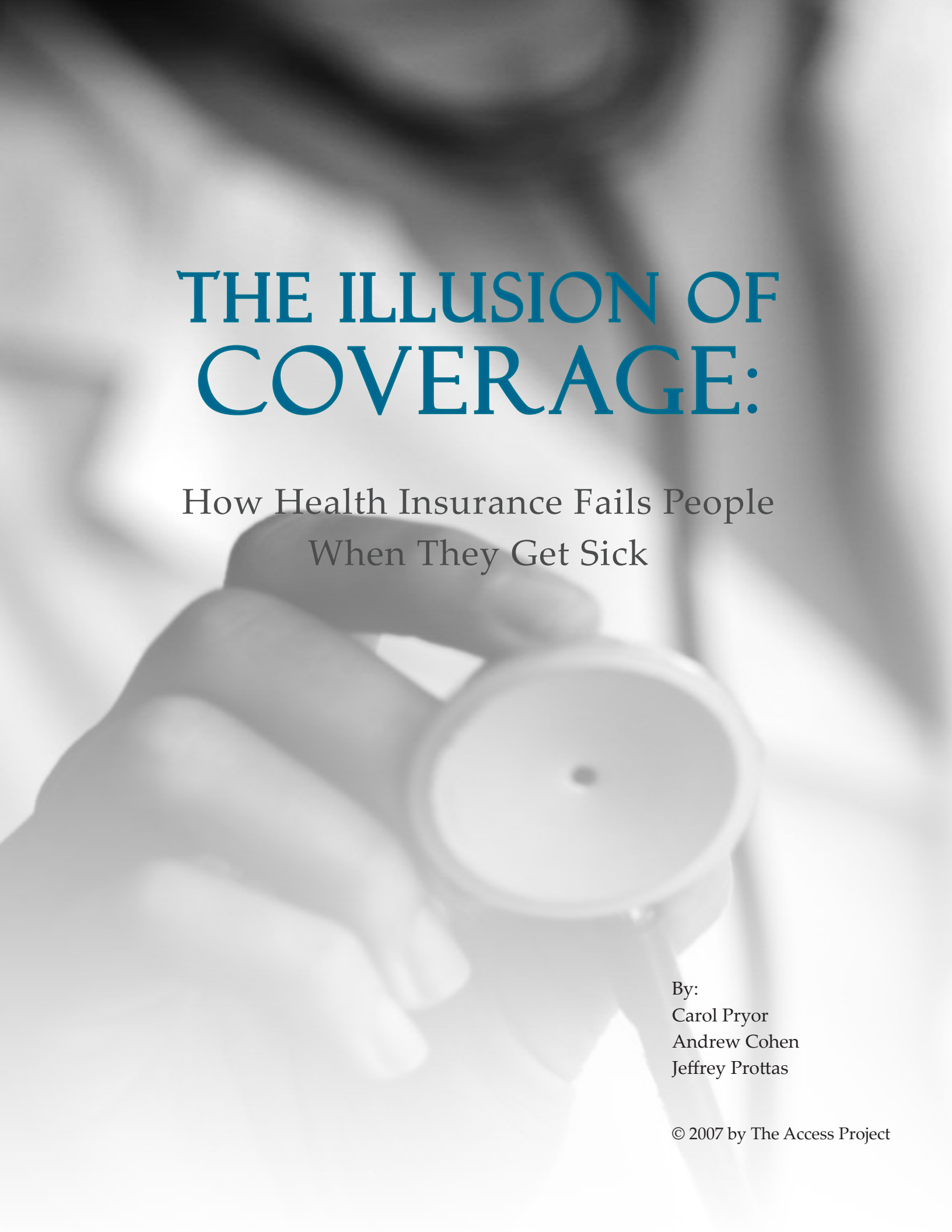

THE ILLUSION OF COVERAGE:

How Health Insurance Fails People When They Get Sick

By:
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The Access Project (TAP) has served as a resource center for local communities working to improve health and healthcare access since 1998. The mission of TAP is to strengthen community action, promote social change, and improve health, especially for those who are most vulnerable. TAP conducts community action research in conjunction with local leaders to improve the quality of relevant information needed to change the health system. TAP's fiscal sponsor is Third Sector New England, a non-profit with more than 40 years of experience in public and community health projects. TAP is affiliated with the Heller School for Social Policy and Management at Brandeis University.

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Executive Summary

Recent research has clearly documented that unaffordable medical bills and resulting medical debt are widespread in the United States. Although the uninsured are most at risk, people with insurance are vulnerable as well; one survey found that more than one quarter of people continuously insured over the previous year had medical bill problems or medical debt. However, while national surveys document the prevalence of medical bill problems among the insured, they are not able to demonstrate the specific ways in which health insurance products fail to protect people financially and fail to guarantee their access to needed care when ill or injured.

The purpose of this study is to investigate the gaps in coverage and the systemic problems that cause insured people to accrue medical debt, as well as the consequences of the debt for individuals and families. The findings are based on in-depth interviews with 45 people in seven states who had accrued medical debt while they were privately insured, either through an employer-sponsored or an individually purchased plan.

The findings are summarized below. However, because summary findings cannot easily convey the complexity of our interviewees' experiences, we recommend that all readers also review the stories and comments in the body of the report. To facilitate this process, we have highlighted some of the stories and comments within the text.

