

Life in Obamacare's Dead Zone

Excluded from the Affordable Care Act because of politics, thousands of poor Americans grapple with the toll — physical and psychological — of being uninsured.

By INARA VERZEMNIEKS DEC. 6, 2016

In the Riverview Gardens apartment complex, roused by the sounds of her neighbors waking, Janet Foy stepped over the anatomy-and-physiology textbook she fell asleep reading and vowed to herself that today would be the day she finally came back to life. That today she could start reclaiming some of the confidence she once felt when she stood onstage at church and sang about forgiveness and redemption and You who make all things new. At 56, Foy was broke, jobless and living with her older sister in public housing in Kansas City, Mo., and she didn't feel much like singing anymore.

Recently, she had been told by a manager at a Victoria's Secret that there was no need to leave her résumé. But not too long ago, she wanted me to know, she was pulling in \$1,000 a week at a Merle Norman makeup store, helping other people look and feel their best. But then she took in her brother to try to help him overcome an addiction, and soon she was pulled under financially as he spiraled out of control. She would show up to work too overwhelmed and exhausted to make any sales, and had to dip into her savings until that was gone. She begged to borrow against her next paycheck but eventually lost her apartment and moved into a friend's spare room.

How are you holding up? people would ask. *I'm good, girl*, she would say. *Praise the Lord!* But inside, she felt like the sci-fi movies she had seen in which “a person becomes encapsulated,” suspended between consciousness and oblivion.

Finally, on the phone with her sister one night, she broke down: *I'm not right, I feel like I am dying.*

“She was always the steady one,” her sister, Karen Smith Walker, says. “The one who could solve any problem. Always with a book. Always studying.” But now, after years of living with this desperation, Foy didn't know how to find her way through it anymore.

“I tried to get Obamacare,” Foy recalls. “I called the number, and when the woman told me what it would cost me, I just about dropped the phone. She told me I'd needed to make at least \$12,000 a year for there to be any help to make it something I might be able to afford. Which still doesn't make a lot of sense to me, even now, that having no money meant I got no help when I really needed it.”

She also learned that she could not expect any help from Medicaid, which in her home state remained available only if you fit the criteria sometimes known by the shorthand “poor and” — poor and pregnant, poor and disabled. As a single childless woman, she could forget about it. There was no going to a doctor, even if she felt, as she put it, “like I was falling to pieces inside.”

But then one day she found herself sobbing in front of a nurse and a social worker, members of a team dispatched by the local safety-net clinic to embed themselves in the lives of the uninsured residents of the apartment complex where Foy lived — a grass-roots, door-to-door, last-ditch effort to reach those who would otherwise, as one resident delicately put it, “remain S.O.L.” The team, part of a program called Community-Centered Care, or C3, developed by the Samuel U. Rodgers Clinic of Kansas City in partnership with the Housing Authority of Kansas City and the Truman Medical Center, used their collective expertise to help the uninsured come up with creative

interventions for their health concerns, beyond relying on a regimen of studious neglect supplemented with panicked, bankrupting visits to the E.R. Some days that meant knocking on apartment doors and offering on-the-spot blood-pressure readings. Other days it meant arranging for guest speakers to come and lead on-site classes about reducing stress or cooking nutritiously with limited ingredients.

In Foy's case, it meant a referral to a therapist, who promptly gave her an explanation for her suffering. "My neurotransmitters were going *pphhht*," she told me. "They were just shot, after all that loss and trauma I had been through." The therapist treated Foy for depression — at no cost. That was a benefit for residents who worked with the C3 team: They received three free visits to the nearby Sam Rodgers Health Center, which they could use for any treatments offered there, including dental work. After her first session with the therapist, Foy started to imagine what it might be like to feel normal again. But after her third visit, sessions would cost \$35; modest, she knew, but still more than she could afford. Over the last few years, she learned there was more than one kind of death, like the inability to lift yourself out of a bad place. Now that she had begun to do just that, she dreaded the possibility of losing it all over again.

