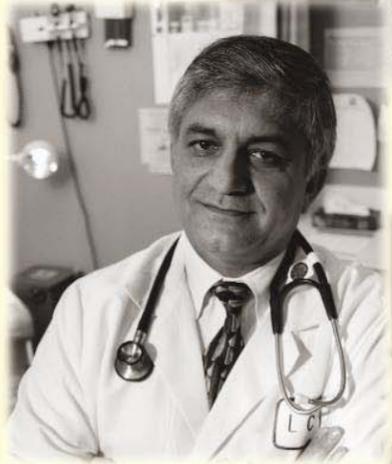


***Life on the Edge of the
Health Care System:***

*The growing problem of
the uninsured in Massachusetts*





The state of health care access in Massachusetts: Progress may soon be reversed.

People living on the edge of the health care system in Massachusetts are facing a period of great uncertainty. In recent years, the Commonwealth has made real progress in reducing the percentage of its residents without health insurance. A major expansion in 1997 of MassHealth, the state Medicaid program, combined with high levels of employment, led to a significant decrease in the number of people without insurance.

A state survey showed that the percentage of uninsured residents fell from eight percent in 1998 to six percent in 2000. While this is welcome news, a six percent uninsurance rate still represents 365,000 people – or the combined populations of Worcester, Lowell, and New Bedford. And recent census data put the number of uninsured even higher.

But progress on the uninsured in the 1990s came during a period of strong economic growth and stable health care costs. Massachusetts now faces a possible recession, and belt-tightening in both the private and public sectors will likely increase the number of people who have no insurance or whose coverage is insufficient to meet their health care needs. When Massachusetts last experienced a sustained economic slowdown, in the late '80s and early '90s, the number of uninsured nearly doubled.

Health care costs are now growing, resulting in increases in insurance premiums. Rising premiums can put insurance out of reach for many – both for those purchasing policies on their own and for those who get insurance through work, but may be asked to shoulder a larger portion of the cost.

Compared to many states, Massachusetts has a strong safety net of programs for the uninsured. But health insurance still matters – a lot. Lack of insurance can threaten or destroy family economic security by leading to health problems that leave people unable to work, or by saddling them with huge medical bills they cannot afford to pay.

Sadly, it is easy to lose sight of real people who are uninsured, or to think that they are somehow “different from me.” In fact, they are not different – they work hard, support their families, live in big cities, suburbs, and small towns. Usually they are uninsured because of bad luck or lack of resources. And they would desperately like to be insured, if only they could afford it.

We hope this report will help portray the financial, medical, and human consequences of living on the edge of the health care system. And we hope it will encourage a renewed debate about how to provide health security to every person in Massachusetts.

Philip W. Johnston
Chairman
Blue Cross Blue Shield
of Massachusetts Foundation

Andrew Dreyfus
President
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of Massachusetts Foundation

The uninsured in Massachusetts: Who are they?

The majority are employed. In Massachusetts, over 70 percent of the uninsured are working or live in families where someone works. Only a quarter of the working uninsured are eligible for health care coverage through their employers. Of those who are eligible, most do not have coverage because they cannot afford the employee share of health insurance premiums.

They are often young adults or adults without children. MassHealth coverage is not available to most children over the age of 18 or to most childless adults. Low-income people in these categories are among the most likely to be uninsured.

They tend to be minorities and immigrants. Latinos, for example, are much more likely to have no insurance than the population as a whole. This reflects their greater likelihood of working in small firms that do not offer insurance and changes in federal laws that left many legal immigrants afraid to apply for MassHealth for fear of jeopardizing their immigration status.

They previously had insurance coverage. In a recent survey, about a third of the uninsured in Massachusetts said they lost their coverage in the previous year. Another third said they last had coverage between 1990 and 1998. A change in job status was cited most often as the reason for losing coverage.

They make too much to be covered by MassHealth. Those least likely to have insurance are low-income people who make slightly more than what is allowed to qualify for the state's MassHealth coverage. Families with incomes between one-and-a-half and two times the federal poverty level – between \$26,000 and \$35,000 for a family of four – are the most likely to be uninsured.

They make too little to buy on their own. For people with low incomes who are not eligible for MassHealth and do not have access to health insurance through their employer, the cost of purchasing insurance can be prohibitive. In addition, their premiums are generally higher than the group rates paid by employers. In 2002, a non-group HMO premium for a young family in Boston will cost \$8,000 to \$12,000 a year – as much as a third of the income of a family living just above the poverty level.

The health care safety net: How a generous system fails many of its residents.

While Massachusetts has a safety net of programs for the uninsured and underinsured, it is confusing, fragmented, and difficult to navigate. As a result, many people slip through its holes, especially when they face serious illness or linguistic barriers. Some programs are highly restrictive, some are underused, and most are not adequately promoted. Here are some of the holes in the safety net:

The Children's Medical Security Plan (CMSP), which covers preventive and primary care, is available for all children, including immigrant children. But CMSP does not cover inpatient services, which can be the most costly form of care.

The Uncompensated Care Pool reimburses hospitals and community health centers for a portion of the free care they provide to low-income people without insurance. But the Pool often does not cover physician services, and individuals who have been hospitalized can still face high bills.

