

THREADBARE:
HOLES IN AMERICA'S
HEALTH CARE SAFETY NET

NOVEMBER 2005



THE KAISER COMMISSION ON
Medicaid and the Uninsured

The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. Begun in 1991 and based in the Kaiser Family Foundation's Washington, DC office, the Commission is the largest operating program of the Foundation. The Commission's work is conducted by Foundation staff under the guidance of a bipartisan group of national leaders and experts in health care and public policy.

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BACKGROUND AND INTRODUCTION

As more Americans go without health insurance and access to affordable health care is decreasing, millions of Americans turn to what is known as the “safety net” for their health needs—those health care providers who maintain an open door to patients regardless of their ability to pay. They are the uninsured, the low-income underinsured, and the many Medicaid beneficiaries who rely on their local community providers. At the core of this country’s safety net are health centers, public hospital systems, and local health departments. Besides these key providers, many others play a role, for example, school- and church-based health clinics, private physicians and non-profit hospitals committed to serving vulnerable patients. All are lifelines in the safety net in their communities.

THE SAFETY NET’S MESHWORK

For those whom it catches, the safety net has made an enormous difference. Health centers have markedly improved access to primary and preventive care for vulnerable populations, serving as the medical home to millions. By tailoring their services to the health, social, and cultural needs of their clients, the quality of care provided is high, evidenced in patients’ satisfaction. Racial and ethnic health disparities would be much greater were it not for the health care safety net serving the uninsured and under-insured.

Established in 1965, the community health centers, migrant health centers, and clinics that make up the federal health centers program now serve over 11 million low-income children and adults in America’s medically underserved areas. These centers care for the inner city and rural poor, homeless persons, migrant farmworker families, millions of the uninsured, and are a critical source of care for Medicaid beneficiaries. In order to qualify for federal status, health centers—unlike those not qualifying for federal funding—must deliver the full range of services set by the government, including preventive, diagnostic, laboratory services, dental care, case management, and health education. Numerous studies have found that besides providing affordable services, federally qualified health centers provide quality care—improving preventive care, decreasing preventable hospitalizations, and maintaining high patient satisfaction.¹

There is an even longer history of safety net hospitals' service to the community, dating back to the 1700s. Safety net hospitals include the over 1100 public hospitals plus those non-profit hospitals that provide disproportionate amounts of care to low-income and uninsured patients. These hospitals, particularly public hospitals, often serve as the only source of hospital and specialty care for the underserved and are under increasing pressure to support entire communities of low-income residents who have no other source for specialty care. Many safety net hospitals are only able to respond to these needs because they also operate physician and nurse teaching programs. Safety net hospitals are principal sources of outpatient services for their communities as well, providing primary care, specialty care, laboratory, x-ray, and other high-tech diagnostic services for their patients. Many also operate busy outpatient pharmacies that provide free or reduced-cost pharmaceuticals to their patients.

Emergency departments in these hospitals are the safety net under the safety net, triaging among those who have nowhere else to go for timely care. Millions of Americans do not have a medical home. There is a growing sense that the local hospital's emergency department is the only health care provider available to them, particularly for services that are outside the scope of what a health center can provide. And although patients can expect to wait hours to be seen in an emergency department (ED), this is often a better alternative than waiting months for specialty care and trying to make several different appointments and trips to complete the tests and procedures they know they will need.² And so the emergency department is a reasonable first choice for many, both insured and uninsured. Emergency departments have remarkably evolved to meet their community's unmet needs for both primary care, urgent care, and diagnostic care. However, at the same time, hospitals weigh carefully whether they can afford to maintain them and the number of EDs in the U.S. has been declining over the past decade.

THREADBARE: HOLES IN THE SAFETY NET

Ideally our safety net would be woven tightly enough to catch all those who cannot afford the health care they need. However, at best, the safety net is threadbare and the demands placed on it are simply too great. Ideally, the

safety net would operate as a system—effectively connecting basic health care services together for its patients. Yet, health services in this country are often disjointed, even in the mainstream, and care in the safety net is even more fragmented. While there are examples of integrated safety net systems able to provide the full range of care to their low-income and uninsured patients, most safety net providers are often only partially able to patch together all the health services their patients need, and then not always consistently. Too often the pieces of the safety net operate separately, leaving patients to bounce from one facility or program to the next to find medications, medical equipment, more expensive lab and x-ray services, rehabilitative therapies, specialty care, and even hospital care.

The strength of the safety net is often overestimated by the general public. However, those who need the safety net, or provide its services, know it is frayed. Over a third of the uninsured report needing care in the past year but not getting it and nearly half report postponing care—rates at least three times higher than those with insurance.³ Studies repeatedly bear out that the uninsured are less likely than those with insurance to receive services for major health conditions, including traumatic injuries, heart attacks, pregnancy, and cancer. At least 18,000 Americans die prematurely each year simply because they lack health coverage.⁴

The purpose of this report is to help us better understand the impact of these holes in our safety net by listening to the voices of those who have experienced the gaps for themselves. These holes exist because:

- the sheer number of low-income people who are in need of care exceeds this country's safety net resources;
- there is a scarcity of subsidized, and thereby more affordable, specialty care services;
- there is no systematic way to finance prescription drugs for those who haven't the means to pay for them; and
- coordinating care outside, and sometimes even within, the safety net can be very difficult and complicated, particularly when a cure or treatments are likely to be very expensive.

Based on interviews in five regions of the United States, the report primarily draws on the perspectives of those who provide care to the uninsured, as well as first-hand accounts of seeking care by the uninsured themselves. These interviews were obtained as part of a larger research project conducted by Susan Starr Sered and Rushika Fernandopulle, which led to the publication of their recent book entitled, *Uninsured in America*.⁵

The report is framed by the types of medical care that people commonly need:

- basic primary care,
- urgent care for untreated or poorly managed health conditions,
- prescription drugs, and
- hospital-based diagnostic and surgical care.

Qualitative research is always revealing—and it is an invaluable tool for gaining deeper insights into how being uninsured affects a person’s health and finances, as well as how it impacts their family, work and social lives. Wide-ranging interviews gave the 120 uninsured people they talked to the opportunity to think about all of the services and programs they have turned to when they needed medical care. Indeed, every person cited in this report had turned to multiple programs and facilities in search of low-cost health care over the years.