According to the most recent census data, the uninsured portion of the United States population has fallen to 9 percent, with the sharpest drop registered among those living in households with incomes of less than 200 percent of the federal poverty level (which, translated into dollar terms, is the equivalent of an income of \$48,600 a year for a family of four, or \$23,760 for a single person). According to the Kaiser Family Foundation, more than 11 million people have purchased private health insurance plans through the Affordable Care Act exchanges, and a majority report incomes between 100 percent and 250 percent of the federal poverty level. It would seem that lower-income Americans are among the greatest beneficiaries of the A.C.A.'s reforms. And yet in some states this same population also remains, paradoxically, among the reforms' greatest losers. This subpopulation is living inside a kind of "dead zone," as Foy put it to me one day, searching for the right metaphor to describe her predicament. A long and suspended silence, she called it, "like when you can't receive a single call, a single text."

How these dead zones formed is a matter of unanticipated consequences. The A.C.A.'s architects did not predict that the Supreme Court would rule in 2012 that it was up to each state whether to expand Medicaid eligibility, which is how they imagined Americans with the most modest incomes would receive coverage. Even though the federal government would have helped fund the expansion, 19 states opted for ideological reasons not to do so, arguing that they are pushing back against government bloat and the fostering of dependency. A result was that the residents with the lowest incomes in those 19 states were now caught between two nonoptions: They made too much to qualify for Medicaid, or didn't qualify at all, but they also made too little for publicly subsidized insurance on the exchanges, their income not high enough to trigger the refundable tax credits and cost-sharing that could make the possibility remotely affordable to someone making just a few dollars above the federal poverty level.

This paradox is referred to widely as the coverage gap. Most people in that gap are on the far side of middle age, with about one in eight edging toward 65 — a time in life when more serious health issues begin to emerge. Almost half are nonwhite. They are almost equally split along gender lines. About a quarter are supporting children, and everyone in the gap is more likely to be working (62 percent) than not (38 percent). Those with jobs work largely for small businesses that employ fewer than 50 people, which aren't subject to A.C.A. penalties for not offering employer-based coverage. Most people in the gap who have jobs work full time. They are agricultural workers, primarily, or service-industry employees, but some hold jobs in education, health and social services, professional administration or manufacturing.

There is little disagreement in the existing literature about the negative effects of being uninsured: You are more likely to receive a diagnosis of late-stage cancer; you are more likely to postpone or forgo care, resulting in more severe consequences as treatable illnesses become increasingly complicated with delay. There's also good, hard evidence from large-scale studies on "the wear and tear that worry and stress has on people who don't have insurance coverage," says Genevieve Kenney, co-director of the Health Policy Center at the Urban Institute,

noting one of the most compelling and most cited: a study in Oregon that found that offering Medicaid to the uninsured reduced bad medical debts, decreased the likelihood of choosing to cover medical expenses over other bills, buffered them from catastrophic out-of-pocket payments and significantly reduced depression.

And yet the coverage gap is a new enough phenomenon that scant on-the-ground research exists into the particular and distinct ways that it is playing out in people's day-to-day lives. Already, a scattering of researchers, mostly medical anthropologists, have taken steps to follow communities where significant numbers of people are caught in the coverage gap, in order to gain the kinds of insights "you don't get from a single snapshot, a one-off survey," says Heide Castañeda, an associate professor in the anthropology department at the University of South Florida. Those insights reveal, as she puts it, "not just how vulnerable people are, but how much agency they have, how much initiative they have to try and find a solution when none seems to exist. You can't code that in a binary way; you have to watch it unfold over time."

In Castañeda's case, she has been studying the lives of the uninsured in Hidalgo County, Tex., which has one of the highest rates of uninsurance in the nation. She has traced the health of dozens of families over the last four years, simultaneous to the rollout of the A.C.A., documenting how they have responded to illness or chronic disease or accident. What she has seen is that to live in the gap demands a creative, improvisational mode of survival — one that often masks the true extent of the disparities to anyone on the outside. "It might be true no one is dying in the streets," she says. "But the uninsured are dying younger; people's life expectancy is affected, people's ability to work is affected. These informal types of health care, as important as they are, actually help us not to see that."

If it can be said that life in the gap tends to inculcate a certain guerrilla thinking among those who have no choice but to consider highly improvisational modes of insurance, then it can also be said that treating the people marooned there requires a similar flexibility of thought. You must manage the strange simultaneity of making someone aware of a grim diagnosis, even as you also know you do not have the means to properly remedy it.