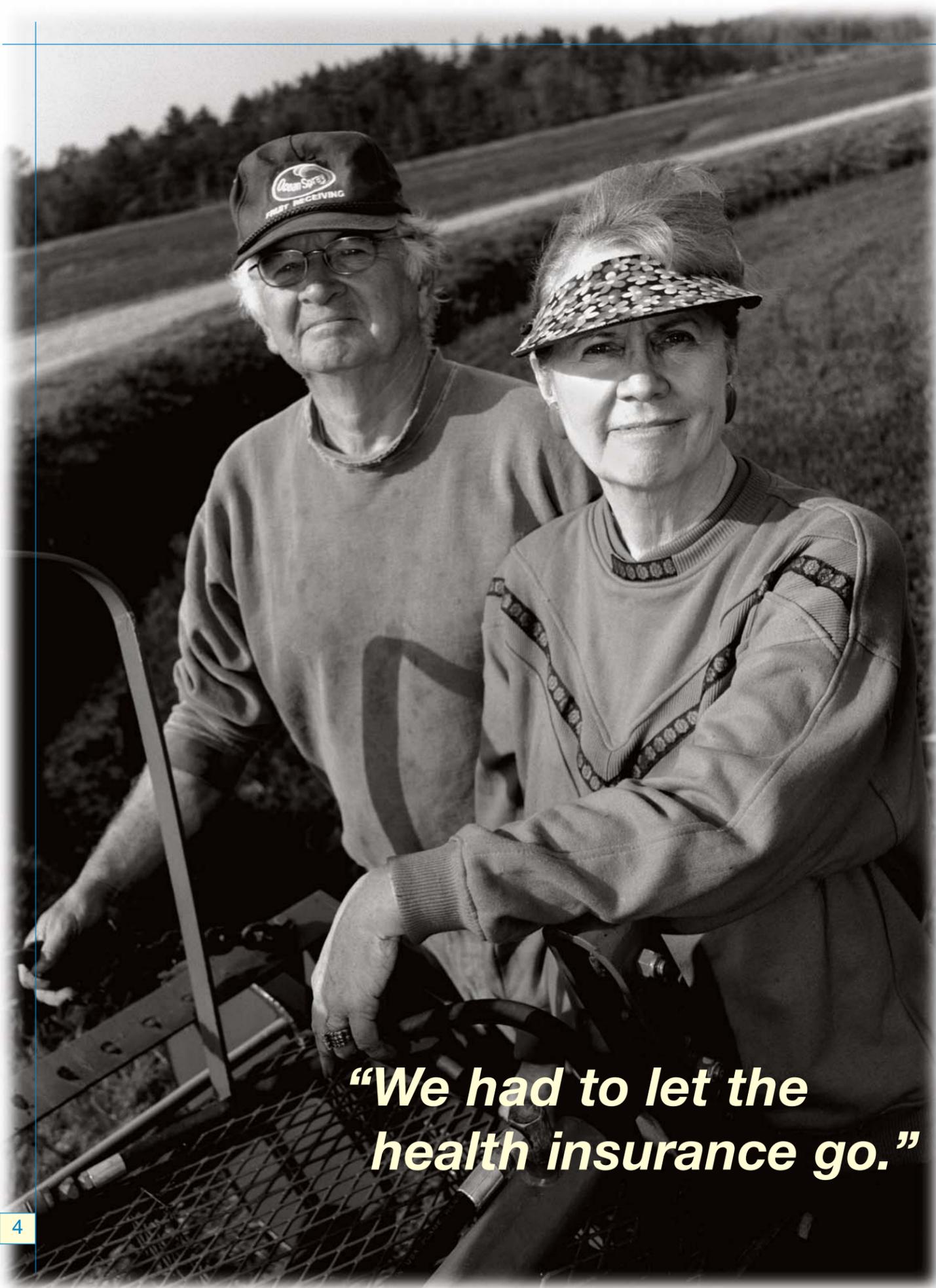
Community health centers and volunteer programs offer primary care to the uninsured in various parts of the state. But these services are not available in many areas of Massachusetts, and specialty care may be difficult or impossible to arrange.

MassHealth coverage is not available to children over the age of 18 and childless adults unless they are disabled, long-term unemployed, or work for certain small employers.

A new Massachusetts prescription drug program covers part of the cost of prescription medications for the elderly and disabled. Most of the state's uninsured, however, are not eligible for this program.

The Insurance Partnership, a state program that provides subsidies to low-income workers and their small-business employers, has limited employer subsidies, contributing to low enrollment in the program.

The Medical Security Plan, a temporary program for the newly unemployed, has restrictive eligibility requirements.



“We had to let the health insurance go.”

NAME: Richard and Cynthia Spencer
AGE: 63 and 60
HOMETOWN: East Freetown
OCCUPATION: Cranberry farmers

Working people in a bind

Cranberries may be the signature crop of Massachusetts, but to Dick and Cynthia Spencer they are a livelihood and a family tradition. It's a way of life that the Spencers are struggling to hold on to, even as the things they counted on for security – health insurance being one – recede from their grasp.

The Spencers live in East Freetown, in a memorabilia-filled ranch house. Behind it lies 10 meandering acres of cranberries. Dick Spencer bought the bogs from his elderly father in 1984. With the price of cranberries moving up, he saw financial opportunity in expanding the farm.

At the time, Massachusetts cranberry farmers dominated the industry, and demand for the fruit was high. Dick hired help, planted new bogs, and turned a family farm into a thriving small business. Cynthia continued to work as a sales representative for a trucking company that served garment factories in Fall River and New Bedford.

“I had health insurance for the family, life insurance, everything,” Cynthia recalls.

The Spencers had no way of anticipating what misfortune 1998 would bring. First, the New England garment industry collapsed and Cynthia's trucking company laid her off.