For the forty-six health care providers who participated in this study, the interviews offered an opportunity to reflect upon successes and failures in their work, how services for the uninsured have changed over time, and how the experiences of those who provide care for the uninsured have changed as the numbers of uninsured and under-insured have grown. Health care providers working in safety net facilities typically work long hours for much lower pay than they could get elsewhere, and many have, at great personal cost, dedicated their careers to serving those who are in need. The problems described in this report do not lie with these providers, but with the gaping holes in care that the safety net is unable to fill and the lack of continuity of care these holes create—continuity that is essential to good health and well-being.

SEEKING PRIMARY CARE

The mission of health centers and other types of charity-based clinics is daunting and demands on them are growing. In 2004 there were a total of 940 federally qualified health centers (FQHCs) and as many as another 1,000 charity-funded clinics. Located in the heart of medically underserved communities, they essentially offer primary care services to three groups of people who often have difficulty establishing a medical home: the uninsured, those with low-incomes and are under-insured, and those with Medicaid coverage. Over 90% of FQHC patients are from low-income families, two-thirds are of racial or ethnic minority groups, 40% are uninsured and more than a third are Medicaid beneficiaries (Figure 1).

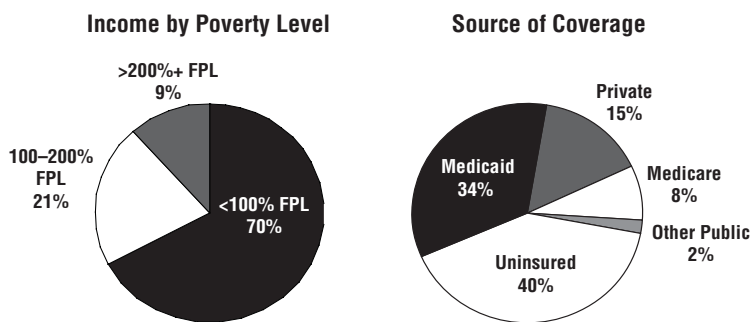
Seymour Mitchell, CEO of the Delta Health Center in Mound Bayou, Mississippi, a federally qualified health center (FQHC), sums up their mission in his own words, expressing the level of commitment it takes to keep these centers running.

It's all about people having equal access. We provide the same experience to everyone, and give good primary care. We try and do all we can when we see people, because we may not see them again for a long time. It's rewarding when you see people have a better quality life. I won't get rich, but that's what matters.

While health centers' purposes are clear, fulfilling them is almost always a struggle. Claudia Lennhoff, Executive Director of the Champaign County

The average per capita payment to health centers for uninsured patients was \$272 in 2004, about half of health centers' annual cost just to provide basic health services.⁷

Figure 1
Characteristics of Health Center Patients, 2004



13.1 Million Patients

Note: The Federal Poverty Level was \$19,311 for a family of four in 2004.
Source: George Washington University Center for Health Service Research and Policy Analysis; Data: 2004 UDS

Health Care Consumers organization describes the supply and demand imbalance in Urbana, Illinois at the Francis Nelson Community Health Improvement Center, an FQHC.

From 1999 to 2004, the number of patients served by health centers grew by 45% from 9 million to more than 13 million. Over the same time period, the number of uninsured persons who depend on health centers grew by 42% or 1.6 million more uninsured patients.⁸

Francis Nelson cannot keep up with the need. They log approximately 4,000 visits per year, but the local Medicaid population is 17,000 people, and that's not counting the uninsured—about another 30,000 people.

The Brady Green Center in San Antonio, Texas (a county-funded clinic that is not an FQHC) also overflows with the needy. A doctor and nurse from the Center sum up the patient fall-out. The doctor explains,

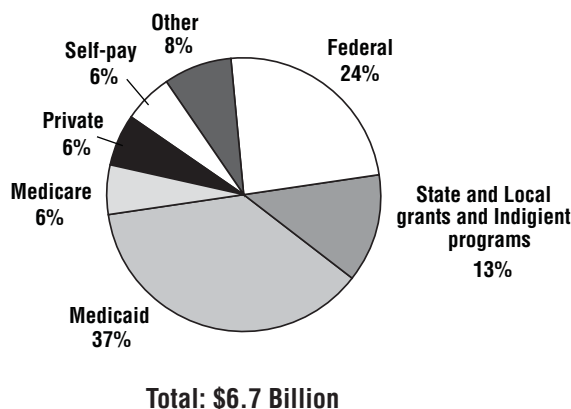
It's always jammed here. The clinic opens at 9:00 and that's when appointments start, but the doctors don't come until 9:15. So, they start their day already behind. And many of the doctors just hold clinics here two or three times a week for half a day. So, it just means that the system is always log-jammed.

But a nurse at Brady Green explains another reason for the log-jam and how it ultimately affects the care patients can expect to receive.

There are not enough providers, whether it's doctors, nurse practitioners or physician assistants. At least half the people who come to the center here don't have a primary care physician because there is no one who can take them on to their panel. So this means they have no continuity of care. They don't see the same person every time they come. So, each time, the doctor starts from ground zero, taking the whole history over again.

A quarter of the financing needed to support FQHCs comes from federal grants. Medicaid is the single largest funder of health centers, which in turn are the single biggest source of primary health care for Medicaid patients (Figure 2).

Figure 2
Health Center Operating Revenue Sources, 2004



SOURCE: George Washington University Center for Health Services Research and Policy. Data: 2004 UDS.

Safety net clinics play a critical role by offering a regular place for people to come for primary care, but may not be able to offer their patients a consistent health care provider—and that is a serious shortcoming.

This is particularly so in free or volunteer clinics. These clinics, unlike federally-funded community health centers, are privately-sponsored by a wide range of civic organizations, including charities, local medical societies, church groups, and local government agencies. They vary in the range of services they furnish, the patients they serve, the hours they are open, and their staff—who are generally unpaid volunteer clinicians.

Despite the benevolence of these clinics and their providers, patients can suffer without continuity in care—case in point:

Jane, a woman in her late forties and formerly a nursing assistant, is more aware than most of the consequences of not managing her health problems properly. She currently works at a local café and lives on an income of about \$10,000 a year. Uninsured and yet ineligible for Medicaid in the state of Idaho, Jane turns to a free clinic that is open two evenings a week for her health care needs.

At the clinic she was diagnosed with diabetes and high blood pressure—two chronic diseases that require regular monitoring to prevent even more serious comorbidities. While volunteers who staff the clinic try to be nice, Jane explains, it turns out that someone different sees her each time, and this has led to some serious mistakes with her medication. She discussed one example when her blood pressure soared (during a bout of back pain, another chronic problem she has) and the doctor that night gave her too big a dose of antihypertensive medication, sending her blood pressure plummeting.

