and they’re not coming back. But the hotels and bungalow colonies always masked the lack of investment in other industries, the absence of colleges and universities, the limited opportunities available to most daily residents. Vacationers would come up to the Catskills for a few months each year, enjoying the fresh air and unspoiled natural resources. When they left at the end of the summer, not much had changed for the people who lived there the rest of the year. The winter was always longer than the summer in Sullivan County.
All of this has made for a particularly vulnerable area for opioids to reach, and a stubborn place from which to rid them. Previous pieces in this series have pointed out just how isolated and disconnected many towns in the county are from each other, and how far they are from the kinds of services cities and suburbs take for granted. Growing up in Sullivan County, I lived this truth.

A brief story will illustrate what I mean. One summer day, when I was eleven, my friends and I decided we wanted to go to the mall. Our parents were working, or taking care of the house, or just had no free time for a spur-of-the-moment trip for idle shopping. It just wasn’t done.

So we hopped on our bicycles, cheap ten-speeds that were hand-me-downs or bought secondhand from older kids. There were three of us, ages eleven, fourteen, and fifteen. We set off mid-morning to ride to the nearest town with the kinds of stores you could wander through. It was seventeen miles away.

To get there — Middletown, New York, in Orange County — we pedaled up forbidding roads that killed our legs and then down at neckbreaking speeds. There is no seventeen miles of relatively flat ground anywhere in the Catskills. There probably isn’t even five miles. It was a long ride, and for most of it we had to ride our bikes on the shoulder of Route 17, the major highway that connects the Catskills to New York City. When tractor trailers flew by, our bikes shuddered from the concussion of the wind. As the youngest, I trailed behind my two friends, straining to keep up with their pace. About halfway there, my friend’s bike hit a loose spot of asphalt. The skinny tire kinked, the bike pitched forward, and he went sprawling into the highway. I watched as he scrambled out of the way of a car that had come speeding around the corner. We tested the bike for fitness and continued on.

It took most of the day to get to our destination. When we arrived, we wandered through a department store for about a half hour, thumbing records in the music section. We had no money. Then we turned around and rode all the way home again. It was a trip born of desperation, of trying to make the world feel a little bit smaller, more conquerable, for one afternoon.

Thirty-six years later, a boy living on my road in Summitville, New York, would find himself just as far from the mall, just as far from the high school. Much has changed in that time, but the fundamental dynamic of too much space and too little money has not. I am lucky that opioids had not arrived to Sullivan County when I was a teenager. There were a lot of hours and days to fill for me, for everyone else. We might have filled them very differently.

My two children were born in Ohio, not New York, but many of the conditions of their birthplace remind me of my childhood. They were born into a thriving college town where I was teaching, but the lively college is only a button on the great green coat of Appalachia, another place of isolation and entrenched poverty. The opioid crisis is there, too. The stories from Sullivan County are only the start.

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It’s no secret that upstate, rural communities like Sullivan County have been hit especially hard by the opioid epidemic, even though the phenomenon is by no means confined to these areas. In 2016, fourteen deaths were attributed to opioid abuse in Sullivan County, and the problem is continuing to grow. According to early estimates for 2017, as many as twenty-seven residents died of a drug overdose in the county last year.

Although no one is sure exactly how to solve the opioid problem in Sullivan County, doing nothing is not an option. What the response looks like, however, depends on whom you ask and where they work. To get a better feel for what the local fight against opioids looks like, we spoke to a range of people in Sullivan County about their experiences. What came into focus was a multifront battle fought along the lines of crisis management, treatment and recovery, and prevention.

**Crisis Management**

Upon recognizing an extensive need for resources and awareness, community organizers and public officials sponsored Narcan trainings throughout Sullivan and Orange Counties.

Narcan, which is a medication used to reverse opioid overdose, “is a prefilled, needle-free device that requires no assembly and is sprayed into one nostril...”

Sandra Oxford, donor engagement coordinator for Rural & Migrant Ministries, at a new community garden in Monticello.
while patients lay on their back.” Between January and December 2017, the Sullivan County Public Health Department trained 246 people to dispense Narcan, Catholic Charities an additional 244, and the Greater Pine Bush Partnership another 300. It’s amazing, one organizer told us, how many lives a single training can save.