Then, almost overnight, their farm profits vanished, a consequence of a nationwide cranberry glut. From a high of more than \$60 per barrel in 1997, cranberries dropped last year to \$10 – a huge loss when production costs average \$35 a barrel.

“We cut back on everything,” Cynthia says. “We let the hired men go and I started helping Dick mow around the bogs. Then he got a part-time job in Boston washing DPW trucks. It was barely enough for necessities. We had to let the health insurance go.”

Cynthia began working the phones and pouring through the newspapers for sources of assistance. She had two goals: finding some way to prop up the farm until cranberry prices recovered, and, second, securing her and Dick's

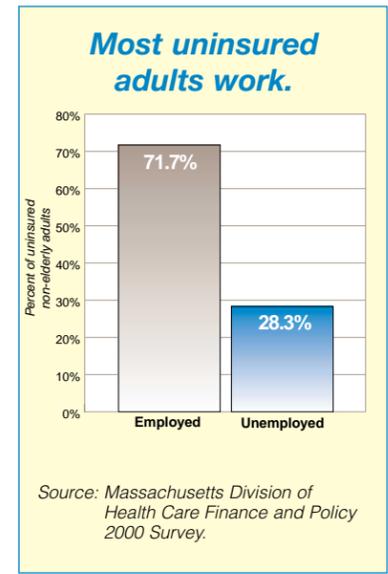
health care. On the first goal, she found a federal farm assistance program and applied successfully for a grant to upgrade equipment and maintain the bogs.

On the second front, she and Dick did not qualify for MassHealth; their income of about \$22,000 plus farm assets also disqualified them for food stamps. But good news came from the Insurance Partnership, a state program that provides subsidies for small-business owners who otherwise could not afford to buy health insurance for themselves or their employees. As family farmers, the Spencers qualified. They tapped

their retirement savings for their share of the premium, and now are insured through the Ocean Spray growers' cooperative.

The reprieve, however, is temporary. To qualify for the Insurance Partnership subsidy, a family of two cannot make more than \$23,220 annually. The expected increase in cranberry prices this year is likely to put the Spencers over the eligibility limit. Yet their income will not be sufficient to cover the full insurance premium.

“We never expected to be in this situation,” says Dick. “We were always careful. We never lived high. We bought used cars, we bought used trucks, we split wood for heat. We've got the big vegetable gardens out back and we'd can a lot for winter. We don't go out for dinners. We don't go to the movies. We thought we were going to be okay.”





“I’ve tried not to go to the doctor. Collections people call me everyday.”

NAME: Kimberly Robinson
AGE: 38
HOMETOWN: Lowell
OCCUPATION: Day care worker

Russian roulette

When Kimberly Robinson was on welfare, she didn't worry about getting sick. MassHealth paid for everything. She signed up for prenatal care and later made sure her son and daughter had regular checkups and immunizations. Medicine, diagnostic tests, treatment – all were covered.

Having grown up on welfare, Robinson wanted something better for her own children. She completed her high school education, then enrolled in a training program to qualify as a licensed home day care provider. In 1998, she realized her dream of self-sufficiency – and quickly discovered the insecurity of life without health insurance.

“I lost my MassHealth six months after I went to work,” Robinson says. “Since then, I’ve tried not to go to the doctor. I can’t afford it. I owe money to all the hospitals around here for when I used their emergency rooms. They’ve sent me to collections. Those people call me every day, starting around 5 p.m. because I guess they figure they’ll catch me at home. I don’t even answer the phone sometimes because I know it’s them. When I do, I tell them, ‘Yeah, I know I owe you the money, but where do you think I am ever going to get it?’”

Robinson owes more than \$1,000 for the emergency room visits. One was for a badly cut hand. The stitches, tetanus shot, and treatment for a subsequent complication came to \$700. Another time, Robinson sought help for severe chest pain. Her heart lining turned out to be infected and she needed antibiotics.

The 38-year-old mother of two cares for children in her Lowell apartment. The number of children varies from month to month, so her income does as well. She averages about \$30,000 per year, which is too much for an adult to qualify for MassHealth. Because of monthly

income fluctuations, she also is periodically ineligible for free care. Her son and daughter are eligible for MassHealth though, due to a 1998 program expansion for children only.

“I am so sick of that ‘eligible’ word, I can’t even tell you,” says Robinson. One time, when she was just getting her business going, she missed the monthly MassHealth income cutoff by \$8.

Robinson frankly admits to playing Russian roulette with her health, to save money. Her doctor at the health center helps with drug samples, and doesn’t charge when she uses the walk-in clinic. But Robinson has been putting off treatment for high blood pressure because the evaluation requires an appointment, for which she’ll be charged.

“Usually I treat myself. I call the 1-800 number for Ask-A-Nurse and tell them what the symptoms are and that I don’t have any insurance and what can I do for it at home,” Robinson says.

“They’re really good; they call right back and give good suggestions. But you can’t treat everything over the phone.”

Robinson’s job can be hazardous to her health. Rare is the day without at least one child sniffling or running to the bathroom with a stomach bug. She’s had one child with scarlet fever, and two exposures to meningitis. Most of the children have MassHealth or other insurance, though, and can get the medical treatment they need. Not so the person caring for them. The irony is not lost on Robinson.

“I never thought I’d ever say this, but I envy people on welfare,” Robinson says. “I envy them for their health insurance.”

“Family child care providers are almost twice as likely to be uninsured as the state’s general population... Sixty-three percent of this uninsured group has annual incomes under \$32,000.”

Source: McCormack Institute for United Way of Massachusetts Bay,



“He could have died.”