On top of not having enough professionals, many clinics depend solely on volunteer physicians and nurses, which presents yet another quality problem—inconsistent standards for care. Michelle Britton, Regional Director for Health and Welfare for the State of Idaho for the five northern counties, and President of the Board of the Dirne Community Health Clinic, comments:

In three counties we have a free volunteer clinic but they're only open one night a week for two hours. People come into the volunteer clinic with just an amazing amount of complexities. It's not only in their medical needs but also in their social service needs and all of the other. It's all interwoven and you've got a volunteer provider there for the evening who doesn't even know where to begin. It is so

CHARITY-FUNDED CLINICS

There is no definitive estimate, but studies suggest that between 800 and 1000 charity-funded “free” clinics that are not FQHCs maintain sites in low-income communities.⁹ Typically charity clinics are modest in size and restrict their care to basic services for uninsured persons. They depend on volunteer help and may be open only a few days or nights per week. Their services are often critical to their patients, but they are very limited in what they can do beyond basic care.

overwhelming and yet they're there to try to do something for the community but it's a struggle.

And you have an array of providers. You have providers who work in a hospital emergency department or who work in a surgeon's office, so [they] have different standards around what kinds of medical protocols they use. When you're doing a volunteer clinic it's real hard to get everyone on the same page.

The number of health center patients with chronic diseases, diseases that often require specialty services outside the scope of health centers has been increasing substantially, likely because older adults (45–64 year olds) make up the fastest growing age group at health centers. Over a quarter of medical visits provided in health centers are for the treatment of a chronic health condition.¹⁰

All health centers have limited resources for providing medication, specialized treatments, or long-term care. While they try to offer a range of primary care services, all other services that need to be referred, such as specialty care and complete diagnostic work-ups, are seldom available. It rests with the clinic's staff to try to find specialists who will see an uninsured patient, and that is often difficult, always time-consuming, and not always successful.

While the lack of more expensive specialty care may not be surprising, the fact that many charity-funded clinics are unable to provide even basic health screening tests is disturbing. In order to offer preventive screening, clinics need regular paid staff to coordinate care, ensuring that patients are contacted and appropriately advised about their test results. Karen Cotton, administrator at Kootenai Medical Center in Coeur D'Alene, Idaho shares this example of non-federally-funded clinics.

None of the free clinics [here] provide pap smear or other diagnostic procedures because of liability issues. There's a liability issue often times to even get into the diagnosis. So we're not doing pap smears in the clinic anymore.

In 2001 Congress endorsed President Bush's call for a doubling of the number of health centers. This has enabled more than 600 new and expanded health centers to serve over three million new patients.

These increases however, fall short of what is necessary to establish at least one health center site in the nation's poorest counties. An estimated 929 counties lack a health center, a number that accounts for almost a third of all counties and more than half of all poor counties. About 20 million persons live in these counties and more than 40 percent have family incomes below twice the federal poverty level.¹¹

Community clinics run largely by volunteers, rarely have tracking systems or sufficient staffing that would enable them to follow-up appropriately—another factor that undermines the continuity of their patient care. If a clinic performs a diagnostic test such as a pap smear and the test result is positive the clinic is responsible for contacting and informing the patient. However, if it fails to do so and the patient develops late-stage cervical cancer for example, the clinic could be held accountable.

Dr. Anne Brooks, Medical Director of the voluntarily funded and run Tutwiler Clinic in Mississippi, summarizes her concern about the holes in the services that community health centers can offer, which was heard from almost all

of the providers interviewed. Brooks explains that at her clinic they try to do a good job of providing at least basic primary care. For urgent care they can send patients to the community hospital 25 miles away. But for health problems that fall in the middle—conditions that are more serious but don't require urgent care that day, or conditions that need to be managed by specialists—there may be little that she and her colleagues can do.

So much of what we see at the clinic can be prevented—dialysis, amputation, blindness, not being able to breathe. Society pays for it eventually, but we won't pay to prevent it.

WHEN A CHRONIC CONDITION NEEDS URGENT ATTENTION

Millions of Americans, both insured and uninsured, do not have a medical home—a physician or place where they can go to get timely care when they need it. Back-logged appointment schedules, work-day only office hours, and limits to the amount of charity care physicians can provide, are all barriers to basic primary care for those with low incomes. Emergency departments are the safety net under the safety net—used by all who have no other affordable source of health care nearby—and particularly for health problems that are outside the scope of what a community health center can provide.

Under federal law, emergency departments at nearly all U.S. hospitals must examine persons who seek their services to determine if a medical emergency exists. If a patient is found to have a medical emergency, the hospital then must either stabilize the patient or assure a medically appropriate transfer to an alternative source of care. It is the only law that, in essence, guarantees a legal right to health care, but at the same time, patients remain responsible for the costs of all of their care. Today emergency departments (EDs) often care for far more than medical crises.

But the law does not require EDs to provide care for persons who do not have an *emergency condition*, that is, a condition that threatens a person's life or long-term health. And in the eyes of some hospital administrators, like Robert Cadenhead, CEO of Kings Daughters Hospital in Greenville, Mississippi, the ED is therefore obligated to only provide emergency care. He describes care for a serious problem that, while not life-threatening at the moment, is likely to become life-threatening if untreated in the coming months as “discretionary,” not an emergency. That often makes clinical choices ethically difficult for the front-line doctors and nurses who triage patients in hospitals' emergency departments.

Marcy, a 48-year old widow chronicled her uninsured son's health history from birth to young adulthood. The symptoms of esophageal reflux, (later diagnosed with a disorder called Barrett's esophagus) began for her son Tim

As insurers have cut payments and the number of uninsured persons has grown, the proportion of physicians providing charity care has declined—dropping from 76% to 72% between 1997 and 1999 alone.¹²

EMTALA

The legal protections afforded by the federal Emergency Medical Treatment and Labor Act (EMTALA) require all Medicare participating hospitals with emergency departments to furnish screening and necessary stabilization services to all who enter the hospital's ED. As the only U.S. law that establishes a universal legal right to basic health care, EMTALA is critical to patient safety, even as it potentially contributes to heavy emergency department utilization.

as a baby. For lack of a regular provider, he was treated most often in an emergency room when her son’s symptoms would flare up, making it difficult for him to swallow. His case shows how very limited the right to health care is: once a patient is stabilized in the emergency department, the obligation to provide further care ends.