Findings

Our interviews suggest that medical debt among the insured results from a variety of causes and the interaction of a number of factors, including the adequacy of people's insurance plans, the nature of their medical needs, the cost of their treatments, and their financial resources. In all cases, however, interviewees found that their insurance failed to fulfill its primary function—to protect them from financial losses and guarantee access to needed care when they became ill.

Insurance Characteristics that Cause Medical Debt

Some of the insurance characteristics that caused interviewees to accrue debt included the following:

- **Premiums, deductibles and other cost sharing.**
  About two-thirds of our interviewees cited premiums, deductibles, co-payments, or co-insurance as one source of their medical debt; many cited a combination of these charges. People with lower incomes and/or chronic conditions were particularly vulnerable, even when their deductibles and other cost-sharing requirements seemed relatively modest. However, many with higher incomes also faced unaffordable out-of-pocket expenses because of high deductibles, co-insurance, and other forms of cost-sharing.

- **Caps on coverage.**
  Some interviewees had insurance policies that set annual or lifetime caps on coverage. If they suffered catastrophic medical events, they then found themselves liable for enormous medical bills. Others had policies that capped coverage for particular services, such as rehabilitation or dental care, which caused them to accrue serious medical debt.

- **Uncovered services.**
  Over one-third of our interviewees accrued medical debt because of uncovered services. Some of the most common were prescription drug coverage, dental services, and durable medical equipment. People with children with special health care needs were particularly vulnerable because their children often required treatment not traditionally covered by insurance, such as occupational therapy or special nutritional supplements.

Insurance Processes that Cause Medical Debt

Many interviewees also described complex and confusing insurance processes that made it difficult for them to get claims issues resolved and left them with unaffordable medical bills and medical debt.

- **Confusing policy provisions.**
  As health insurers have added complex combinations of cost-sharing components to their plans in order to shift risk to consumers, policies have become increasing difficult to understand. Interviewees often found the provisions of their policies confusing, which made it difficult for them to understand which services should or should not be covered.

- **Out-of-network fees.**
  A number of interviewees cited increased co-insurance or deductible payments that resulted from getting care from providers not in their plan's network. Many received care at hospitals that were in their network, but were not told that doctors who provided care in the hospital were not in their network. Others were charged out-of-network fees even when in-network providers were not available.

- **Procedural problems.**
  Complex insurance plans often placed on patients the burden of complying with a complex web of requirements and procedures. Some interviewees were left with unpaid bills because they were not informed about procedures they needed to follow, or were asked to comply with procedures that seemed unnecessary.

- **Insurance disputes and errors.**
  Many interviewees found they had to devote enormous amounts of time and energy to resolve insurance errors. When they tried to clarify issues with insurers, they often received confusing, inconsistent, or inaccurate information, and sometimes found it took

weeks or months to resolve problems. Some were unable to resolve problems and were left with unanticipated, unaffordable medical bills.

- **Complex provider billing and collections systems that compounded problems resulting from complex insurance processes.**
  When people were left with unaffordable bills resulting from complicated insurance policies and difficult to navigate insurance systems, they often found their problems compounded by equally hard to navigate provider billing and collections systems. Often people found it hard to reconcile confusing hospital bills with confusing insurance statements. Providers also sometimes made mistakes when submitting claims to insurers, which created problems for interviewees.

  When interviewees did end up owing money to hospitals and other providers, they often found themselves subject to aggressive billing and collections processes. Some were never informed about hospital financial assistance options. Many said they were willing to pay reasonable charges for services but felt that providers charged grossly inflated prices.

Lack of Meaningful Choice of Plans

Interviewees did not willingly choose to have insurance that left them vulnerable to serious financial exposure if they became ill. Usually they had inadequate insurance because it was the only option offered to them or because it was the only option they could afford. As a result of problems with their coverage, many interviewees began to question whether their policies were worth the premiums they paid for them, or whether they would be better off without coverage.

About 70 percent of our interviewees had group insurance, that is insurance provided through their employer. The following problems were experienced by people with group insurance:

- **No real choice of plans.**
  Only about half of interviewees who received coverage through their employment were offered a choice of plans. Those with the highest deductibles—$2,000 or more—did not have a choice of plans. Even when people had a choice, they often chose the policy with the lowest premium because they felt it was all they could afford, even though it left them subject to other unaffordable out-of-pocket expenses.

- **Increasing costs and worsening coverage.**
  The majority of interviewees with group coverage said their premiums and cost-sharing had gone up significantly in the last few years, while their coverage had gotten worse. Some noted that their wage increases had not kept pace with their increased insurance-related expenses.

Almost one-third of our interviewees had coverage they purchased individually or through associations they joined simply to be eligible to purchase coverage. While people purchasing coverage in the non-group market theoretically have a choice of plans, in practice their choices were often highly constrained by cost factors. In addition, people purchasing insurance in the non-group market were particularly vulnerable to certain types of problems.

- **Higher premiums and levels of cost sharing.**
  Interviewees with non-group coverage tended to have higher levels of cost-sharing than those with employer-sponsored coverage. Almost all interviewees with non-group coverage who reported on the size of their deductibles had deductibles equal to or greater than $2,000 a year, compared to only one of the interviewees with group coverage who reported on the size of their deductibles. People with non-group coverage also tended to have higher monthly premiums.

