Heart Of The Uninsured

When a young heart patient ages out of Medicaid—then dies because she can’t afford her medication—her physician takes up the cause of the uninsured.

by Arthur Garson Jr.

I think of her often—almost every day. We met when she was five years old; well, not exactly “met.” She was asleep, and I was awake. Tape and tubes covered up her face, but there was a picture of her that her family had attached to the intensive care unit bed: cute, really cute. She had just come out of surgery after a long operation on her heart to change her color. Born a blue baby, she was now a normal pink.

It was my first night on call as a pediatric cardiology fellow. My job was to get her through the first night after surgery. She was fine for the first three hours; my supervising doctor went home, and we settled in. Suddenly, the dreaded “Dr. Garson, stat, ICU, bed 4.” It was a cardiac arrest—just like on television’s ER—nurses, doctors, chest compressions. Someone shouted “clear,” and we did. The shock through the paddles caused her to jump—flat line. Then a beep came from her monitor and another and another. She was back. The science of medicine.

And then the art of medicine—telling her parents. I had only met them briefly on rounds (“Take care of our little girl—she’s all we have.”)

I told them what had happened and held their hands; they cried, and I almost did. Her parents were wonderful; we helped each other. That night, her heart stopped three times, and three times science triumphed; three times art comforted. By morning she was stable, and the four of us had bonded. I found the “art” so satisfying. Guidelines, computers, and technology will increasingly improve the technical care of patients, but what about their fear and helplessness? That night I was proud to be a doctor who couldn’t be replaced by circuitry.
Watching, Monitoring, And Graduating

Her name was Ginny. Without the tape over her mouth, she had a bright smile and was fun to be around. Five is a wonderful age. She had a long recovery. The day she was discharged, we traded home phone numbers, just like family. I saw her monthly for a while and, as she improved, every six months in the clinic. We traded ten sets of birthday and holiday cards. She did beautifully until her check-up at age sixteen, when we discovered a heart rhythm problem.

I had spent the ten years while Ginny was growing up investigating heart rhythm problems in the laboratory, and I knew how devastating they could be, even leading to sudden death. For Ginny, we tried a number of drugs and eventually found exactly what we needed: a once-a-day medication that was easy for her to remember to take, although, unfortunately, it was very expensive.

She again did beautifully and was beaming when she introduced me to her friends at her high school graduation. She decided she wanted to work for a couple of years before going to college to help her parents with her medical bills (they both worked in a small grocery), but after she went through six job interviews, all with small businesses (no large employers in her town), no one would hire her. She told all of them that she had congenital heart disease. She told me that she was proud of how well she had done and wanted others to know. I couldn’t tell her to lie about her heart disease, but she didn’t need to volunteer the information. By the time she called to tell me, it was too late; there were no other jobs she could apply for in town, and she had no car to travel elsewhere. Was it illegal for those businesses to turn her down? Yes. Immoral? Yes. Change anything? No.

In this country, fewer than half of small businesses with three to nine employees offer health insurance to their employees, compared with more than 90 percent of those with more than 200 employees. For those small businesses that do offer coverage, there is, by definition, a small pool of employees who share the risk of high medical costs, so that if a person has a known high risk, such as Ginny, many employers will not employ him or her for fear of the effect on their insurance rate, despite the fact that this practice is illegal under the Americans with Disabilities Act. However, the more likely scenario is that the small business would not offer health insurance at all: More than 70 percent of uninsured Americans are in families with at least one full-time worker.

One Sunday I received an early morning call. Sobbing...then “Tim, we’ve lost her!” Ginny’s mom found her dead in bed. It didn’t take long to figure out what had happened. Ginny’s pill bottle was empty. The last refill was five months before—

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just before her nineteenth birthday, when her Medicaid eligibility ended and her prescription drug coverage stopped. She had no job, and we guessed, though we were not certain, that she was trying to save the family money.

Making The Uninsured An Issue

I think of Ginny often—almost every day. I never could understand how the "system" that had paid to fix her heart, and paid for her medicine, dropped her at nineteen. But that's the way it works. Medicaid (and the State Children's Health Insurance Program [SCHIP]) covers children of the poor, like Ginny, but between the ages of nineteen and the Medicare age of sixty-five, the so-called safety net has huge holes—and Ginny fell through. Surprising to some, Medicaid rarely covers anyone in this age group.

The day of Ginny's funeral, I made the uninsured my personal issue.

At the beginning of the 1990s, health care reform was on everyone's agenda. The country was finally going to cover the uninsured by changing the entire system—a goal that made sense to me. I arranged my schedule so that I could spend three days each week in Washington working with other academic health center leaders to help change the system. But nothing happened. A Peanuts cartoon at the time said it all. Charlie Brown was walking dejectedly off the pitcher's mound, and Lucy was saying, "It's OK, Charlie Brown, you win some and you lose some." Charlie Brown responded, "That would be nice."