But not everyone is as enthusiastic about administering Narcan in this way. In fact, we heard about growing frustration among first responders who are concerned that Narcan doesn’t just save lives, it also enables an addiction. Indeed, it is not uncommon for police officers, EMS workers, and family members to revive the same person multiple times — even in the same day. In response to the argument that Narcan offers little more than a safety net for risky behavior, one public health administrator pointed out during a meeting of the Opioid Epidemic Task Force that, although the county can’t mandate substance abuse treatment, people at least need to be alive to get there. From this perspective, Narcan gives public health professionals another chance to intervene, and people struggling with addiction another chance to seek treatment.

A second, yet related, approach to crisis management in Sullivan seeks to cut off immediate access to opioids in the county by removing drugs from people’s homes. The Prescription Drug Abuse Prevention Task Force thus organizes Take Back Days in partnership with the local Sheriff’s Office. According to Public Health Director Nancy McGraw, the purpose of these events is to prevent prescription drugs from “falling into the wrong hands and being abused or sold on the streets.”

On any given Take Back Day, people with unwanted pills can drop them off at a temporary collection site, no questions asked, and the Sheriff’s Office will transport them to Poughkeepsie for incineration. The county hopes to obtain its own incinerator soon so transport to Poughkeepsie becomes unnecessary. In addition to numerous Take Back Days sponsored throughout the year, permanent drop boxes have been installed at the following local police stations: Liberty, Fallsburg, and Monticello, as well as the lobby of the Department of Family Services building. As a result of these combined efforts, more than 1,700 pounds of unwanted medication have been removed from Sullivan County.

For its part, the Sullivan County Sheriff’s office has made a concerted effort to identify and arrest the leaders of major drug trafficking organizations. In 2014, for example, as a result of two teenage overdose deaths in Livingston Manor, Sullivan County Sheriff Michael Schiff  

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1 United States Drug Enforcement Administration, “Major Heroin Supply Chain from New York City to Upstate Counties, Long

### Sullivan County Narcan Trainings by Specialty Area, 2017

<table>
<thead>
<tr>
<th>Specialty Area</th>
<th>Count</th>
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<tbody>
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<tr>
<td>Refresher Law Enforcement</td>
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<tr>
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<td>65</td>
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<td>School Personnel and Students</td>
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<td>County Employees</td>
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<td>911 Call Center workers</td>
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<td>County Commissioner Refresher</td>
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<tr>
<td>2017 Total Trained by Sullivan County Public Health</td>
<td>246</td>
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launched an investigation into the drug’s supplier. In less than a year, a partnership between the Sullivan County Sheriff’s office, the New York City Police Department, and multiple federal agencies led to the arrests of five members of a Bronx-based drug trafficking network and the seizure of nearly $5 million (twenty-six pounds) of heroin. In addition to takedowns and investigations, the county is considering adopting a program like Wallkill Cares, which allows people in the neighboring town of Wallkill to request treatment for substance abuse from the police in Orange County.

Although county-level officials and organizers are coming together to combat opioids in any way possible, many people believe that the problem is only getting worse. Indeed, with so much time and energy being invested in crisis management, some of the more expensive solutions, like medical treatment and prevention, seem even further out of reach. “It’s like treating someone for a burn when they’re still in the fire,” one public health administrator told us — we’re “treating the problem upside-down.”

### Treatment and Recovery

Ironically, in a place overrun by vacant rooms and abandoned beds, remnants of the luxurious hotels, bungalow...

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colonies, and boarding rooms of the past, one of the greatest challenges facing Sullivan County is limited access to drug treatment facilities and housing. Although two hotels — Paul’s Hotel in Swan Lake and the Grand Hotel in Parksville — were purchased and converted into adult residential facilities by Samaritan Daytop Village, both were closed in the early 2010s after the comprehensive human services organization filed for Chapter 11 bankruptcy.

The Daytop facilities were generally reserved for New York City patients; still, it is difficult to comprehend why the number of drug treatment facilities would decline as the number of opioid deaths skyrocketed.

Sullivan County is not alone in watching its long-term treatment facilities close down. As the Substance Abuse and Mental Health Services Administration observed, long-term residential treatment, which can have lengths of stay anywhere from twelve to eighteen months, is “relatively

uncommon.”5 Quite frankly, some people in the community are convinced that long-term care is rare because it’s exorbitantly expensive. “If we’re really committed then why aren’t people getting services,” exclaimed one frustrated member of the Sullivan County Opioid Epidemic Task Force at a recent meeting. “Why aren’t we paying for it?!”