- **Pre-existing condition exclusions.**
  People with non-group coverage also confronted problems related to the exclusion of pre-existing conditions. Some were only able to purchase coverage that excluded their medical condition, some were faced with prohibitively high prices if they had existing conditions, and some were refused coverage altogether. One interviewee had his coverage rescinded when he became ill and started to file claims.

- **Deceptive marketing practices.**
  People with non-group coverage were particularly vulnerable to deceptive and possibly fraudulent marketing that misrepresented the coverage being offered. Some interviewees purchased high-deductible policies that they thought would provide catastrophic coverage. However, when they needed care, they discovered that fine print exclusions in the policies meant that almost none of their care was covered.

Consequences of Medical Debt

Medical debt had serious consequences for our interviewees related to access to care, financial security, employment, access to credit, and psychological quality of life.

- **Access to care.**
  Nearly nine out of ten interviewees said their medical debt affected their ability to access care, and nearly half said reduced access to care had negatively affected their health. In most cases, people postponed or did not get needed care because they couldn't afford the cost sharing and feared incurring more debt. In some cases, providers refused to see them because of their unpaid bills. Sometimes people did not get preventive or diagnostic care.

Sometimes the failure to get care in a timely way resulted in more serious and expensive health problems later on. Most interviewees feared getting sick because, even though they had insurance, they felt they could not afford the cost of the care.

- **Financial consequences.**
  Almost all of our interviewees experienced negative financial consequences as a result of their medical debt. For some people who experienced catastrophic medical events, enormous medical expenses required them to take out very large loans. For people with lower or moderate incomes, medical debt contributed to the existing difficulties of living on a limited budget. Over one-third of our interviewees used up their savings or were unable to save for retirement because of their medical bills. Many interviewees were forced to refinance their mortgages or take out loans against their homes to pay medical bills. In the most extreme cases, some interviewees were forced into bankruptcy.

- **Employment consequences.**
  Almost three-quarters of our interviewees said medical bill problems affected their employment. Some people were forced to reduce their work hours or stop working because of their or a family member's illness. Other people found they had to work longer hours to help pay their families' medical bills. A number of interviewees felt they needed to find new employment because their health benefits were so poor. The costs of health insurance also made it difficult for people to start or maintain their own businesses.

- **Access to credit.**
  Medical debt had negative affects on many interviewees' ability to access credit. Nearly half had been contacted by collection agencies because of their medical bills, and several were encouraged to pay their bills with credit cards, which can saddle people with interest payments and sometimes excessive late fees. Some were denied loans, for example to pay for a child's education, and others had to get loans with higher interest rates.

- **Psychological consequences.**
  Most interviewees reported that their unpaid medical bills contributed to increased stress and tension in their families. A number of interviewees felt that the increased stress had affected their health and ability to heal.

Discussion and Recommendations

In recent years, much attention has been paid to hospitals' lack of transparent pricing and their aggressive billing and collections practices. However, similar attention has not been paid to the policies and practices of insurance companies. Our interviews suggest that states are not seriously monitoring benefit packages and premium rates to ensure that consumers are being offered real value in exchange for their premiums. They indicate that insurance companies are not being held accountable for inadequate customer service systems and error-prone claims handling processes that often leave consumers liable for expenses that they should not have to bear. And they reveal that some insurance products are being marketed deceptively and possibly even fraudulently.

These issues assume particular importance as policymakers increasingly turn to the private insurance market as the vehicle for expanding coverage. Some propose shifting more costs to consumers in order to make them more prudent purchasers of health care. Others support allowing the sale of policies with limited benefits, maintaining that such plans will make coverage more affordable or allow people to choose the level of coverage that best meets their needs. Our interviews indicate that the assumptions behind these proposals are deeply flawed. Most of our interviewees had few meaningful options when they purchased coverage and, rather than frivolously seeking inappropriate care, have gone deeply into debt to obtain needed care or delayed necessary care because of the cost.

In addition, some policymakers are proposing that uninsured individuals be required to purchase private insurance; Massachusetts has already passed a law including such an "individual mandate." However, before relying on the private insurance market as the means of expanding coverage for the insured, it is important to understand how well the market is working, identify existing problems, and, where they exist, rectify them. Otherwise, we will simply replace the problems related to lack of health insurance with problems related to inadequate insurance. For insurance to fulfill its primary goals of mitigating the financial risk associated with illness and guaranteeing people access to necessary care, it must meet three criteria:

1. It must be comprehensive. This includes covering medically necessary and effective treatments, such as prescription medications, as well as preventive care and disease management.

2. It must be affordable. Affordability must take into account not only the cost of premiums, but also all of the other out-of-pocket expenses for which people will be liable, such as deductibles, co-payments, and out-of-network fees.

3. It must be accessible, including to people who have pre-existing medical conditions or health risk factors.

To achieve these goals, we recommend the following:

Set standards for what constitutes comprehensive, affordable insurance.
Standards must include both the range of benefits covered and the out-of-pocket amounts for which consumers may be liable.

Ensure that people are provided with information that allows them to be informed consumers when they try to purchase health insurance.
For example, insurance companies could be required to provide consumers with standard disclosure forms that clearly detail the services products cover and the out-of-pocket expenses for which consumers are liable.

Enact guaranteed access, guaranteed renewability, and community rating laws in states where they are not already in place.
These types of laws prohibit insurers from refusing to sell insurance to individuals because of health status and prevent them from charging premiums based on health status that would effectively shut people with medical conditions out of the insurance market.