NAME: Julia Arroyo
AGE: 42
HOMETOWN: Springfield
OCCUPATION: Community health worker

The human bridge

When Julia Arroyo came to Massachusetts from her native Puerto Rico 20 years ago, she headed straight for Springfield’s North End, home to Puerto Rican émigrés and, more recently, Mexicans and Guatemalans. You don’t need to speak English in the North End. Every store is bilingual: Medina’s Market, the Old San Juan Bakery, the check-cashing place on Main Street, the McDonald’s.

But the very things that make the North End cozy also isolate residents from the larger community and its benefits, such as health care. Lack of insurance is only one problem. There are also language and cultural barriers, as well as confusion about safety net programs and how to use them.

Arroyo knows. Her full-time job is going door to door to teach her neighbors about health care. Arroyo is a *promotora de salud* or community health advocate, a human bridge between isolated immigrants and “The System.” Besides teaching good health practices, the *promotores* work to make health service affordable. Many North End residents are poor enough to qualify for MassHealth. If they aren’t, Arroyo tries to enroll their children in the less restrictive CMSP (Children’s Medical Security Plan). If their immigration status is a barrier, she tells them about free care options.

“The programs are so many, sometimes I am mixed up, too,” says Arroyo. “I have to look at my lists. Sometimes they need medicine, and there are programs to get it for free. I help to fill out the papers.”

Arroyo was the North End’s first *promotora*. She came up with the idea in 1997, knowing of neighbors who waited until medical crisis drove them to an emergency room. Such a waste! Arroyo thought. The neighborhood has a low-cost health center, many health-related educational programs, and a hospital. People simply weren’t using the system effectively.

One of Arroyo’s tasks is to bird-dog her clients’ applications to safety net programs. Navigating bureaucracies is especially difficult for sick people with poor English skills. “I call and say, ‘So, what is up with this person’s

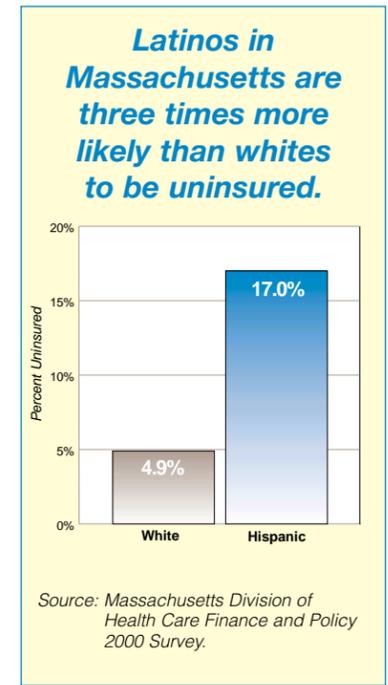
application? We don’t hear for three weeks,’” Arroyo recounts. “And they say, ‘Oh, we don’t have it. She never sent it.’ And I say, ‘Oh, excuse me, that is not the story because I sent it myself.”

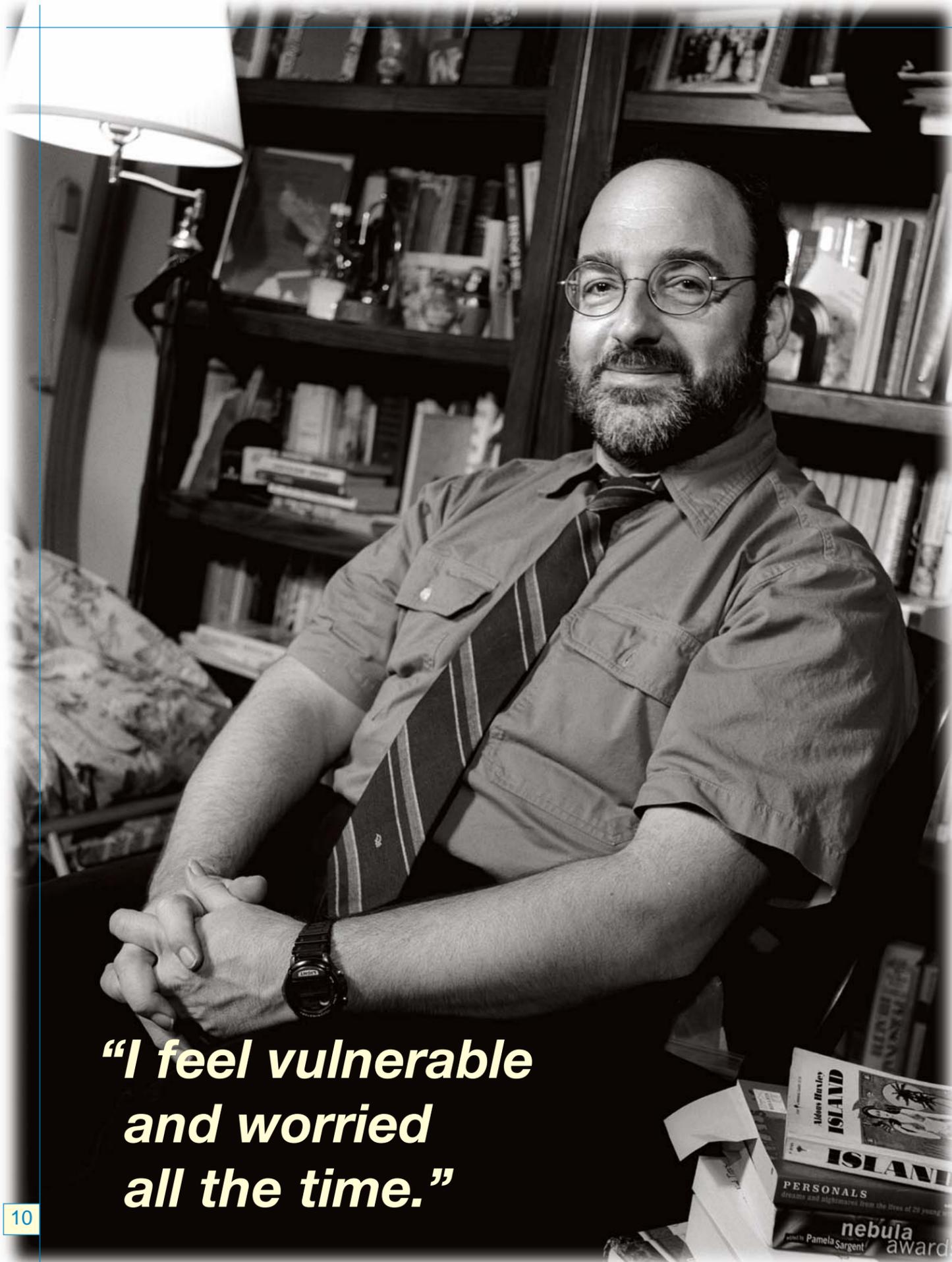
Today, there are 10 *promotores* working through a community agency called NEON (North End Outreach Network). Arroyo works with 640 families, and uses color-coded pushpins on a wall map to note the medical conditions in each household: black for heart disease, green for asthma, blue for diabetes. The *promotores* work closely with the local health center, even accompanying patients on visits.