Still, people in the public health community offer an alternative explanation, which is that the model of care has changed. While putting a person in long-term treatment might help them achieve sobriety, it does not always equip them with the tools they need to successfully navigate challenges at home. “Long-term treatment programs closed because they weren’t successful,” one public health administrator said, though not everybody agrees.

For people seeking treatment in Sullivan County, one option available to them is Catholic Charities, a comprehensive human services organization with a chemical dependency clinic in Monticello, in the heart of Sullivan County. In addition to providing medically supervised detox and withdrawal programs, Catholic Charities offers intensive day rehabilitation services; residential programming for men and women; and community-based supportive housing apartments. Surprisingly, the detox center at the public hospital closed a few years ago. “They were never at full census,” explained one public health administrator, after the hospital changed its admission criteria to include physical withdrawal. “If you’ve ever encountered an addict, they are not going to let themselves go through physical withdrawal because it’s so uncomfortable, especially for opiates, it’s unbearable…. So their census began to deplete, and it wasn’t cost effective. It’s very high cost to run a detox center in a hospital.”

For those on the other side of treatment, the process of recovery begins. According to one public health administrator, more needs to be done to prevent people from relapsing in recovery. Drawing a comparison between the safe environment of a long-term treatment facility and the challenges people face back home, she expressed frustration over her inability to mandate patient participation in Alcoholics Anonymous (AA), which was deemed a “religious activity” by the federal Court of Appeals.

“We can’t mandate AA/NA [Narcotics Anonymous] which is driving me crazy, because of the legality,” she explained:

I think the field actually lost it when they stated that AA/NA was a religious affiliation and that we couldn’t make people go, ‘cause we were more successful when they had that buffer, if that makes sense, they had a safety net. Now they have to find it on their own. We can suggest it. Some people still do it. The majority of them don’t, you know... So without being able to mandate some kind of buffer to help them and support them through the process while they are out there, I think a lot of them trip and fall.

Instead of mandating participation in Narcotics Anonymous, public health administrators can connect individuals to a licensed peer recovery coach. In addition to developing a recovery plan, these coaches assist clients by putting them in touch with a wide variety of services and acting as a personal guide and mentor. The program, known as Friends for Recovery, circumvents some of the bureaucratic red tape found in hospitals. “HIPAA [the Health Insurance Portability and Accountability Act] impairs self-help groups,” one peer recovery coach told us. “It squashes the intimacy between recovering addicts.” By comparison, Friends of Recovery, which emphasizes holistic healing and other spiritual principles, creates a place where people can talk openly about their problems and build fellowship.
In addition to peer recovery coaches, the county is working with local organizations to start a support group for those who lost loved ones to overdose.

Prevention

In light of the growing death rate, people in Sullivan County recognize the need for something more than just treatment. “We need treatment, we absolutely need it,” one provider explained. “But the word treatment is what it is — it’s treatment. It’s not a cure. Prevention is a cure. It’s an absolute cure.”

Growing recognition of the need to stop drug addiction before it starts has led to a range of responses directed at prevention. Hindering these efforts, however, is a lack of resources. Although treatment in Sullivan County remains vastly underfunded, there are even fewer dollars earmarked for prevention. The State Targeted Response (STR) grant awarded to Catholic Charities is a perfect example of this disparity in funding. In September 2017, Governor Andrew Cuomo announced that Catholic Charities Community Services of Orange and Sullivan would receive a $2 million grant to enhance access to prevention, treatment, and recovery services. However, little more than a $100,000 was set aside to deliver an afterschool, evidence-based prevention program known as Too Good for Drugs. Although the program seeks “to promote life skills” and “resistance to the use of illegal drugs,” schools have difficulty freeing up staff for trainings and integrating the program into an already cramped curriculum.7

In the absence of money, community organizers have done what they can to raise awareness. In February 2017, the Tri-County Community Partnership (formerly the Greater Pine Bush Partnership) launched its “Have a Slice” campaign to encourage parents to talk to their kids about drugs. Eight pizzerias participated, placing stickers on pizza boxes with facts about drug use that could be used as conversation starters. Numerous panel discussions and events have also been held to educate the community about drug and alcohol abuse. In October 2017, the Sullivan County Drug Abuse Task Force sponsored a public health conference at Bethel Woods entitled “Local Solutions to a National Opioid Crisis.” In addition to covering such topics as the “biology of substance use disorders” and “medication assisted treatment,” elected officials, public health experts, and law enforcement officials discussed ways of working together to end the opioid problem. In a community strapped for cash, something as simple as a conversation can go a long way.