As the years went by he didn't get better. He kept getting worse. We didn't have insurance, so I wasn't able really to get him treated. Anytime I'd take him to the emergency room for his symptoms, they would treat you like you didn't belong there. ... And he was having problems like choking, couldn't swallow his food, he was getting to where his esophagus was closing up, and I didn't realize that was the problem. I knew there was a problem, but he wasn't given any testing whatsoever.

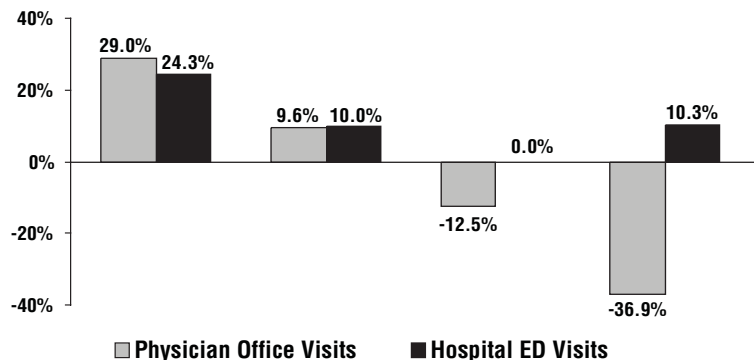
Then her son did experience a real emergency when a piece of meat became stuck in his throat one day when he was about seven years old.

I took him to the emergency room and they finally did the test—an endoscopy. And they said, 'Well, you're going to have to go to his doctor ... They didn't want to treat him at the emergency room. And at first they wanted to send him in an ambulance, but I said that I didn't have any insurance. The doctor at the emergency room said, 'Well, drive fast.'

Having stabilized Marcy’s son, the emergency department had met its obligation to handle the urgent problem, but follow-up care needed to be done elsewhere. Health conditions that are not immediately life-threatening, but urgent and should be managed initially by specialists, fall through the

Comparing the 1996–1997 period to 2001–2002 period, ED use among uninsured persons grew by 10%, while their use of physician services declined by 37%. In contrast, among those with private insurance, both emergency department and physician service use climbed by more than 20%. (Figure 3).¹³

Figure 3
Percent Change in Ambulatory Care Use by Insurance Type, 1996–97 to 2000–01



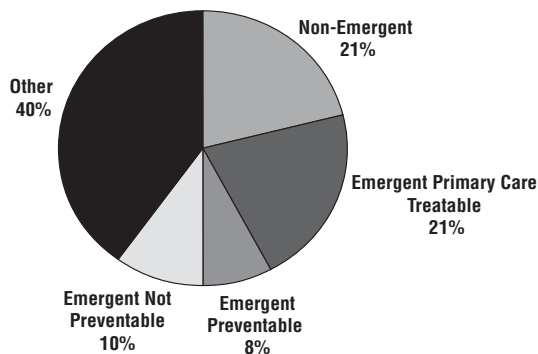
Source: Cunningham and May, 2003.

holes in the safety net. Community clinics are not armed with the diagnostic equipment or the specialists to care for them, emergency rooms necessarily avoid chronic disease management, and if you are uninsured, so do some private physicians' offices.

A 39 year-old family man from Mississippi, starting up his own small business, fell through this very hole in the safety net. After being transferred several times in his job with a national chain of transmission shops, the family landed in Mississippi when the company began lay-offs. To keep their ties in the community, Jack decided to open his own shop in a rented gas station. He was beginning to build up a clientele when the chronic back pain he lives with (from an old injury, followed by an unsuccessful surgery) became unbearable and he had trouble working. Self-employed without job-based health insurance, with assets exceeding Medicaid eligibility, and no medical home, Jack went to the local emergency department because of the pain and loss of feeling in his arm. At the emergency room, he was told to 'take a couple of weeks off'—not advice that he could follow and keep his business going. A few days later Jack was back in the emergency room with pain that had become excruciating.

That's when I met up with Dr. K. Well, Dr. K. gave me a couple of shots, put me to the MRI the next morning. Then they found out that it wasn't just a crushed disk, it was three crushed disks. So he referred me to Dr. C. He is a neurosurgeon. We made the quickest appointment we could, but that was two to three weeks later. Well about a week or so later, way before that appointment, I was bad again.

Figure 4
Emergency Department Visits, Emergent vs. Non-Emergent, 2002



About 20% of emergency department visits are not for emergency conditions and another 30% are for urgent conditions, but problems that could have been prevented or treated with primary care (Figure 4).¹⁴

Source: M Regenstein, et al. 2004. *Walking a Tightrope: The State of the Safety Net in Ten U.S. Communities*

Hospital emergency departments in the U.S. are a vital source of health care for the entire population. However EDs are operating under increasing stress. As the number of emergency departments declined between 1992 and 2002 by 15%, the number of ED visits grew by 23 percent. In 2002 alone there were 110 million hospital emergency department visits made in the U.S.¹⁵ In 2002 more than 3 in 5 hospital emergency departments reported operating at or over capacity.¹⁶

Jack returned to the emergency department for unbearable pain, but the medical staff that day refused to give him pain medication. He believes the staff assumed, despite having records of his medical history, that with three ED visits so close to each other, that he was trying to wheedle narcotics from them.

At this point Jack is in a bind. The neurosurgeon told him that he needs surgery, but that he won't perform the operation until Jack gets health insurance. However, Jack hasn't been able to obtain health insurance because of his pre-existing condition.

FILLING PRESCRIPTIONS

Even when the uninsured receive free or low cost medical services they often cannot afford to purchase the medication that has been prescribed for them. As a result, low-income people often skip doses or cut their pills in half to last longer, share medications with other family members, or simply never fill the prescription at all.

Managing their patients' needs for medication is a constant issue for clinicians and trying to fill the gaps with free samples from pharmaceutical companies is far from a good solution. Barbara Dunn, Executive Director of a community health center in Urbana, Illinois, describes this problem.

The main problem is that a patient will get samples that will last for a couple days, and they'll come back to the doctor and ask for more samples. The doctor won't have any more of that particular medicine and so he'll have to switch them to a similar medicine ... So there's just no continuity of medication over even sometimes just a ten day course of drugs and certainly not if it's something that they take more often. And people end up with just little bits of medicines and ointments and pills and all kinds of stuff in their drawers and they don't even know what any of these things are.

And while giving partial prescriptions may be the best some clinics can do, doctors and nurses in community clinics know all too well the impact on their patient's health of doing so. Dr. Richard Ferguson, director of hospice in San Antonio and founder of two church clinics in the city explains how partial medicating can actually do harm.

People get half a prescription, which is dangerous if they take something that needs a steady state blood level and when they miss doses they get peaks and valleys of blood level. And peaks of blood pressure, for example, put more of a strain on the heart.