Not everyone opens the door to Arroyo or stays in touch. People lose

their MassHealth and don’t tell her. It can be discouraging to discover months later that a family she thought she’d plugged into the system is back on the fringe. But other experiences reaffirm the value of *promotores*.

Arroyo recalls the day she found the son of a family she’d visited, crying on her doorstep. His parents were away, the teenager explained. “He was crying, ‘Julia, I feel so bad, it hurts so much.’ I put him in my car and went to the hospital. They gave him an operation right away – his appendix. He could have died.”





“I feel vulnerable and worried all the time.”

NAME: Charles Kroll
 AGE: 50
 HOMETOWN: Tyngsboro
 OCCUPATION: Part-time college instructor

Hard lessons for the teacher

Charles Kroll came to Massachusetts in 1997 from a disintegrating marriage in Texas; he was eager for a fresh start. An experienced college English instructor with a love for scholarship and teaching, he looked forward to new job opportunities at Massachusetts’ many colleges and universities.

Four years later, Kroll is deeply discouraged. Not only are his professional prospects limited, but he is increasingly anxious about continuing in a job that – while thought to be solidly middle-class – does not provide health benefits. At 50, he knows his risk of serious illness is greater today than when he began his career.

“I feel vulnerable and worried all the time,” he says.

Kroll is one of thousands of adjunct professors in Massachusetts who are paid on a course-by-course basis. The course load for each teacher is limited to keep them on part-time schedules, thus exempting the schools from having to provide health, retirement, and other benefits. It’s a cost-saving trend in Massachusetts and nationally, where 43 percent of college and university teachers are adjuncts, according to the U.S. Department of Education, double the proportion in 1970.

Kroll recognizes that his plight is not unique, but results from market forces that changed the rules of his profession virtually overnight. The last time he held a full-time faculty position was in Texas. Then, in 1992, “50 of us were swept out, just like that – eight in the English Department alone,” Kroll recalls. “I loved that job. We were all good teachers. They replaced us with part-time instructors. That college went from an almost entirely full-time faculty to a heavily part-time faculty.”

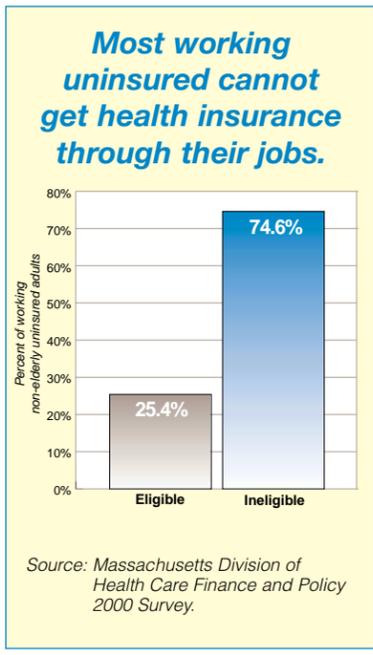
Kroll teaches part-time at the University of Massachusetts at Lowell, and will make about \$12,500 in the current academic year. As a single man with no dependents, he does not qualify for MassHealth, but he makes too little to