Conclusion

The fight against opioids in Sullivan County is carried out not only in police stations and hospitals but around the kitchen table. Although many people expressed concern that the opioid problem is growing, the inability to contain the spread of opioids has less to do with a lack of resolve in the county than a lack of resources. Even though a permanent solution remains elusive, folks in Sullivan County continue to hold the front-line.

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Rockefeller Institute’s analysis of aggregate data show that opioid use is growing, deadly, and especially difficult across New York State, but the numbers are particularly troubling upstate. These data don’t show, however, exactly who in the community is affected by opioid use and how they are affected. We asked policymakers, health officials, providers, and activists in Sullivan County about how opioids have an impact on their communities. As we expected, they told us the sheer quantity of drug overdoses has a huge impact on the public health and criminal justice systems. What we didn’t anticipate, but heard often, were the spillover effects on families, social services, and schools.

Families

Opioid use can be, in the words of one parent, “devastating” to families. We spoke with four mothers whose teenage and adult children battled addiction. In our discussions, we heard how expensive, time-consuming, and emotionally exhausting addiction is for family members. It puts stress on relationships with other family members. The stress, guilt, and anxiety can break up marriages. One expert described living with an addict as “walking on eggshells.”
Even for families with resources, like education and jobs, it can be difficult for parents to navigate the complex system to get help for their children with addictions.

According to National Public Radio (NPR), the number of children in foster care is skyrocketing, in some places doubling. In New York State, foster care placements have declined substantially since the 1990s, in part driven by a large decrease in New York City. Still, in Sullivan County, the number of children in foster care is up from a low of forty-eight children in foster care in 2009 to eighty-two in 2016. According to one county official, normal action plans just aren’t available because “mom and dad are both on drugs and the kids require placement.” Child Protective Services is dealing with these kinds of cases and is overwhelmed finding homes for and placing children, let alone the additional cost, estimated at a million dollars.

Although better than unsafe environments, foster care can disrupt children’s lives. Children in foster care “can’t get access to ... their driver’s license because they’re in foster care, can’t go to work, get working papers cause they’re in foster care.... You know, sleepovers, the typical things that kids do, is limited in that service.” Local officials try mightily to make their lives as “normal” as possible and to keep them in their schools with friends, but parents’ opioid use is — at best — disruptive for children.

In the end, there just aren’t enough services of all kinds for children of parents with addiction. One county health official explained that addiction can be traumatic for a child who has “watched their parent get taken out in handcuffs, or watched their parent and walked in a room, and they’re stoned out of their mind, or I can just imagine what a child is seeing.” These children need resources: psychiatrists, social workers, trial workers, guidance counselors, foster families, and medical doctors. Yet,
Sullivan County has a hard time attracting people to fill these positions. People in Sullivan explained that the pay is low, the work is hard, and the potential for official reprimand is high.

The epidemic is also straining the county. Already meager resources are spread even thinner. Caseworkers have dozens of files, and state funding is based on “units of service,” i.e., time spent with clients, not the quality of care they provide. A sixty-minute visit in the office or clinic would count as one unit of service, but social workers do not get compensated for the coordination they must perform among all of the other actors. “[W]hen you talk about a child, you have a social worker … the trial worker…. You have the guidance counselor in the school. They might be on probation in the community. You have a medical doctor that might be treating them for something else. You have the parent. You know, so you have a multitude of service providers that you’re supposed to be coordinating care with…. We do a sixty-minute unit of service with the client sitting here, but yet I have to call parole. I have to call the school. There’s the care coordination component and we don’t get credit for that. How do we get paid for that?”

Schools

Although opioid deaths are highest among New Yorkers age forty-five to fifty-four, the effects of opioid use by grandparents and parents has an effect on schools, as does the smaller (but growing) number of youth who use opioids. One former school resource officer noted that Sullivan County’s schools are impressive for what they do offer, like access to psychologists. But guidance counselors who reach out to kids who are troubled can’t always mitigate the problems associated with bullying and the self-medication that comes from it.