In order to obtain medications for their patients, many safety net providers turn to a variety of pharmaceutical assistance programs, offered by many pharmaceutical companies, which provide a certain amount of free medication to people whose medical and financial needs meet eligibility requirements.

Eligibility forms of course need to be completed by the clinic and often stretch staff and volunteers thin. For example, in one Mississippi clinic that

As of 2003, pharmaceutical companies operated about 150 different patient assistance programs (PAPs) offering about 50% of the 200 most commonly prescribed medications. Generic medications are not available through the PAPs.

There has been tremendous growth in PAPs since 1996. In 2002 there were 5.5 million patients enrolled in PAPs and they received 14 million medications valued at \$2.3 billion.¹⁷

While PAPs provide a great service, they present challenges for both patients and providers. Each company's PAP is different, including the application procedures, eligibility criteria, how the medication is actually obtained, and the application forms.

In an effort to streamline the application process, several drug companies have recently joined together to form *Together Rx*, which allows low-income individuals and families who may be using multiple drugs from multiple sources to file a joint application for assistance from any of the twelve participating pharmaceutical companies.

operates just one night a week, the administrator estimates volunteers put in about an hour per patient each week trying to obtain the right medication from the various prescription drug programs.

Diana Lading is a case aide working with the MedAssist program on behalf of Catholic Charities in Decatur, Illinois. Her full-time job consists of filling in the forms for the pharmaceutical assistance programs on behalf of uninsured and under-insured patients. Having helped hundreds of clients apply, Diana identifies two particularly troublesome safety net gaps:

People who go to the emergency room with an acute problem and are sent home with two days worth of medication, but can't afford to fill the rest of the prescription. A pharmacy assistance program can't help them. It only helps people with long-term meds.

But the gap that really frustrates Diana is the need for diabetes test strips, critical to the safe self-management of medications for diabetes.

I have begged and begged the companies that make them, but I can't get diabetes testing strips. I can get a machine every day [to read the test strip results], but not the test strips. I can get a case of needles sent to the doctor's office, and insulin you can get and the diabetic pills, but not testing strips.

Unable to monitor their blood sugar levels, Diana explains that despite the availability of free medication, in this case for diabetes, patients end up with serious medical complications that may have been averted or at least delayed had the patient been able to measure their blood sugar levels as often and as accurately as prescribed by their doctors.

Some free and volunteer clinics, faced with particularly limited resources, don't have the staff available to search for free medication and have to set limits on the amount of medication they provide. Vermilion County clinic in Danville, Illinois, is a successful volunteer clinic open only to the low-income uninsured, with a budget sufficient to pay a director and a nurse. While they believe they provide good quality primary care, their financial situation requires they limit each patient to a life-time cap of \$200 in free medication. They tell their patients to try the Salvation Army, where limited assistance once every six months may be available. But the clinic knows that even with the best of intentions, they often are sending away patients without the medication that their volunteer doctor prescribed.

Generally speaking, PAPs require:

- the patient be a US resident, some require legal citizenship;
- the patient have no prescription insurance coverage;
- the patient be low-income—and the eligibility thresholds vary; and
- the patient must be taking a long-term medication since the application process may take several weeks.¹⁸

STATE PHARMACY ASSISTANCE PROGRAMS

Twenty-nine states offered one or more pharmacy assistance programs as of the spring of 2004.¹⁹ All programs serve the elderly and half make services available to persons with disabilities who are under age 65.

Total state spending on pharmacy assistance programs in 2001 reached \$1.5 billion, and program costs since then have grown at an average annual rate of 15%.

Medicare Part D prescription drug coverage commences in 2006 and the future of state pharmacy assistance programs that have targeted older individuals is unclear.

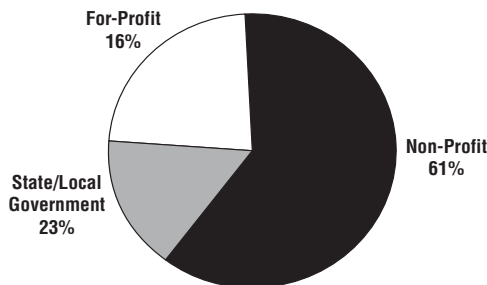
SEARCHING FOR AFFORDABLE HOSPITAL CARE

For surgery and intense medical management the uninsured, like anyone else, need hospital care. However, access to care at public and non-profit hospitals has become increasingly difficult for those who lack health coverage. In addition, hospitals are becoming more aggressive about collecting payments, which has kept some of the uninsured and other low-income persons from hospitalization (e.g., for surgery) until it becomes truly urgent.

Hospital consolidation has decreased the number of hospitals with charitable missions, leaving even more low-income families turning to public hospitals. Today's approximately 1100 public hospitals offer much less in the way of support for the uninsured than the number alone might suggest. About 70 percent are small hospitals (<100 beds) and nearly three-quarters are located in rural settings.²¹ Small and rural hospitals are essential to their communities, but modest in terms of the level and complexity of care they can furnish. Only large metropolitan regions—and by no means all such regions—have the type of large complex public hospital and health care systems that can offer a significant volume of reduced cost care for tertiary services.

A major source of health and hospital care for millions of Americans is the Veterans Administration, but this system has its holes also. VA hospitals are located largely in metropolitan areas and like other public hospitals,

Figure 5
U.S. Hospitals by Ownership, 2002



4,926 Non-Federal Community Hospitals

Source: Kaiser Family Foundation. www.statehealthfacts.org

There are about 5,000 community hospitals in the U.S. and all but 240 are owned by entities other than the federal government. Nonprofit hospitals make up about 60 percent of all non-federal hospitals. For-profit hospitals account for another 16 percent and the remaining public hospitals (about 1100 facilities) are owned by state and local governments (Figure 5).

particularly hard to access for those living in rural areas. In addition, many who might qualify for Veteran’s care do not apply because they are unaware of their eligibility.

LOCATING AN AFFORDABLE HOSPITAL

Marcy, the mother of the child with Barrett’s esophagus described earlier in this report, discussed how without regular monitoring as a young child, her son Tim eventually developed a constricted esophagus with frequent choking spells. He needed surgery. The family qualified for the children’s program the state of Illinois offered at the time and the surgery’s costs were covered.