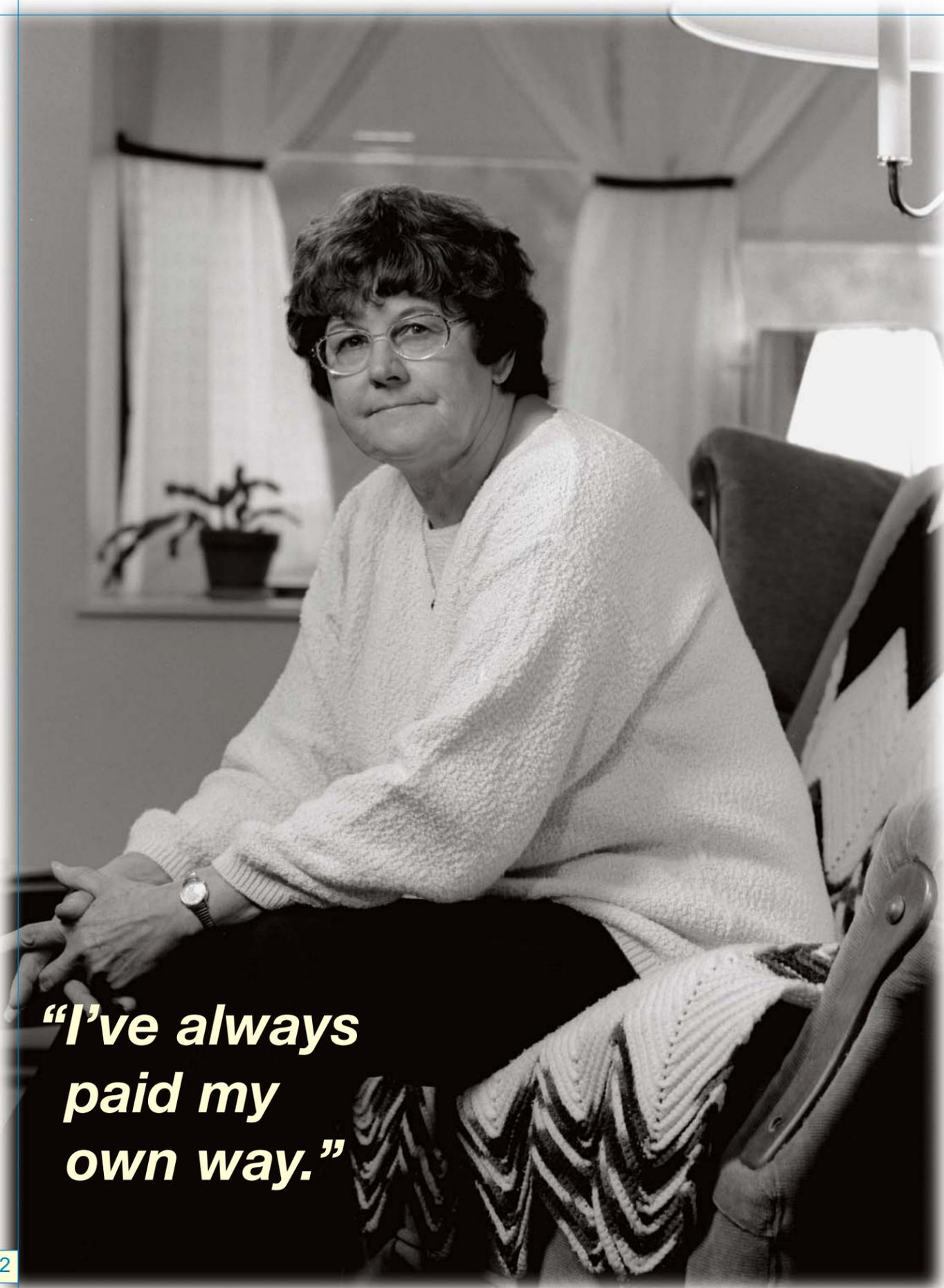
purchase health insurance on his own. He looked into buying insurance, but the cheapest quote for barebones coverage was \$260 a month. With housing costs, car expenses, and other necessities of living eating through his modest paychecks, he literally has nothing left for health insurance.

Kroll tries to stay healthy with vitamin supplements and immune-system boosting products from health food stores. Last year, his fiancée – also a part-time adjunct instructor – insisted that Kroll get a physical since he hadn’t seen a doctor in more than five years. The routine blood work – cholesterol tests, basic red and white blood cell counts – added up to \$200.

“I didn’t have it. I didn’t know what to do, so I called the hospital and explained my financial circumstances, and they very kindly forgave the bill,” Kroll says. He didn’t realize it at the time, but his income – about \$5,000 that year – qualified him for the state’s Free Care program. Next year, who knows?

“In one respect, I’ve been lucky. I come from strong healthy stock,” Kroll says. “But that’s not a guarantee forever. I’m getting older. Anything could happen anytime.”





“I’ve always paid my own way.”

NAME: **Frances Alibozek**
AGE: **63**
HOMETOWN: **Adams**
OCCUPATION: **Supermarket cashier**

Insurance isn’t always enough

Fran Alibozek and her husband divorced when the youngest of their three children was finishing high school. She was 39, working as a secretary in an insurance agency, but dependent upon her husband’s job for health insurance.

She immediately went looking for a job that would protect her from the financial catastrophe of serious illness. She found one at a company in North Adams, where secretaries received health and life insurance, in addition to competitive wages.

When that company went out of business, Alibozek found similar employment in Pittsfield. Over the years, she came to take her health insurance benefits for granted. Then, at 54, a heart attack gave her new appreciation for their value. Alibozek’s hospitalization and treatment were fully paid for, and accumulated sick leave enabled her to draw income while recuperating at home.

Soon afterwards, however, Alibozek was laid off. She briefly kept health coverage as part of the layoff package. But it ran out before she could find a comparable job. For the next three years, Alibozek juggled two jobs, making barely enough to meet Spartan living expenses and pay \$175 a month in heart medicine. She worried constantly about another heart attack. Her doctor gave her drug samples whenever he had them. But it was too hand-to-mouth for Alibozek’s peace of mind.

“I realized I had to find a job with health insurance, because I was completely on my own and getting older,” she says. So at the age of 58, she put her secretarial resume in the drawer and went to work as a supermarket cashier. The

pay was low, but she could get health insurance through the employees union. That clinched it.

What Alibozek didn’t realize was that the insurance plan capped payments for medical expenses at \$20,000 annually. This she would learn the hard way.