The cost of treating opioid addiction — through county programs, Medicaid, Medicare, private insurance, or out-of-pocket costs — is so high that many people push for prevention to avoid problems. During the 1980s and 1990s, schools adopted the Drug Abuse Resistance Education (D.A.R.E.) program, which encouraged students to “just say no” to drugs. D.A.R.E. was originally developed in Los Angeles by police officers and teachers to reduce drug, tobacco, and alcohol use by youths, as well as to improve relations with police. Although D.A.R.E. programs were adopted across the country, there was little evidence
that it actually worked. Schools stopped using it.

Now, prevention advocates are looking for alternatives to be used in its place, like “Too Good for Drugs,” a program targeted by grade level that teaches healthy lifestyle choices (including not using drugs). Still, schools in Sullivan — like New York State more generally — are overwhelmed with requests for teachers to do a lot more than simply teach the basics. One teacher explained that for prevention programs to work, teachers have to really believe in them and not see them as just another thing they have to do. And they have to resonate with students. She gave the example of a school art teacher who planned events for students, enabling them to express and share their work. One student called her the “antidrug teacher,” for her ability to create a program that was meaningful for students. “Three-fourths of them would roll their eyes at a drug program,” she explained.

When we think about the opioid problem, we think about people with addictions and treating those addictions. But the effects of opioid addictions spill over past those people who are addicted and into their families, the social services in a community, and to schools. Policies and programs to address opioid addiction also need to take into account the needs of these other important institutions.
PART 6

#MeToo in the Wake of Addiction

Research on abuse and drug treatment overwhelmingly focuses on how childhood abuse causes trauma and how individuals use drugs as a way to deal with it. Women are more likely than men to have experienced sexual and physical abuse,\(^1\) and women who have experienced sexual violence are five times more likely to misuse prescription opioids.\(^2\) But women and men don’t just use drugs because of trauma caused by sexual assault. They are also more vulnerable to sexual assault because of their addictions.

Research shows that rape commonly occurs with drug or alcohol usage, especially for young adults. A study on opioid use among young adults in New York City found that women who use

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opioids were perceived at greater risk for sexual violence because they were often disoriented or unconscious. Further, the study found that opioid users are often seen as “unworthy of sexual respect and as readily willing to sell sex for drugs or money.”

The numbers back up this idea. Both women (82%) and men (43%) report frequent propositions for sex, often by strangers, because of their addictions. And both women (39%) and men (24%) have exchanged drugs or money for sex. But women experience this more often and more severely than men. Forty-one percent of women and 11 percent of men report being forced to have sex without their consent when they were using drugs. One mother in Sullivan County, where we are studying the opioid problem on the ground, told us: “It’s very different to be a woman and to be in the addiction cycle because of that.” It “takes your self, it continues to eat away at your self esteem.”

Another mother told us about her daughter, Tina, who was living with an addict, panhandling for money. The only way he let her get out of panhandling was if she had sex with him. Tina’s mother tells us that wasn’t at all like her daughter, who is fastidious about her body and is gay.

It isn’t just dealers or other users who take advantage of opioid users. It’s also the very individuals who are supposed to be helping them. According to media reports, doctors in Atlanta, Detroit, Chicago, and San Diego have prescribed opioids in exchange for sexual favors, and, in at least one case, prescribed opioids and then demanded sexual favors to refill prescriptions once women were addicted.4

In our discussions in Sullivan County, we heard how one young woman was offered


drugs in exchange for sex by a doctor at the treatment center where she was seeking help. Her mom explained, “the doctor ... was soliciting women for sex, when they would go to get Suboxone from him ... not uncommon. There’s a guy up here ... too, was doing the same thing. I saw a text one time from that doctor to my daughter ... it’s this, the whole thing with women who are addicts and the trading of sex, and the soliciting of sex.”

This young woman did not want to report the doctor for fear that she would see him at the local Shoprite grocery store and for fear that she wouldn’t be able to get the treatment she needs. In rural counties, like Sullivan, where there are only four doctors licensed to dispense medically assisted treatments, like Suboxone, what happens when there is one fewer?