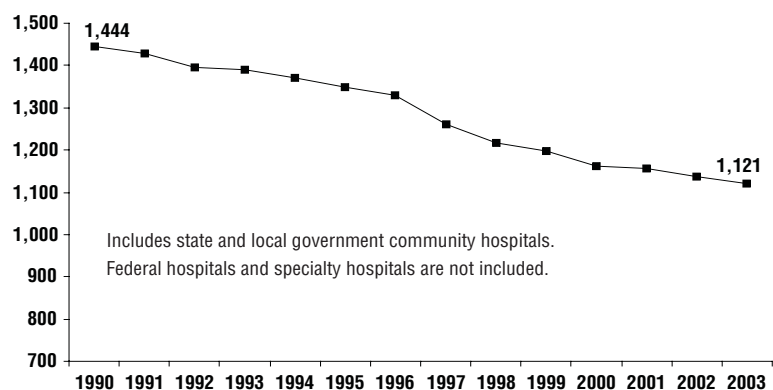
Then when Tim was fifteen and needed an endoscopy and biopsy, the family had just narrowly lost their public coverage (because of Marcy’s hourly raise of 12 cents). The family had planned on going to Barnes Hospital in St. Louis this time, seven hours away, and so she contacted them about the financing.

‘What do I do?’ and they said, ‘Well, let us know when you get insurance.’ They weren’t even willing to work with me to arrange the matter. We tried everything. We tried St. Jude’s (a pediatric cancer hospital about six hours away). They said when he gets cancer bring him. Nobody would take him.

Because public hospitals that provide more charity care are few and far between, those in need of hospital care often have to travel far and then deal with those costs on top of their medical bills.

The number of public hospitals, who are the epicenter of the safety net, has been decreasing steadily since 1990 (Figure 6).

Figure 6
Number of Public Community Hospitals, 1990–2003



Source: Health Forum LLC, an affiliate of the American Hospital Association: Hospital Statistics, 2002, Table 1 (1990–2000 data); American Hospital Association Annual Surveys (2000–2003 data) at www.hospitalconnect.com

Sylvia is a self-assured woman from Texas in her fifties. Having worked with a grass roots community organization in Rio Grande Valley (Texas) for over 15 years, she knows the safety net system there well, but has not been very successful on her own behalf. Diagnosed at Hidalgo County Clinic with a sinus tumor, she was referred to a private specialist (since they provide no specialty care at the county clinic). The specialist recommended further diagnostic work-up and surgery during a visit that by itself cost her a week's salary of \$275. He also told her that the closest, affordable care was 12 hours away at the state hospital in Galveston.

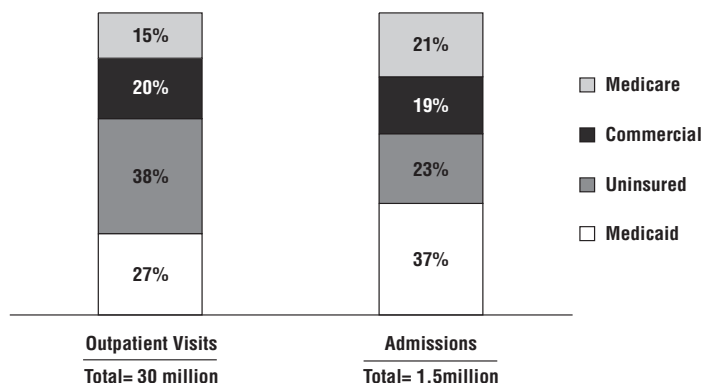
Three years later, when she was better able to afford some of the costs and after the tumor had grown four-fold, Sylvia made the trek—many times over to Galveston.

To go to Galveston, you know, I can't go by myself and I had to stay there because they gave me an appointment for the first check-up and they re-scheduled me for an MRI and then they rescheduled me for another. So, for these problems, I went probably nine times until I got the surgery and then for surgery I stayed there for three days and came back.

Isobel, a well-spoken and resourceful middle-aged woman from south Texas told of even more difficulty in her experience driving a sick brother to a VA hospital five hours away when there were several large hospitals much closer to their home. When her uninsured 39 year-old brother was diagnosed with a brain tumor, and while his wife repeatedly tried to gain Medicaid coverage

More than five million people, including veterans and their dependants, received care in VA health care facilities in 2004, and about 75 percent of all disabled and low-income veterans were enrolled with the VA for health care of some sort.²² At the same time, the VA system is not sufficiently funded to offer comprehensive health care to all veterans and their families. Consequently, the VA uses a complex priority ranking approach with prioritization tied to the nature of the health need and in some cases, income. Highest priority is given to veterans with severe, service-related disabilities (50% or more disabling). Veterans who simply cannot afford the cost of care, or who seek care for a broad array of conditions that are linked to service but not considered "service-related" are given lower priority.

Figure 7
Percent of Inpatient Admissions and Outpatient Visits in Safety Net Hospitals, by Payer, 2002



Urban public hospitals bear a disproportionate percentage of the uncompensated care burden, accounting for an estimated one third of all uncompensated care in the U.S. A survey of some of the nation's largest public hospital systems showed that nearly 40 percent of their outpatient visits and nearly a quarter of their inpatient admissions involve uninsured patients, suggesting the great financial stresses under which they operate (Figure 7).

Source: Regenstien, M and J Huang. *Stresses to the Safety Net: The Public Hospital Perspective*. Kaiser Commission on Medicaid and the Uninsured (report #7329), June 2005.

for him, the family belatedly was informed that he was eligible for care through the Veteran's Administration.

The Veterans Administration is a very large health care system, yet more people qualify for care than the VA can accommodate. Many of VA's services can be found in only limited parts of the country. Isobel recalls,

We took turns driving him to and from San Antonio every weekend. It was hard for us, but harder for him going to and from so many times in his weak state. Eventually he had surgery and was started on radiation. It didn't help any and a second surgery was done. The second surgery left him paralyzed on the right side ... It was getting harder and harder to move him on the five hour drive to San Antonio.

Two weeks before her brother died at age 41, the family learned that he had finally gained eligibility to Texas' Medicaid program—the key to the door of his community's hospitals.

DEALING WITH HOSPITAL DEBT

As of 2005 the VA maintained over 1100 health facilities, including 157 hospital-medical centers, with at least one in each state. Nearly all VA hospitals are located in large urban areas.²³

The uninsured know that there are serious limits to what hospitals can afford in the way of charity care. When they do gain access to their local hospital, they quickly face sizable hospital bills. Liz, a heavysset Idaho woman with salt and pepper hair, works on the secure wing of a nursing home. This job, which pays \$6.40 per hour, offers medical insurance to employees after they have worked at the nursing home for six months. After only two months on the job Liz was diagnosed with hypertension and diabetes, and accumulated several thousand dollars of debt to the local hospital. Making matters worse, Liz received five different bills for the same hospitalization, and she has not been able to work out a payment plan with so many different billers.