My curiosity about this mind-set is what had brought me to Kansas City, and would ultimately draw me into the state of Kansas, covering more than 1,000 miles in five days. The area had already established something of a reputation in medical and health-policy circles, even before the emergence of the gap, for the innovative ways its providers had adapted to the overwhelming demands of treating the uninsured and medically isolated. Kansas City was, until recently, home to the largest free clinic in the country (before the clinic's board voted to accept insurance in anticipation of the A.C.A. and the expansion of Medicaid in its state, which then did not happen). And it is currently the home of the Health Care Foundation of Greater Kansas City, which gives away \$20 million each year to help fund organizations looking for alternative ways to reach the uninsured and to expand community access to quality medical care — the same foundation that supported the efforts of the team embedded at the local housing project where Janet Foy lived.

The president and chief executive of the foundation is a primary-care physician named Bridget McCandless, who for 13 years before taking her current position headed a Kansas City-area free clinic. She is widely considered a thoughtful and measured voice in larger conversations about community health, having served as president of the Metropolitan Medical Society of Greater Kansas City and serving currently as a citizen representative on a Missouri House of Representatives working group devoted to Medicaid reform. McCandless seemed the perfect person to speak to about any unlikely innovations that had emerged to work around the lack of immediate legislative solutions for those in the gap.

She told me a story about one of her former patients, a man with a seizure disorder: "He's well controlled on inexpensive medicine. However, he has to see a doctor to get the prescription. Because he lacks insurance, he inevitably runs out of medication and has a seizure. This means that he can't drive to work for six months. It's

really hard to work in construction when you have to admit to having a recent seizure — preventable or not. He collects cans on the side of the road to support himself now.”

It was hard to be innovative, in other words, when you didn't have anything to innovate with.



Janet Foy and her goddaughter, Marionna. Foy lacks health insurance, falling into the “coverage gap” affecting 19 states: She doesn't qualify for Medicaid but makes too little for assistance under the Affordable Care Act.
Credit Malin Fezehai for The New York Times

A program manager named Rebecca Anderson at the Kansas City CARE Clinic, which was once the nation's largest free clinic and which also receives funding from McCandless's foundation, put it to me this way: When she first started working for the clinic, she did H.I.V. case management, “which feels really heavy. But there are so many resources available to those patients. Then I transferred over to this area” — she now oversees a team of community health workers assigned to work one on one with uninsured patients — “and this is way harder. These patients really have access to nothing. Absolutely nothing.”

In the case of Kansas, where Gov. Sam Brownback's experiment in radically reducing government has included not only refusing to expand Medicaid but also on paring back its existing program, the question of what it meant to have access to nothing took on a particular resonance.

My first stop was Iola, where the foundation that McCandless heads also funds initiatives for the uninsured. In the parking lot of the local safety-net clinic, nearly every spot was filled. Rich seams of coal, natural gas and zinc fueled huge mining operations in this region during the early part of the 20th century, but by the 1930s the seams were already becoming depleted, leading to less and less work. Today the area is largely defined by entrenched generational poverty, unemployment and poor health. People who live in rural areas are much more likely to fall into the coverage gap than those who live in cities, distance and isolation amplifying the complications associated with the patchwork way they must care for themselves.

Cyndy Greenhagen worked out of a converted closet in the Iola clinic, and as the designated patient navigator, she ran the numbers for community members who came in without insurance and looking for assistance. She would tell them whether they fell into the gap. Iola was small enough that she could remember the people she couldn't help — like Suzan Emmons, who lived across town with her two granddaughters, ages 10 and 12. For almost three decades, Emmons, 56, ran her own business cleaning houses. She had become parent to her granddaughters only recently, after seeking their guardianship to remove them from an abusive situation. The girls no longer hoarded food in their room for fear that they would not get another meal, but they were still getting up in the night, sometimes three, four times. The therapist who worked with them told Emmons that the girls were checking to make certain she hadn't left them.

Last year, Emmons made just over \$13,000. She carried private insurance until two years ago, when it became too expensive. But she imagined, when she went to see Greenhagen, that she would now qualify for some kind of assistance. Instead she learned that with the two girls in her household, she fell into the gap.

It was the kind of incongruity that Greenhagen regularly experienced in her job. She had said no to people with cancer; people who worked three jobs but still didn't make enough to bump themselves out the gap; people who had been laid off and who had made the decision to return to school but now had no income as a result, and so fell beyond the borders of assistance.