Like the young woman in Sullivan, opioid users rarely report sexual propositions and assaults. There are almost no consequences for perpetrators. The stigma of drug abuse means that drug users often blame themselves and feel that others will not believe them, contributing to what the authors of the New York study describe as “a drug using culture with few social consequences for perpetrators of sexual violence and little support for those who are victimized.”

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“It’s hell,” one mother told us, describing her son’s heroin addiction.

Over the past fifteen years, Sam has been in and out of treatment, in and out of jail, and back and forth to medical appointments. She told us that it is “impossible” to succeed after addiction, and even harder in rural areas. Who will take him to probation meetings? Who will take him to doctor’s appointments? He has no car and there is no public transportation. She doesn’t give him money, but she does buy food for him and help with his rent. “Some people might say I’m enabling,” she says, but there is no playbook on what to do when your child has a substance-use disorder and few resources to help guide the way.

Although much of the conversation about addiction focuses on the individuals — how opioids affect the brain or if a “bed” is available for detox or treatment — a peer recovery specialist described addiction to us as a “family disease.” According to a national survey conducted by the 2004 Faces & Voices of Recovery Campaign,¹

¹ The Faces & Voices of Recovery Campaign Raises Awareness About Recovery from

Julie Pisall founded the Kingfisher Project, a radio program that aims to raise awareness of heroin addiction, after her daughter’s death in 2014.
more than two-thirds of American families have been touched by addiction. What does this mean for families? And, where can they go to get help?

Addiction is “devastating” for families. It creates stress, anxiety, and disagreement between family members. According to Sullivan County District Attorney Jim Farrell, people with substance-use disorders may betray their families by stealing from them. They may lie to them too. While parents can feel exploited, they still worry about their kids. But continued support for children with addictions can lead to conflict with other family members. “They’re constantly telling me why do I do it, you know, he’s never going to change. I do it because of my son and ... I’ll do it until I cannot” do it anymore.

Feelings of guilt and loneliness stem from the stigma of addiction. Most of the mothers we spoke to didn’t want to be identified; they didn’t want to shine a light on their children (we use pseudonyms to protect their identities). Parents struggle, feeling that they might have done something wrong, they might be bad parents. They feel shunned “by the entire universe.”

Early one night at a forum on opioids in Liberty, a mother raises her hand. She, too, has been dealing with her son’s addiction for more than a decade. She, too, doesn’t know what to do. She is frustrated. Facilities treat individuals with opioid addictions, she says, but they don’t provide help, support, or therapy for families. Where can she go for help?

Families need support. But it can feel as if the system is designed to punish them.

There are alternative, more comprehensive models of care. Maryland, Rhode Island, and Vermont implemented a health home model for people with substance-use disorders. Health homes are not physical “homes” for people to live, but rather an administrative structure that allows states to provide coordinated care for high-need, high-cost Medicaid beneficiaries with chronic health needs.

Woodbourne Correctional Facility in Woodbourne, New York. For parents of children with substance-use disorders, jail is not always the worst option — it means a drug-free environment, housing, and regular check-ins afterward.

probation and goes back to jail. “Who’s being punished?” his mother asks. “My son is, of course, because you’re not giving him the tools to ever make it out.” But she’s been living in the wake of addiction for years.

Without the proper supports, parents in this situation feel like they are “left to their own devices.” Libby has been involved with opioids for more than a decade, and her mom describes the public, private, and nonprofit services available to families as a “big blanket with a lot of holes.” There are no standard protocols across different agencies and the rules are contradictory. When asked where families can go for help, mothers we spoke to said there isn’t one place.

Family support groups can help. “My mother started going to Al-Anon and Nar-Anon support groups and she started talking about what was going on,” one person in recovery told us. “She stopped hiding it and took a step forward, and with that she learned a lot,” Surprisingly, her involvement in the group and the information she obtained also helped her son. “A lot of my manipulative behaviors that I was trying were no longer successful. I think in the long run that did help me. I had to finally kind of face the music for some of my stuff.” Still, such meetings aren’t for everyone. A friend took Libby’s mom to an Al-Anon meeting. “It was terrible,” she explained. Some people say that Al-Anon doesn’t “fit” opioid problems, and it doesn’t fit young people. What works for one family
in Sullivan County doesn’t necessarily work for another.