Conduct oversight to ensure that health insurance premiums are reasonable.
States should require insurers to file requests for premium increases and hold public hearings on the requests. Requests should be evaluated with respect to insurers' efficiency (the amount of each dollar they spend directly on covering health insurance claims) and resources (profits, surpluses, and reserves).

Develop public/private partnerships to help share the cost of comprehensive, affordable coverage for people with limited resources.
Some states have already implemented programs that combine state and private funding to provide comprehensive coverage for groups that could not otherwise afford it.

Create mechanisms to help consumers resolve insurance-related problems.
States should create and staff strong customer service departments to record and investigate customer complaints about health insurance contracts and practices. Some states have appointed independent ombudsmen to assist consumers who have insurance-related problems and to intercede with insurance companies to help resolve them.

Set rules that prohibit unfair insurance practices.
These might include prohibiting post-claims revocations of policies or charging out-of-network fees when patients receive care in in-network hospitals. States also need to regularly

monitor insurance industry compliance with existing laws and require corrective actions when necessary.

To protect people who are left with unaffordable medical expenses that their insurance will not cover, require hospitals and other providers to offer appropriate discounts and financial assistance.

Financial assistance programs should be available to both the uninsured and to people with inadequate insurance.

Introduction

Unaffordable medical bills and resulting medical debt are widespread and growing concerns in the United States. Although the uninsured are most at risk of having medical bill problems and medical debt, recent research has clearly documented that many people with insurance are vulnerable as well: one survey found that more than one-quarter of people continuously insured over the previous year had medical bill problems or medical debt.[1] However, while national surveys can document the prevalence of medical bill problems among the insured, they are not able to demonstrate the specific ways in which health insurance products fail to fulfill their primary purpose, which is to allow individuals and families to access needed health care without compromising their financial security. The purpose of this study is to investigate the gaps in coverage and the systemic problems that cause insured people to accumulate medical debt. To gather this information, we interviewed 45 people in seven states who had accrued medical debt when they were privately insured, either through their employer or an individually purchased plan.

Prevalence of Medical Bill Problems Among the Insured

A 2005 survey by the Commonwealth Fund found that more than one-third (34%) of adults ages 19 to 64 had medical bill problems in the past year, such as medical debt, inability to pay medical bills, life changes due to medical expenses, or being contacted by a collection agency. A majority of these individuals (62%) was insured.[2] In a 2006 survey by The Kaiser Family Foundation, two-thirds (69%) of these people were insured.[3]

Other research has documented rates of underinsurance—that is, percentages of insured people at risk of having medical bill problems. A 2005 article defined the underinsured as people who had: 1) medical expenses amounting to ten percent or more of income, or 2) among low-income adults (below 200% of the Federal Poverty Level), medical expenses amounting to at least five percent of income, or 3) health plan deductibles equaling or exceeding five percent of income. Using this definition, the authors estimated that 15.6 million Americans were underinsured.[4] A December 2006 study that used the same definition of underinsurance found that, in 2003, 17.1 million people were underinsured.[5]

It should be noted that definitions of underinsurance based on the percentage of income spent on health care necessarily underestimate the underinsured population. These definitions only identify insured people who have been ill or injured and accumulated medical bills. Many more people may have inadequate insurance but have not yet become sick.

Insurance Policy Characteristics that Increase Risk

Certain characteristics of health plans put insured people at greater risk of experiencing medical bill problems, medical debt, or being underinsured. One study found that the underinsured (as defined above) were less likely than the adequately insured to have prescription drug coverage, dental coverage, or vision benefits; more likely to have deductibles greater than $500; and more likely to encounter limits, or maximum caps, on what their plans will pay.[6] Another study reported that nearly half (49%) of adults with yearly deductibles of $500 or more had medical bill problems, whereas fewer than one-third of people with deductibles below $500 had similar problems.[7]

The high cost of insurance premiums also contributes to underinsurance. Among non-elderly adults with employer-based health coverage in 2003, 5.5 percent spent more than ten percent of their disposable income on out-of-pocket health care costs. When premiums were factored in, however, almost one in five people (18%) spent ten percent of their income on health care expenses. These numbers represent people across all income levels.[8] Another survey found that two-thirds of people with annual insurance premiums that equaled or exceeded ten percent of income had medical bill problems, compared with 31 percent of those with premiums lower than ten percent of income.[9]

Groups at Risk

Among both insured and uninsured populations, people with chronic health concerns and lower incomes are most vulnerable to financial hardship caused by medical expenses. A 2003 survey of non-elderly adults found that one in three people (33%) with incomes at or below 100 percent of the Federal Poverty Line (FPL) spent more than ten percent of their income on medical care and insurance premiums, compared to about one in four people with incomes between 100 percent and 400 percent of FPL, and ten percent of those with incomes over 400 percent of FPL. The same survey found that one-third of people with "perceived fair or poor health" spent more than ten percent of their income on insurance premiums and out-of-pocket medical expenses.[10]

While the percentage of income that people devote to health expenses is highest among the poor, it is also rising rapidly among people with moderate incomes (200-400% FPL). In 1996, 15.6 percent of people in this income group spent more than ten percent of their incomes on premiums and other health care expenses; by 2003, the percentage had risen to 22.7 percent. The proportion of income spent on medical costs is also rising significantly among those who earn more than 400 percent of FPL: in 2003, one in ten people in this income category spent more than ten percent of their incomes on health care costs, including insurance premiums, an increase of nearly 150 percent since 1996.