Following President Clinton's failed attempt at health care reform, America turned to managed care as the solution for everything. The notion of significant health care reform was off the table. In that context, I worked with Louis Harris and Associates to prepare a poll. It was to be a barometer of public opinion, asking the central question, "Should the U.S. have a new health care system?" We hypothesized in 1997, three years after the downfall of Clinton's Health Security Act, that the country would be at a low point—with perhaps 10 percent answering in the affirmative—but we would follow the results yearly, and when increasing numbers answered positively, the time might be right to launch some new ideas. Much to our surprise, in 1998 the USA Today article written on the basis of the first results from the poll told a different story. Of those queried, 78 percent said that the United States should have a new health care system. That meant that the country was ready for a new system, right?

The next year, as president of the American College of Cardiology (ACC), I had the opportunity to interact daily with physicians, patients, public officials, industry leaders, and policymakers, and I decided to develop principles for a new national health care plan. The plan's principles, endorsed by the ACC, called for cov-
verage for all on the basis of competitive public and private plans, with coverage for
the uninsured paid for by new appropriations as well as redirected current ones. I
presented this plan in my final presidential address to a massive convention center
full of cardiologists. Cheers! More cheers! Press conference! The entire speech was
carried on the front page of the Houston Chronicle Opinion section. It went nowhere.
No, despite the poll, the country was not ready for a new system.

The embers continue to smolder. In 2002 an Institute of Medicine (IOM) com-
mittee on which I worked produced a report, Rapid Advances in Health Care, that pro-
posed “state models” as the basis for change. States could serve as testing grounds,
and perhaps the country, when ready, could choose from among the best models.
The report proposed that states focus on two major critical areas: achieving in-
creased access to affordable insurance through public or private insurance pro-
grams, or both, and establishing statewide electronic insurance clearinghouses.

A year later, I worked with Sen. Jeff Bingaman (D-NM) to originate legislation,
using the IOM concepts as its basis, that featured a program in which states
would apply for grants to help improve health care coverage, quality, and cost; the
program included a requirement for a state-based health information technology
infrastructure. Senator Bingaman was joined by Sen. George Voinovich (R-OH) as
cosponsor of The Health Partnership Act introduced in May 2006 with a compan-
ion bill in the U.S. House of Representatives.

“The Plural Of Anecdote...”

In August 2006 I was appointed to the Virginia Health Reform Com-
mission. Ever hopeful, I reminded my colleagues on the commission of the
well-known aphorism that “the plural of anecdote is policy.” I told two anec-
dotes: the first was Ginny’s story, and the second was as follows:

The LED on the automobile clock in a car pulling into a field in rural southwest-
ern Virginia says 2:00 a.m. The driver turns the key, killing the motor. The field is huge and
dark. At first light, the driver and her two pas-
sengers roll over and out the door. Betty is a
twenty-nine-year-old, 230-pound mother of six
who works at a restaurant. Her boyfriend, Jake,
who works at the dry cleaners, has been having
pain in his side off and on for almost a year.
Betty’s fourteen-year-old daughter, Molly, has
had such a bad toothache for three months that
she is unable to eat and has lost fifteen pounds.

They put their arms around each other and walk half a mile to the end of the line.
Already people are lined up quietly for a quarter of a mile across the field. They are
waiting for the gates to open for the Rural Area Medicine Clinic—a weekend
event that occurs once a year for anyone who has no health insurance and can get there. About 1,500 volunteers (doctors, dentists, nurses, and staff) provide more than 6,000 visits in two days. It is a true “health fair” where every person can get a physical examination, teeth are pulled, mammograms performed, eyeglasses made, and blood sugars checked. Follow-up visits are planned to those few clinics that will see uninsured patients.

I attend the yearly Rural Area Medicine Clinic and was there a few weeks ago, along with a number of state officials who also volunteer. As we gathered at the end of the day, one of the officials said, “Isn’t it horrible—that we need this?” And another answered, “Isn’t it wonderful—that we have this?” And I said, “Yes.” During that day, Betty learned that she had diabetes; Jake, abdominal cancer that could have been found much earlier with a physical examination; and Molly, such a severe dental infection that eight teeth had to be pulled. No wonder there is a 20 percent higher mortality rate in middle age for those without health insurance.

Most people in the United States would agree that the uninsured are a problem—just not their problem. As more Americans and their neighbors become uninsured, it will become their problem. Local solutions seem to offer promise. Efforts at reform are under way in states, and experimentation in both public programs and private insurance strategies (that would help small businesses afford insurance for people like Ginny) should be encouraged. The federal government can help by providing support such as that proposed in the yet-unpassed Health Partnership Act. In any of these public approaches, it is helpful to remember that in the United States, the uninsured are forty-six million individuals, and each has a story to tell.

I think of Ginny often. Almost every day.