Another person Greenhagen had recently said no to was Shanette Smith, who lives with her two daughters and her in-laws in the home where her husband was raised, not far from the town of Toronto, on the edge of a state park where some of the oldest trees in Kansas still stand. Her girls ride their bicycles in dizzying loops up and down the same driveway that a police cruiser rolled down in the early hours of a morning four years ago — a trooper dispatched to inform her that her husband had been killed in a single-car accident on a stretch of highway just a few miles away.

'I'll take my chances with dying, if that's what it comes down to. We have no money.'

"After that, things fell apart for a while," she told me, as we stood together in the dining room, where her mother-in-law keeps her collection of Pepsi memorabilia in curio cabinets. The girls were debating whether tonight they would be able to go take showers at the state park, for which their grandmother had purchased a yearly pass. Shanette, her mother-in-law and the girls sometimes went there in the summer to wash up because it offered not only the promise of inexpensive entertainment — *Do you think we'll see frogs in the bathrooms again, like we did last time?* — but, with only one bathroom for all of them at the house, also efficiency, measured in terms of both time and water.

Three years ago, at her in-laws' invitation, she and the girls moved their things into the two back bedrooms of the house. With her in-laws' help, Smith, 28, was able to return to school full time, taking classes at a community college an hour's drive away. Smith found that she liked school, that she was a good student. She realized that she could finally study to become a nurse, something she considered before her husband's accident. One by one, she ticked off her required prerequisites, hunted down transcripts and secured letters of recommendation. She was ready, she thought, to turn in her application to a program in September. But then, while attending an informational meeting, she heard of one last requirement she had not anticipated: Students had to prove they had health insurance.

Up to that point, she had simply gone without. The school suggested she look into Obamacare. Which, in turn, led her to Greenhagen's office. Smith had assumed that the \$700 a month she received in widow's benefits and the fact that she was a full-time student would qualify her for some kind of help; she didn't know about the gap, or that her state was one of the places where it existed.

Greenhagen kept looking at her screen, as if she didn't believe it. "I'm so sorry," she said.

After she left the little closet office, Smith walked to her truck, locked the doors and cried. “It just felt like a huge loss,” she told me. “How could everything I had been planning toward, all the work, how could it all be for nothing?”

Smith had been trying not to show her daughters how frightened she felt ever since Greenhagen had delivered the news that insurance was out of her reach — and so, therefore, was nursing school. “Shall we get a broom to fight off any frogs we might find in the shower?” she asked them as they prepared to head to the park. But the same thought was repeating over and over: Now what am I going to do? She thought it as she put her daughters to bed, her youngest daughter saying to her through the dark, “I can’t wait to go to school, so I can have homework, too.” It frightened her that she felt too numb to try to come up with an answer.

The day after my visit with Smith and her family, I drove to the town of Pittsburg, to the Community Health Center of Southeast Kansas, the largest safety-net clinic in the state. The center’s doctors tend to more than 43,000 patients a year, regardless of their ability to pay — “We will never take anyone to collections,” a founding member of the center and its C.E.O., Krista Postai, told me. Many patients here have complicated their medical problems by going for years without seeing a primary-care doctor, fearing a bill they couldn’t afford. “This,” Postai said, gesturing around the building, “is all catch-up.”

The guiding philosophy at the health center has always been to “always simply say yes — yes, we can help you, whatever it takes,” Jason Wesco, the clinic’s executive vice president, told me. Sometimes that meant staff members’ volunteering to drive someone to Kansas City in their own cars. In the doctors’ cases, it frequently meant, with their patients’ permission, serving as unofficial specialists — reading up, consulting experts and doing as much as they could within the perimeters of their training — for those who could not afford to see one. Still, there was only so much a doctor could do for a man with bone cancer, for a woman who required a heart transplant.