Those who purchase insurance in the non-group market are more likely to face financial strains due to medical costs than other insured people. A 2006 study by the Commonwealth Fund found that 43 percent of adults covered by non-group insurance spent more than ten percent of their income on medical expenses and premiums, compared to 24 percent of people with employer-sponsored insurance products.[11] Among lower-income families with high medical costs, those with non-group health insurance spent nearly half of their income on premiums and out-of-pocket health care costs (48%). This was similar to the rate for the uninsured (51%) and three times the rate for those with employer-sponsored coverage.[12]

Consequences of Inadequate Insurance

Like the uninsured, people with inadequate insurance face serious health access and financial consequences. The Commonwealth Fund found that 54 percent of underinsured people (as previously defined) went without at least one of four needed medical services because of cost—twice the rate of those with adequate insurance.[13] A 2005 Kaiser study found that the care-seeking behavior of those with private coverage and medical debt was more like the uninsured than the insured without medical debt: about 28 percent of both the insured with medical debt and the uninsured postponed care because of costs, compared to six percent of the privately insured without medical debt.[14]

Financial consequences of health-related debt can run the gamut from marred credit and tough spending choices to the extremes of home foreclosure and personal bankruptcy. Among the underinsured, The Commonwealth Fund found that 46 percent had been contacted by a collections agency. Additionally, 35 percent had to change their way of life to pay medical bills, compared to only seven percent of those with adequate insurance.[15] Another Commonwealth Fund report found that one in five (19%) continuously insured people was unable to pay for basic necessities due to medical expenses, and one in three (33%) used up all of their savings to pay these bills.[16] Researchers have also estimated that medical expenses or lost income due to illness or injury are factors in about half of all personal bankruptcies.[17]

Medical Bill Problems Among the Insured are Likely to Grow

Insurers are increasingly shifting more health care costs to consumers, which will inevitably result in growing rates of medical bill problems among the insured. In recent years, health care premiums have risen significantly—a 2006 Kaiser survey found that two-thirds of adults with insurance said their health insurance premiums had gone up in the previous five years, and 31 percent said they had gone up a lot.[18] In 2006, health insurance premiums for employer-sponsored plans increased by 7.7 percent. Although this number represents a smaller increase than

in previous years, premiums still rose more than twice as fast as inflation and workers' wages. Overall, premiums for family coverage have increased by 87 percent since 2000.[19] In addition, insurance policies are increasingly shifting other out-of-pocket costs to consumers. In 2005, over one half (52%) of adults in employer-based plans said their co-payments had gone up in the past year; almost one half (49%) said their deductibles had increased.[20] Out-of-pocket medical expenses, excluding premiums, for individuals with non-group insurance are almost twice those of people with employer-based plans.[21]

Methodology and Respondent Characteristics

Methods

The findings in this report are based on in-depth telephone interviews with 45 people in seven states: California, Florida, Illinois, Massachusetts, Missouri, New York, and Ohio. In order to participate, interviewees had to meet two criteria: they had to have 1) accrued debt resulting from the purchase of medically-related goods or services, and 2) had private health insurance—either through employer-sponsored coverage or through individual purchase—when they began accruing medical debt (although their insurance status may have changed since that time).

We included people with medical debt from all sources, such as hospitals, doctors, dentists, prescription medications, ambulance services, and laboratories. We considered debt medically-related if it resulted from the purchase of these goods and services, even if the debt had been converted to other forms, such as credit card debt or loans. We used accrued medical debt as a criterion for participation in the study because it is a clear indicator of financial problems resulting from unaffordable medical bills. Of course, many people may experience medical bill problems even if they have not yet resulted in medical debt.

The Access Project worked with local research partners in each state to find and screen potential study participants. Our local research partners were:

California:	Health Access California
Florida:	CHAIN (Community Health Action Information Network)
Illinois:	Champaign County Health Care Consumers
Massachusetts:	Health Care for All
Missouri:	Missouri Citizen Education Fund, Jobs with Justice, Saint Louis University School of Law
New York:	New York Immigration Coalition
Ohio:	UHCAN Ohio (Universal Health Care Action Network of Ohio)

The partner organizations used a variety of methods to identify people with medical debt and health insurance, including consumer hotlines, outreach to local unions and advocacy groups, email alerts to local and state-wide listservs, and outreach among staff and membership. Partners completed a short form with basic information about potential candidates; The Access Project reviewed this information and chose final participants. The Access Project also identified participants through its web-based story collection tool. Between five and seven people were interviewed in each state.

Access Project staff conducted the in-depth interviews using an open-ended interview protocol. We received signed consent forms from all interviewees. The Access Project digitally recorded the conversations and had them transcribed, and then used qualitative research software to analyze the interview transcripts.

Respondent Characteristics

Most of our interviewees were white, although about 15 percent were minorities. About two-thirds were female, and most were between the ages of 36 and 65.

Nearly three-quarters of our interviewees lived in a family where they and/or their spouse were currently employed. Four interviewees were retired and one was a full-time student. Among those interviewees who were not employed and did not have a working spouse, most had to leave their jobs because of their or a family member's medical condition.

Close to one-third of our interviewees had household incomes above the national median of $46,326,[22] and a majority had incomes above $30,000. Incomes ranged from $100,000 at the upper end to zero at the lower end.