Although there are many services in Sullivan County for people with addictions, families we spoke to were frustrated with the red tape. It’s hard to find help, and parents say they can’t give up just because an agency turns them away. Tammi, for example, has been battling addiction for years. When she tried to get out of an exploitative relationship, she called her mom for help. Together they looked into a women’s shelter. It was 3:30 on a Friday and social services didn’t want to have anything to do with them. Tammi’s mom echoed a common complaint: What was she supposed to do? Where was she supposed to go? She had set boundaries: her daughter couldn’t live with her while she was using, but Tammi’s mom couldn’t send her daughter back to a bad situation and agencies weren’t going to help.

Jail isn’t always the worst option. The mothers we spoke to told us how, after decades of drug abuse and decades of navigating a complex system, they have learned to leverage the criminal justice system to help their children. Going to jail, for example, means their children will have little care (no detox, for example) and will come out with a record, making it hard to get a job. But it also will prevent their children from using and it will give them housing (however bedbug ridden) and regular check-ins afterwards. Libby’s arrest “saved her life.” But it didn’t stop the addiction.

Child Protective Services (CPS), too, can be leveraged both to motivate drug-using parents as well as to provide appropriate care for young grandchildren. CPS requires parents with addictions to work out plans for the continued care of their children. It gives authority to other members of the family to provide adequate care for the young. Libby’s mom was glad CPS got involved, “because now they are going to write a safety plan where they can’t have their own child until they … are doing all the things in the safety plan.”

Is this really the best that we can do? There are alternative, more comprehensive models of care. Maryland, Rhode Island, and Vermont implemented a health home model for people with substance-use disorders. Health homes are not physical “homes” for people to live, but rather an administrative structure that allows states to provide coordinated care for high-need, high-cost Medicaid beneficiaries with chronic health needs. Health homes cover the costs of six core services: care management, care coordination, health promotion, transitional care and follow-up, individual and family support, and community services.

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Jail isn’t always the worst option. The mothers we spoke to told us how, after decades of drug abuse and decades of navigating a complex system, they have learned to leverage the criminal justice system to help their children. Going to jail, for example, means their children will have little care (no detox, for example) and will come out with a record, making it hard to get a job. But it also will prevent their children from using and it will give them housing (however bedbug ridden) and regular check-ins afterwards. Libby’s arrest “saved her life.” But it didn’t stop the addiction.

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New York State already has health homes for high-needs populations, especially people living with HIV. But it has not expanded it to people with substance-use disorders. Even if health homes were to provide care for substance-use disorders, it is unclear how the range of necessary services would reach rural areas, like Sullivan.

In our trips to Sullivan County we’ve talked with many mothers, women who bear the disproportionate burden of caring both for their children who have opioid addictions and for their grandchildren who are affected by addiction. Although the particulars of their stories are different, they describe a similar problem: opioid addiction is a family disease without adequate family supports.
PART 8

What Can State and Federal Officials Do to Help in the Opioid Crisis? Listen.

The opioid problem has hit upstate New York and its rural areas particularly hard. We’ve written both about the demographics most likely to use opioids¹ and the spillover effects on families, social services, and schools.² In Sullivan County, it seems as though opioids affect nearly everyone, and nearly everyone has a stake in what happens. Yet, community members feel they are working harder than ever and still falling further and


further behind. Although we asked, repeatedly, what state and federal officials could do to help, people in Sullivan County most often said they wanted officials to understand the problem from their point of view.

Over breakfast at a local diner, community members explained that even though awareness is growing, they see the problem getting worse. For example, the county’s premier hospital, Catskill Regional Medical Center (formerly Harris Hospital), does not have a detox center. In fact, the number of available treatment beds has shrunk even as the opioid problem has grown. A community activist noted that people in Sullivan are inundated. It’s a sentiment that we heard a lot: People in Sullivan are working hard, but they can’t keep up.

In our visits to Sullivan we heard several people compare the opioid problem to the AIDS epidemic of the 1980s and 1990s, which created fear and had no easy solutions. Like AIDS, the current opioid problem is out of control. It’s spreading. And to those on the ground, it feels as though there’s nothing anybody can do to stop it. People in Sullivan believe that addressing the opioid problem means, like AIDS, focusing on both prevention and crisis management.