“I had been losing strength for several months,” Alibozek recalls. “I thought it was my heart, but when I went to the doctor he found I had a low blood count. So I had to have a CT scan and they found an inflammation in my colon. The tests came back that it was cancer and I needed surgery. I was in the hospital for a week.

“After I got out, I called the insurance company and they told me my benefits were exhausted. That’s how I found out that my insurance wasn’t good for anything serious.”

Alibozek now owes \$5,000 to her doctors. She needs a follow-up examination by her oncologist before the end of the year, and also must

have a second CT scan (the last one cost \$1,300). Her annual income is about \$13,000, which, after rent and other living expenses, leaves little for new medical expenses. As it is, she’s paying \$25 a month towards the \$5,000 in doctor bills her insurance didn’t cover.

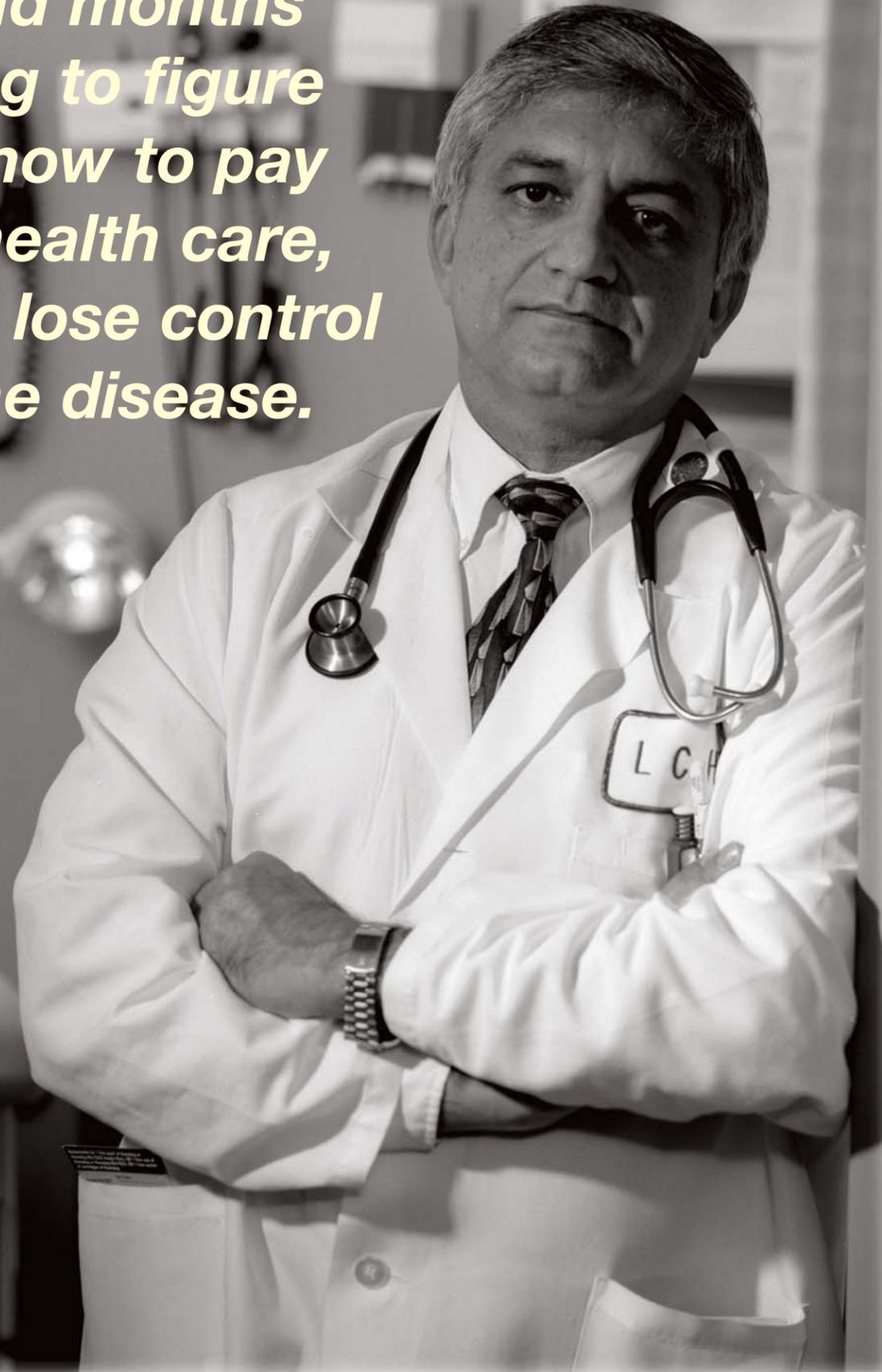
A charity program in western Massachusetts called Ecu-Health is working to negotiate discounts on future treatment. It is charity that Alibozek accepts reluctantly.

“I’ve always paid my own way,” she says. “I thought I had everything covered. I thought insurance was insurance. The insurance was why I took the job. I never imagined it would run out when I was sick.”

More than two-thirds of adults in the 50-64 age group worry that they will not be able to afford health insurance. One in five reported a time without health coverage since turning 50.

Source: The Commonwealth Fund

While patients spend months trying to figure out how to pay for health care, they lose control of the disease.



NAME: **Toryalai Amiri**
 AGE: **53**
 HOMETOWN: **Saugus**
 OCCUPATION: **Physician**

Catch-22

Shuttling between his private medical practice and a clinic for poor patients in Lynn, Dr. Tor Amiri sees the consequences of life without health insurance.