The amount of money people currently owed for medical care and related costs (among those who reported their debt) ranged from zero to $175,000. About one-quarter of interviewees had debts under $1,000. Slightly more than one-quarter had debts between $5,000 and $15,000. Four people had debts over $50,000.

Interviewees were insured by a wide range of companies, including major insurers such as Blue Cross Blue Shield, Aetna, United HealthCare, Humana, and Cigna, as well as many other smaller companies.

How Does Health Insurance Fail People?

Economic theory maintains that health insurance has value because it allows people to mitigate the financial risk associated with illness, and because it allows those who become ill to afford care they would otherwise not be able to purchase.[23] The dictionary defines insurance as "protection from loss."[24]

Our interviews suggest that medical debt among the insured results from a variety of causes and the interaction of a number of factors, including the adequacy of people's insurance plans, the nature of their medical needs, the costs of their treatments, and their financial resources. In all cases, however, interviewees found that their insurance failed to fulfill its primary function—to protect them from financial losses and guarantee access to needed care when they became ill.

Three Stories

The following stories reflect some of the many ways that people can end up with major medical debt in spite of having health insurance.

Kathleen's Story: *People with conditions that require ongoing care often face unaffordable medical bills, even if their cost-sharing requirements appear to be moderate. This is especially true for lower-income people with chronic diseases.*

Kathleen is 58 years old. She has bi-polar disorder, a chronic mental illness, which only allows her to work part-time. Her income is $21,000 a year, which includes monthly payments from her husband, from whom she is separated. She has health insurance through her husband's employer, for which he pays $300 a month. The plan includes a $250 annual deductible, co-insurance of ten percent if she goes to in-network providers, and co-pays of $15 per visit.

While these amounts seem modest, given her limited income and her ongoing needs for medical care, she can never really catch up on her bills. "The deductible…of $250 actually sounds like a small amount, but it causes a problem every year…. I can't pay $250 even in two months…and I can't even pay $50 a month, so it stretches out to six or seven months…. I haven't finished paying on my $250 deductible this year because of high other expenses…. My electric bill shot up in November. The rates went up. Oil was high this year."

Although the $15 per visit co-pays also do not seem excessive, Kathleen typically needs to visit her doctor about 40 times a year, which amounts to $600 in co-payments annually. She also has significant co-pays on her prescription medications. Finally, other expenses are often not covered in full. She needed glasses, which required a $68 payment for a vision exam and a $15 co-pay for the ophthalmologist—because of the cost, she is delaying her follow-up appointment. When she needed laser treatments on her eyes, she also had to pay 10 percent of the bill in co-insurance. In addition, she needed three crowns and a root canal in the last two years, and her dental benefits are capped at $1,000. She currently owes about $500 in medical bills and another $400 on her credit card, which she used to pay for her dental care.

Linda's Story: *Some people find themselves in debt because of seriously inadequate insurance policies. Sometimes these policies are marketed deceptively. People think their insurance will protect them against major medical expenses but in fact, when they get sick, they are left financially exposed.*

Linda and her husband live in Massachusetts, where he is a self-employed contractor. He had had a heart attack nine years earlier, when he was uninsured, so they were anxious to get catastrophic coverage that would protect him in case he ended up with very large medical bills. In shopping for insurance, they found that the premiums for most policies were unaffordable. However, one policy offered through an organization for self-employed people seemed reasonable, with premiums around $250 month and a deductible of about $2,000. When Linda and her husband asked the representative how the premiums could be so low, they were told that it was because self-employed people are very reliable and don't abuse the system. The agent also said that if Linda's husband did not enroll that day, the premiums would rise. Linda said, "We thought that we had a million dollars of coverage over the life of the policy, up to 80 percent."

In 2005, Linda's husband suffered a heart attack that required quadruple cardiac bypass surgery. The total charges came to about $60,000; Linda expected the insurance to cover 80 percent after they paid the deductible. However, they soon found that the insurance covered only a fraction of the bill. "[T]hey have this clause that refers to miscellaneous charges, and almost everything that involves your care, other than just simple room and board itself,…basically had a $4,500 cap." The insurer even refused to cover some services to that limited extent. With one bill, she said, "They just keep changing the coding on the bill. First they said it was outpatient, even though he was admitted. And then when I complained about that, they changed to coding to day surgery, which they don't cover." When Linda later researched the company on the Internet, she found that it had been sued many times for these kinds of practices.

Massachusetts has an uncompensated care pool that in the end paid about $50,000 of the medical expenses; however, Linda and her husband were still left with about $10,000 of debt. Since Linda's husband can no longer work because of his health and she is on disability, their income has dropped sharply; the debt represents about half of their current annual income. Financially, she said, "we're just making it by…the skin of our teeth." The problems with the insurance also created a great deal of stress and tension. "When we saw what was happening, he really did have some problems with his recovery, his cardiac recovery. He did have a kind of a set back, and I think a lot of it was emotional."

Ron's Story*: Even those with relatively comprehensive coverage can accrue medical debt if they experience catastrophic medical events, especially if their policies contain caps on coverage.*

Ron is a state employee in California. He earns about $60,000 a year. His health plan is a PPO, purchased through his employer. According to Ron, his insurance had been very good. "I have my co-payments and stuff but other than that they have been very good at paying the doctors and… the x-rays and the labs and all that kind of stuff." However, in October of 2002, he developed an infection in his leg. He was in the hospital for over a month in intensive care and then needed to transfer to a rehabilitation facility. Because he required special equipment, only one hospital in the area would accept him. However once he got there, he discovered the hospital didn't have the necessary equipment to provide treatment. He was in this hospital for a year but received little care, so his functionality did not significantly improve.