According to one county health official, it feels as if they are “just spinning [their] wheels.” They really need to address (1) reentry into the community (after treatment or the criminal justice system) and (2) the availability of opioids. Otherwise, “nothing’s going to change.” We’ve heard over and over again how insurance doesn’t cover the cost of treatment. As a result, long-term programs are closing, shortening the length of stays, or reducing what they provide. “[I]t becomes, really, the responsibility of the community providers to fill in the gaps, and we don’t have the resources. And that’s what it comes down to, we just don’t have all the resources.”

It isn’t that the county doesn’t want to do more; it can’t do more. A provider explained, “the county itself doesn’t seem to have the resources, nor sufficient infrastructure, to keep its attention focused on social-determinant, health-related issues.”

What can state and federal officials do to alleviate the burden? We asked folks in Sullivan that question. Given the common feeling of being overwhelmed and inundated, we were surprised by the response. Local community members want more resources, for certain. But more than that, they want to be heard.

When we asked one mother what she wanted policymakers to know, she tells us she’s given up on them. This mother, with political bumper stickers on her car and signs in her yard, doesn’t have faith in officials for the most pressing problem in her life: her daughter’s addiction.
They feel government doesn’t understand the problems they face.

Sullivan County lacks physicians and facilities to treat people with opioid addiction, housing and jobs to keep addicts from relapsing, and wraparound services to navigate the system. A lack of transportation, along with poverty, make the opioid problem particularly difficult to solve.

Local officials and service providers have extensive experience with state and federal regulations, but they see them as often hindering, rather than helping, them. As a county health official explained to us, the state is very good at handing down directives based on studies done in labs. However, there is a disconnect between what the community provides and what the state sees.

Federal rules, too, can seem to people on the front-lines as hindrances. For example, federal HIPAA rules, which protect patient privacy, have admirable goals. However, the effect is to make coordinating care in offices that handle multiple health issues much more difficult. A provider explained to us how, at one point, two sides of the same clinic were treating the same person for the same set of problems related to addiction but couldn’t talk to one another.

Local actors do not have much faith in other levels of government to help them. When asked if local government and other organizations think they can go to the state and get money from the state, a service provider responded: “No.… you’re...
not living in the real world when you think that way.” This provider explained, “You can walk through the streets and see [local elected officials]... So there’s more of a connection that way. And we’ve got to look each other in the eye.” He contrasted the personal, responsive relationship community members have with local officials to the relationship they have with state officials, who are located farther away, and federal officials, who are not seen as invested in the community, noting that he was thinking of putting one official’s picture on the side of a milk carton saying “have you seen this guy?”

A community advocate told us how she focuses not on government but on hope. Opioid addiction can seem very dark, and the reality is that parents lose their children. She doesn’t shy away from that. But there’s also hope, and people need that. They need more than the numbers, more than empty words from political officials. When we asked one mother what she wanted policymakers to know, she tells us she’s given up on them. This mother, with political bumper stickers on her car and signs in her yard, doesn’t have faith in officials for the most pressing problem in her life: her daughter’s addiction.

Certainly, people in Sullivan could use more resources, and they often said as much. They don’t have what they need in terms of infrastructure to handle the primary problem (people with drug addictions), let alone the secondary effects on families, foster care, and schools.4 They think that policymakers are throwing money at cities. They encounter all kinds of government agencies: OMH, OASAS, SSDI, Medicaid. But these agencies make it difficult to get help, rather than facilitate it. When we heard suggestions of what government can do, it was to get out the way. Local government officials and nonprofit providers said they’d like fewer regulations that make it difficult to do their jobs.

People in the community seem to think that other levels of government don’t “get” them. They feel left behind. They worry about the future. They do not want to be the photo op for a politician’s campaign, and they don’t want to be lectured by public officials who may have never met a person addicted to opioids, let alone work or live with them day in and day out.

This sentiment is not unique to Sullivan County. When we asked an addiction specialist who works for a public facility in a different state what she wanted officials to know, she responded that addicts and the people who work with them “are worth it.” She choked up as she explained, “we are worth spending the money on. We are worth spending time. We are throwing [addicts] away. We throw them away. They are someone’s father, someone’s son. I’m tired of us throwing them away. I’m tired of them being treated as though they don’t matter.”

People on the ground want engagement. They want people in high positions to understand them and the problem they face. They want public officials to care.

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