Gary, a fifty-year-old skilled mechanic, lost his medical coverage when the car dealership for which he previously worked closed down. A few weeks after being laid off, an accident led to a compound fracture in his left arm. Four surgeries later, Gary, for the first time in his life, was in debt—for \$40,000. As the bills piled up, Gary recalls,

With no health insurance I realized that I was just playing with monopoly money

at this point, and it sounds good that you can pay \$10 a month to the hospital to keep the wolves off your door. However, the reality is that isn't enough when you are looking at \$40,000 worth of debt. It ended up where I did a bankruptcy.

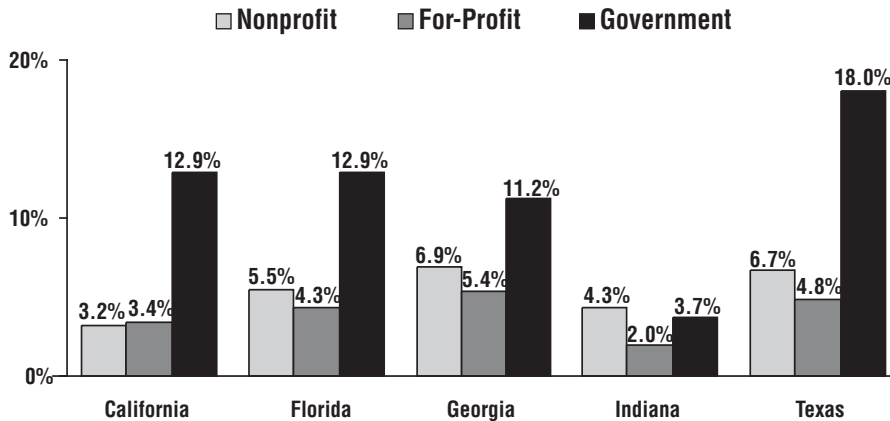
Bankruptcy was part of Marcy's story also. Failing to find an affordable hospital for her son's esophageal surgery, her son eventually required both an emergency endoscopy and surgery. She recalls how the medical debt at that time led her to file bankruptcy.

No one had ever said to me that there's free care, charity care, or that we can make a payment plan. And there wasn't any arrangement, because when we tried to get one because of the exorbitant cost, I ended up trying to make payments, \$25 a month. Believe me, they don't accept \$25 a month. That was turned into the credit company. They garnished my wages. Other times I borrowed money to try and make large payments.

The role of hospitals in the safety net has changed in recent years as non-profit community hospitals compete for patients and also are increasingly merged into larger for-profit national chains. The missions of for-profit hospitals, while not completely avoiding it, require less charity care and may choose to aggressively collect patient debts. Seymour Mitchell, the Director of the Delta Community Health Center in Mound Bayou, Mississippi describes hospital collection practices he has seen.

A GAO study of uncompensated care by hospitals in five states found that the burden of uncompensated care is concentrated in public hospitals. The study also found that nonprofit hospitals more closely resembled for-profit facilities than public hospitals in terms of the uncompensated care they furnished (Figure 8). Moreover, GAO found that in each study state, a small number of nonprofit hospitals accounted for the bulk of uncompensated care furnished by nonprofit facilities generally.²⁵

Figure 8
Share of Patient Operating Expenses Devoted to Uncompensated Care, by Hospital Ownership (5 States)



Source: GAO. Nonprofit, For-Profit, and Government Hospitals: Uncompensated Care and Other Community Benefits. Testimony May, 2005.

Several of the county hospitals were losing money, so they leased themselves to for-profit chains. They now hire collection agencies. If insurance doesn't pay fast enough, they send you to collection.

Theresa Hanna, State Insurance Administrator in Mississippi, further explains that the problem doesn't rest with for-profit hospitals alone.

The issue isn't that they (for-profit hospitals) behave any differently from the not-for-profits. To be honest, the bigger problem is the not-for-profits and the religious hospitals acting like they are for-profit. They are faced with the same pressures as the for-profit hospitals. Instead of showing a profit for investors, they need the profit as a way to finance capital improvements in order to compete.

And Claudia Lennhoff of Champaign County Health Care Consumers, who works closely with people struggling with hospital bills describes her local bill collection experiences.

They will sue people, they will garnish their wages, they will put liens on their homes, and things like that. What we see, the people who are in court for not paying hospital bills, these are overwhelmingly poor people, and the hospitals know this ... Sometimes some of the people taken to court, if you look at their records, you will see that they are the hospital's charity care patients. They have actually already qualified for and received some charity care, so the hospitals are suing their own charity care patients.

IN CLOSING

This report provides many insights into the frustrations of seeking and providing medical care for those who need, but cannot afford it. In so doing, a worn and fragmented safety net “non-system” is laid bare. Our safety net is neither comprehensive, nor is it well-integrated. In many of this country’s health centers, public hospitals, and health departments, providers have established a fairly high quality of service, offering care that meets the unique medical and social needs of a very diverse group of patients. But these providers are limited in what each delivers and finding the affordable specialty care, the surgery, the medications, the medical equipment and assistive devices that their patients need is no doubt, their greatest frustrator.

In the absence of universal health insurance coverage, the health care safety net has served as the back-up for millions of this nation’s disadvantaged, young and old. Just how dependent we have become on it was recently unmasked in the aftermath of Hurricanes Katrina and Rita which hit our poorest region, the deep south. One unexpected event in a community—a hurricane or an earthquake—that closes or cripples its health center or public hospital, takes away the medical home of its low-income residents. Finding a clinic, a new family doctor or a specialist, particularly in a new community, has always been difficult if a person has no health insurance. As demonstrated in the weeks that followed the hurricanes, safety net providers can never be a replacement for the security and portability that health insurance coverage affords.

Concerned about the tenuous nature of the health care safety net with the growing numbers of uninsured Americans and the lack of agreement on how to address this problem, the Institute of Medicine published a report in 2000 entitled, *America’s Health Care Safety Net: Intact but Endangered*. Since their report was published, pressures have continued to mount on the safety net. In the report’s summary they had forewarned:

A resurgence of inflation in health care costs, an economic downturn, or further increases in the rolls of the uninsured could further destabilize the safety net and place essential care for America’s vulnerable populations at the risk of significant peril.²⁶

All of these threats have come to pass in the five years since the report was written.