Because he wasn't making progress, his insurance policy would only pay for a 100 days of treatment. If he had improved, he would have been eligible for advanced rehabilitation coverage, but because of the inadequate care he wasn't able to do so. When he was finally able to transfer to another facility, the hospital presented him with a bill of $138,000, but offered to discount it to $83,000 if he paid immediately, and threatened to put a lien on his house if he didn't pay. He and his wife were forced to borrow the money against their home to make the payment. They still owe about $60,000 on the loan.

The problems that Kathleen, Linda, and Ron faced were not anomalies; many of our interviewees described similar difficulties. Taken together, the interviews present a picture of a health insurance system that is not working—it places too much risk on individuals; it fails to protect them financially; it is hard to understand and navigate; and it does not guarantee access to care when people need it.

Common Themes

Our interviewees commonly cited the following as causes and consequences of medical debt.

Unaffordable cost-sharing requirements

The cost-sharing provisions of insurance policies leave many people vulnerable to unaffordable medical bills. Along with the monthly premiums, people often are required to pay deductibles, co-payments, and co-insurance when they seek medical care. For some, vulnerability results from high levels of cost-sharing. For others, especially those who are chronically ill and/or low income, even relatively modest levels of cost sharing leave them constantly struggling to catch up.

Annual, overall, or benefit limits on the amount insurance policies will pay for goods and services

Some insurance policies set annual limits on how much they will pay for care, while others set overall limits for how much they will pay over the entire period in which an enrollee is covered by the policy. In addition, many policies set limits on how much they will pay toward certain specified services.

For people with catastrophic medical events and overwhelming medical expenses, limits on services, as well as overall or annual caps, can leave them with enormous medical debts. For those with more limited resources, caps on services still leave them with bills they cannot afford to pay even when their medical needs are not extreme.

Uncovered goods and services

Insurance policies generally exclude coverage for certain types of medical services. It is not uncommon for policies to exclude coverage for prescription medications and dental care, but other types of services may also not be covered. For example, one of our interviewees had a policy that covered diagnostic tests but not preventive ones, while others did not have coverage for certain types of durable medical equipment. In addition, in some states people could only purchase policies that excluded their existing medical conditions.

The costs of these goods and services often left people with medical debt. In addition, these costs did not count toward paying off deductibles if their policies included them, as deductibles only apply to money paid for covered services.

Complex and hard to understand benefit packages

The complexities of insurance policy provisions make it extremely difficult for policy holders to

understand what their policies do and don't cover. For this reason, people are often not aware of the limitations of their policies until they need medical care and find they are left with large and unanticipated expenses. In some cases, the confusion surrounding the insurance provisions seemed to be a deliberate effort by insurers to mislead people about the nature of their coverage.

Hard to navigate insurance systems

The complexities of insurance policies are often compounded by insurance company practices. Insurers may provide inaccurate, incomplete, or inconsistent information when policy holders try to find out what their insurance will cover or why certain claims have been denied. Individuals often find they need to invest a great deal of time and energy to resolve insurance-related problems.

Incomprehensible hospital bills, inflated prices, and aggressive collection techniques

An insurance system that is difficult to understand and navigate is overlaid on a hospital billing and collections system that is equally opaque. Patients often find it difficult to understand what their providers are charging them for and what their insurance has and has not paid. When they do have uncovered expenses, they can also become subject to inflated hospital prices and aggressive hospital collection techniques. Many interviewees said they were willing to pay reasonable charges, but expressed outrage over prices they felt were grossly inflated and unfair.

Inadequate consumer protections, particularly in the individual (non-group) market

Consumers may have inadequate protections when they purchase insurance, especially in the individual (non-group) insurance market. Many of our interviewees purchased insurance on their own, either in the non-group market or through associations they joined specifically to purchase coverage. Because of the complexities of insurance products, people were often confused about the provisions of the policies they purchased and only realized the limitations of their coverage and the degree of their exposure to out-of-pocket medical expenses when they actually needed medical care.

Barriers to accessing medical care and negative financial and emotional consequences

The cost of medical care and medical debt often created serious barriers to people's ability to access needed care. Most interviewees reported delaying or forgoing care because of their medical debt. Families with unaffordable medical bills also suffered serious financial and emotional consequences that lingered long after their medical situation was resolved.

The following sections describe in greater detail how these problems affected our interviewees.

Insurance Characteristics that Leave People at Risk

Premiums, Deductibles and Other Cost Sharing

- In 2005, two-thirds of insured adults said their health insurance premiums had gone up in the past five years; more than one-third said they had gone up a lot.[25]
- Over half of insured adults said their co-payments had also risen, while almost half said their deductibles had risen.[26]
- More than two of five adults with deductibles of $1,000 or more spent 10% or more of their incomes on premiums and out-of-pocket medical expenses, compared to slightly more than one of five in plans with deductibles of $500 or less.[27]

Most insurance policies include some level of cost-sharing, that is, portions of medical bills that policy holders must pay out-of-pocket. Along with the premiums, policies may include deductibles (an amount policy holders must pay before the insurance starts covering services); co-payments (a fixed amount they must pay each time they receive a service); and co-insurance (a percentage of the bill they must pay). These charges are, of course, in addition to other out-of-pocket expenses they may incur, such as costs resulting from uncovered services.