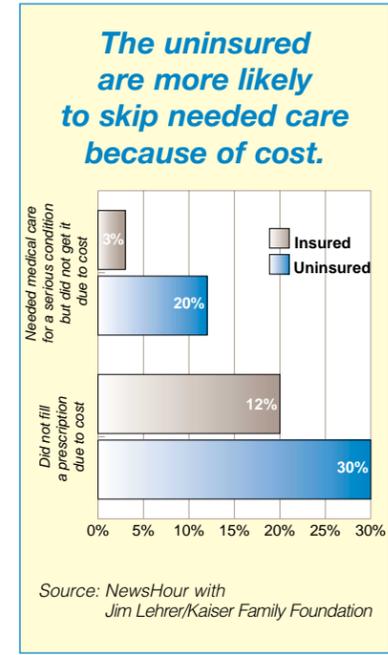
His uninsured patients generally are sicker, with more advanced stages of disease than his insured patients. They do not always follow up on prescribed treatment because of the prohibitive cost of medicine or tests. They rarely see specialists, such as cardiologists, who routinely consult in the cases of insured patients. As a result, they are more frequently hospitalized or disabled by illness or injuries that could have been treated successfully at an earlier stage.

Amiri's observations come from 13 years as a staff physician at the Lynn Community Health Center. The Center provides basic medical and obstetric care to low-income patients, about one-third of whom are uninsured. Last year, the Center experienced a record high 112,409 visits from patients, more than 90% of whom have incomes at or below 200% of federal poverty guidelines (about \$35,000 for a family of four).

The Center uses sliding-scale fees to make care affordable to all who come through the doors. But there are gaps in the health center's services – no cardiology, orthopedics, or ophthalmology. Diabetics (the health center has more than 1,000 on its rolls) must travel to Boston Medical Center for annual eye exams – essential to monitor vision problems suffered by many diabetes patients.

Heart patients are referred to private doctors even though the cost of a cardiac workup often discourages uninsured patients from following up, according to Amiri. As a last resort, health center staff wait until the patient's deteriorating condition justifies a hospital admission.

In the hospital, the patient can get all the diagnostic testing and specialized care necessary because the hospital is eligible for reimbursement from the state's free care pool.



Amiri and the center's medical director, Dr. Norma Lopez, frankly admit to working Massachusetts' patchwork system of safety net services to get patients around potentially lethal gaps. The gaps also threaten the financial health of the system.

For example, stabilizing a heart patient through hospitalization costs at least \$4,000, Amiri estimates, versus about \$600 if it were done outside the hospital.

Poor coordination among Massachusetts' myriad public and private medical assistance programs complicates care for low-income patients. Application forms vary from program to program, as do eligibility requirements.

Resources are unevenly distributed, favoring some patients over others – pregnant women and infant children, for example, over adults with chronic illnesses.

The burden often falls on patients and busy caregivers to navigate the bureaucratic maze. Delayed care and, sometimes, permanent damage to health are the results.

"We see this all the time," says Amiri. "A patient applies to a program that seems obviously to be for him. But for some reason, he doesn't qualify. So then he tries again with another program. Eventually, he finds one that accepts him. But in the two or three months it takes to get the help, the patient loses control of his disease."

Life on the edge of the system: Inadequate coverage has serious consequences.

For people who are uninsured or underinsured, the medical and economic consequences can be overwhelming.

They do not get preventive care. A recent Massachusetts survey found that 53 percent of uninsured adults reported no physician office visits in the prior year, compared to 15 percent for insured adults. A national report found that uninsured people are less than half as likely as those with insurance to receive care for a condition that physicians deemed serious.

They get sicker. Because they are less likely to visit the doctor, get prescriptions filled, and use screenings such as blood tests, the uninsured are more likely to need hospitalization for conditions such as diabetes and congestive heart failure.

They pay more for health care services. Uninsured patients may be charged more for health care services than patients with insurance coverage who benefit from discounts negotiated by their insurance company.

They have trouble paying medical bills. Thirty-six percent of the currently uninsured report having problems paying medical bills over the course of the year. Of those with insurance, only 11 percent report such problems.

They are pressured by collection agencies. Almost one in five working-age adults report being contacted by a collection agency about unpaid medical bills in the past year. For those with annual incomes below \$20,000, the number is one in three.

They are forced to declare bankruptcy. More than half a million middle-class families in the U.S. declared bankruptcy following an illness or injury in 1999, representing nearly half of all personal bankruptcies.

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The Blue Cross Blue Shield of Massachusetts Foundation: Expanding access to health care.

In 1937, a group of Boston-area philanthropists established Blue Cross Blue Shield of Massachusetts (BCBSMA) as a private, not-for-profit company to address an important social need: to make affordable health care available to the people of Massachusetts. For more than a half century, the company has taken a leadership role in extending health insurance to the state's residents. Today, the company retains its not-for-profit status and provides health coverage to more than 2.4 million people.

Many Massachusetts families, however, still lack the security of dependable health care. More than 365,000 people in the state have no health insurance, others are inadequately insured, and many low-income people face barriers to getting the care and services they need.

In 2001, BCBSMA created a new charitable organization – the Blue Cross Blue Shield of Massachusetts Foundation – as a contemporary expression of its historic commitment to those in need. The mission of the Foundation is to expand access to health care. Through grants and policy initiatives, the Foundation works with public and private organizations to broaden health coverage and reduce barriers to care. The Foundation is governed by a 17-member Board of Directors and operates separately from the company. It is one of the largest health philanthropies in the state.

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