“It’s very hard to know that because of a lack of resources, someone will die,” Julie Stewart, a physician at the center, told me. “To have to look in a patient’s eyes and say: ‘Your prognosis is different than that of someone who lives in another state. Your prognosis is less because you don’t have access to insurance.’ ”

An evangelical Christian, Stewart was featured heavily in state and national news accounts of the coverage gap over the last year, and she spoke with the conviction and eloquence associated with the tradition of religious testimony. “There’s a disconnect between politicians and people’s lives on the ground,” she said. “I’m strongly pro-life. I testified for the fetal-pain bill because I believe God created life. I’ve said babies can feel the same pain as adults, and that position was applauded, so why, when adults are experiencing the kind of severe debilitating pain that I am seeing because they cannot afford the care they need, are the same people not also working to do something about that?”

Currently she had a patient with lupus who was particularly worrying to her. The medications Stewart had tried did not seem to be working. “I keep telling her it’s time to see a specialist” — she had arranged for one at Kansas University to see the patient for \$200 — “but she keeps saying no, she can’t possibly afford it.”

Stewart wanted to check up on her, so we drove to her home, in a corner of Kansas that Wesco had told me was, until the center opened a satellite office there, so medically isolated that the doctors were seeing cases they had not seen in their residencies or in medical school.

“I’ll take my chances with dying, if that’s what it comes down to,” the patient, Brenda Hannah, told me, sitting in the living room of the home she shared with her husband, Bill. “We have no money. We live on Bill’s disability.” She had been working at Walmart when the pain first started to become unbearable. She couldn’t stand long enough “to make a sandwich.” By the time she finally connected with Stewart, she had to quit working, and had already racked up several emergency-room bills. “The pain would just become unbearable,” she said. “It got to

the point where I told Bill to hide the guns — I didn't want to know where they were.” Bill, silent, rocked harder in his recliner.



When Suzan Emmons gained custody of her granddaughters, she was surprised to hear that her larger household size made her ineligible for A.C.A. subsidies. She now lacks health insurance.

CreditMalin Fezehai for The New York Times

Since she started working with Stewart, Hannah rated her pain at about a 5 on a 10-point scale, which Stewart counted as an improvement. But Hannah was still in a lot of pain. “You should really go to that specialist,” she told Hannah, who just shook her head. Bill required dialysis three times a day, which she handled at home. “I’ve sat here and thought, What can I pawn? The house is the only thing we have. We’re behind on bills so bad” — she pointed to a table where she had stacked unpaid medical bills and all other bills in two piles, each over an inch thick — “and now the car tags are due.”

Next to the front door, Brenda had taped two Post-it Notes at eye level, the last thing she would see on the way out of the house. *You are smart (smart ass included). You are fun to talk to.* “For my depression,” she explained. “To remind myself of the good things about me.”

Summer gave way to fall. Shanette Smith sent off her application to nursing school, hoping that maybe by the time she heard, something would have changed and Greenhagen would not say no. Suzan Emmons gave a speech at a community forum sponsored by a coalition of organizations working to urge the Kansas state government to expand Medicaid and end the gap. “I have worked my entire adult life,” she said. “For the past 26 years, I have been self-employed as a housekeeper. I make an honest wage. I feel I am doing all the right things to be a good citizen.” Janet Foy was trying to ignore a painful knot on one of her breasts. She had heard once of a folk remedy involving iodine, and at first she treated herself this way, ingesting three drops each day. The pain stopped, but

when she ran into members of the C3 team in one of the common areas, they urged her to attend a free mammogram event at the local health clinic as a precaution. Until she found the knot, Foy had, in fact, been feeling the best she had in months, like she “might have something in the tank after all.” The therapy sessions she received free through the interventions of the C3 team had proved a turning point, she told me. She spoke of wanting to sing again. And she had finally come up with a plan that she was certain would bring herself back to life: medical billing and coding.

She had found an online review course for \$20 a month to prepare for the accreditation test. She followed up this news with a trip to Kmart, where she could lease a \$200 Chromebook. Next, she placed a folding table and chair in a corner of the apartment, where she planned to do her homework. My little office, she called it.

Through contacts in the housing authority, she had recently learned of the possibility of a paid internship in the medical records and billing departments at a local insurance company, and she wanted to do whatever she could to position herself for consideration. “I’ve already researched all the bus lines,” she told me.

So she waited for the news from the mammogram technician with particular anticipation. When the woman told her the mass was benign, she felt it was nothing less than permission to believe that things were going to get better, even if she did not yet know how. “I’m doing all I can for now, with what I have,” she says. “Sometimes that’s all you can do. You just have to take your little life, and walk it out.”

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