Between 2000 and 2005 health insurance premiums have risen by 73 percent, and their annual growth rate has outpaced both general inflation and wages by at least two-fold.²⁷ During this period more middle-income families have shifted into the lower, even poverty classes, causing the number of uninsured, under-insured, and Medicaid beneficiaries to climb. Employer-sponsored insurance has been steadily waning. On any given day last year, over 45 million Americans had no health insurance coverage. In addition, over 50 million Americans rely on the Medicaid program and many of these families turn to their community's safety net providers for their health care. While there are no current estimates of the number of under-insured Americans, at least 16 to 18 million privately insured adults are dealing with a substantial medical debt and so are more likely to be looking for charitable sources of care.²⁸ Our health care safety net, largely centered in health centers and public hospitals, is stretched thin to meet their needs.

Recognizing the role that health centers play in delivering care to the uninsured, the federal government has committed to a five-year initiative to expand health center capacity—with some of the largest funding increases ever over the 40 year history of health centers. This has enabled more than 600 new and expanded health centers to serve over three million new patients. Yet the new funds do not approach the level of demand. The National Association of Community Health Centers reports that one in three *qualified* applications for new centers were approved for federal funding in 2002 and 2003; with less than one in ten approved in 2004 due to the availability of funds.²⁹

Health center funding however, is only a small slice of federal dollars aimed at improving access to care for the uninsured. Federal dollars for health centers comprised just three percent of total federal spending on uncompensated care for the uninsured in 2004.³⁰ The federal government partially supports most all of this country's safety net providers, including other direct care programs such as the Veterans Health Administration and the Indian Health

Service, as well as through even larger Medicare and Medicaid subsidies to hospitals that provide a disproportionate share of care to the uninsured.

However, federal funding to support the broader safety net has also not kept up with the growing demand for services. A recent study analyzing changes in federal spending for uncompensated care for the uninsured between 2001 and 2004 found spending grew by less than two percent (after adjusting for inflation) as the number of uninsured increased by 11 percent over this period. The result is that federal spending per uninsured person fell from \$546 in 2001 to \$498 by 2004—a decrease of almost nine percent.³¹

Rising health care costs threaten all safety net providers who have slim operating margins and are often reliant on government sources of funding. Medicaid dollars are their single largest source of revenue, providing over a third of public hospitals' and community health centers' revenues. The first of five recommendations the IOM panel made to protect and bolster the safety net was that policy makers "take into account and address the full impact of changes in Medicaid policies on the viability of safety net providers and the populations they serve."³² But as states have grappled with beleaguered budgets and growth in Medicaid enrollment, they have cut provider payment and eligibility levels, both of which directly impact safety net providers' operations. Likewise, increases in beneficiaries' co-payments by some states are often absorbed by safety net providers because the poor are least able to afford these co-payments. States have renewed efforts to enroll more of their Medicaid beneficiaries into managed care plans, which have the potential of eroding safety net providers' patient and revenue base.

Cuts in Medicaid payment levels have made safety net hospitals even more dependent on disproportionate share hospital (DSH) and other supplemental payments from federal and state sources. And paradoxically, as public hospital systems grow their outpatient services to better meet the community's needs, their operating budgets suffer because Medicaid payment levels for outpatient care are generally quite low. Since outpatient services also do not factor into the calculations for DSH funds, this source of revenue can actually decrease if the new outpatient services reduce inpatient care for uninsured and Medicaid patients.³³ In addition, the full impact of Medicaid managed care contracts

needs close monitoring as safety net providers compete for the patients they have been previously and primarily serving.

These changes in Medicaid policies do not trickle down to the safety net; they impact these providers with full force. Meanwhile, the overriding health policy challenges this country faces—how to gain control of escalating health costs and at the same time expand health coverage to more Americans—are not being squarely addressed, which leaves health centers, safety net hospitals, and health departments facing ever greater demands.

It also leaves patients who are turned away, to then seek care outside of the safety net, where help is even harder to find. A poignant example, as told by a Louisiana Medicaid official, followed the closure of the Medical Center of Louisiana at New Orleans, which includes Charity Hospital, due to hurricane damage this year. An uninsured New Orleans resident with a growing brain tumor had been scheduled for surgery at Charity Hospital. Following the hurricane the patient was transferred to another public hospital in Baton Rouge, the Earl K. Long Hospital. Not able to provide the service, this second public hospital then referred this patient to a large private hospital with the capacity to perform the surgery. However, the private hospital refused to admit the patient because he was uninsured.

Although it's just one story, it says a great deal about how tightly linked the safety net, health insurance, and access to critically needed care are. Without health insurance, patients turn to the safety net for affordable care. When the safety net cannot provide what is needed, health insurance is the requisite key into the mainstream of medical care. And finally, without sustained financing, largely through public insurance, the safety net will not be able to continue its mission to the poor and uninsured. In order to improve the health of America's most disadvantaged, both the health care safety net—the preferred medical home of many low-income patients—and insurance coverage will need to be expanded.

METHODOLOGY

Over the course of twelve months in 2003 and six months in 2004 Susan Sered and Rushika Fernandopulle conducted open-ended, wide-ranging interviews with 120 uninsured men and women in Idaho, Texas, Mississippi, Illinois, and Massachusetts. In order to qualify for this study, uninsured interviewees had to:

- 1) be uninsured at the time of the interview (people with Medicaid or Medicare were not eligible for the study) and
- 2) be working at the time of the interview, or have a working spouse, or be between jobs (unemployed for less than 2 months).

Uninsured interviewees were contacted through local churches, community organizations, friends and colleagues at local universities, at yard sales, libraries, lines at local pharmacies and grocery stores, and via notices tacked up in public places. One contact often led to another, and their conversations covered matters directly related to illness and medical care, as well as more general personal anecdotes, family stories, and observations about neighborhoods and workplaces.

The youngest adult interviewed was 19 and the oldest 64 at the time of the interview. Most were in the middle of that age range, and spoke about the health concerns of their entire families over periods of many years. Reflecting common expectations that women are responsible for the health of their families in addition to their own health issues, the majority of the uninsured interviewees were women. Among the uninsured interviewees were twenty Hispanic families and twenty African American families.

Interviews lasted approximately one to two hours, and sometimes were followed up by phone calls or letters. Each interviewee received a \$25 honorarium as a token of appreciation for participating in the study. All names of uninsured interviewees have been changed, as have other identifying details.

In addition to the interviews of uninsured individuals, 46 health care providers were interviewed, including physicians, administrators, help-line and hot-line workers, social workers, outreach workers, and nurses who work with uninsured people in the five states visited.

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