About two-thirds of our interviewees cited premiums, deductibles, co-payments, or co-insurance as one source of their debt; many cited a combination of these charges. People with lower incomes and/or chronic illnesses are particularly vulnerable to accruing debt because of these types of charges.

David lives in Ohio and earns about $24,000 a year. He has Type 1 diabetes and chronic digestive ailments, and has experienced problems with his shoulder requiring prolonged treatment. Although he has always had insurance, his out-of-pocket expenses were significant. He told us:

"Over the years as my insurance has changed either due to changing employment or changes in the health care industry…the premiums kept rising. The co-pays kept rising and the care has been more limited. Right now even just routine appointments with my primary care, specialist or primary care physician, my diabetes specialist, nutritionist…and ophthalmologist I'm supposed to see on a regular basis, those co-pays add up to a fairly large portion of my income. As well as all the co-pays for medication, insulin, and other supplies."

To pay his medical bills, he has used his savings, borrowed from family members, and accumulated credit card debt. He paid off some of his bills by selling his house, and now rents rather than owns.

While even limited deductibles can cause problems for lower-income people or those with chronic diseases, research shows that the likelihood of having medical bill problems or medical debt is greater for those with higher deductibles (over $1,000).[28] Peggie, a 49 year old woman in Florida, had a deductible of $2,500. She had two bouts of breast cancer that required treatment over a two and a half year period.

> I was diagnosed in November, and so I had to pay the $2,500 at that time, and then January 1, as I'm still in treatment, I had to pay it again. Even though it's one disease and it's every single year that you are getting treatment, you're out that $2,500 again.

High deductibles also cause special problems for people who change jobs frequently and get coverage through their employer; each time they change insurers, they need to pay the deductible before their insurance starts covering any services.

Caps on Coverage

- More than one-third of non-elderly adults with private health insurance had plans with maximum benefit caps.[29]
- More than one-quarter of underinsured adults said they had reached the limit of what their insurance would pay for a specific treatment of illness, compared to 14% of all insured adults.[30]

Caps on coverage come in a variety of forms. Sometimes health plans impose a maximum on how much they will pay for care over the duration of the period in which a person is enrolled in the plan. These are often called lifetime caps. In addition, some health plans impose annual caps on coverage. Health plans can also cap what they will pay for a particular type of service or for the number of times they will cover a given service.

LIFETIME AND ANNUAL CAPS

People who experience catastrophic medical events are particularly vulnerable if their policies include lifetime or annual caps. Ray's debt resulted from both of these types of caps.

Ray's wife Cindy left her employment when she married him and was able to continue coverage under an individual health plan. When she and her husband moved to California, she switched to a plan in that state. As Ray put it, "we went along for years, no problems." However, his wife was diabetic and began to have serious and ongoing health issues that required expensive treatment, including amputation of her leg. It was only then that she learned her insurance policy had a $100,000 lifetime cap, and she had already spent all but $25,000 of it.

(cont'd from previous page)
Ray and his wife then enrolled in a state high risk pool that covers people other insurers will not cover. It was expensive—the premium was $850 a month. This insurance had an annual cap of $75,000 that would gradually increase each year they had the policy. The first year, they quickly exceeded this amount to cover the cost of Cindy's prosthetic and other medical expenses. However, toward the end of the year, she developed heart problems and had bypass surgery and a pacemaker, but died shortly afterwards. If her medical problems had occurred the following year, her insurance would have covered at least some of her expenses. However, because she became ill at the end of the year, she had already exceeded her annual limit so the insurance did not cover her treatment. Ray found himself owing $340,000 to two hospitals. One agreed to cut his bill in half if he paid immediately, so in the end he owed $190,000. To cover the costs, Ray was forced to take a loan against his home of $150,000, which he is currently trying to pay off.

CAPS ON SERVICES

A number of interviewees faced caps on certain types of services that resulted in medical debt. Ron's story at the beginning of this report showed how caps on particular services, in his case rehabilitation services, can leave people with enormous bills if they become seriously ill, but even people with moderate health care needs can accrue debt because of service caps.

Insurance coverage of dental services is much less common than coverage of other medical services; in the most recent data (1989) about 40 percent of people had private dental insurance.[31] However, even when insurance includes dental coverage, insurers generally cap the amount they will pay annually for dental care. Slightly more than one-quarter of our interviewees reported having dental insurance and, of these, more than half had dental debt. Most reported limits on their dental coverage of $1,000 or $1,500 a year. Because dental care is frequently very expensive, dental debt was often significant and almost always resulted from receiving services whose cost exceeded these limits.

Andrew had previously been forced to take out a loan, in part to pay for orthodontia work for his son. He had been uninsured for a while and thus he and his wife put off going to a dentist for themselves. When he got a new job that had health insurance benefits, including dental coverage, he and his wife went for care. She needed treatment that cost about $2,600 and he discovered he needed work that would cost another $3,000. However, his dental plan covered only $1,000 a year. His wife received services, which left them with about $1,600 of dental debt; he had only a cleaning and put off getting other needed services because he did not want to accrue more debt and have to take out an additional loan.

Uncovered Services

- Only 36% of the underinsured had prescription drug, dental, and vision coverage, compared to 54% of those with adequate insurance.[32]
- Eleven percent of the underinsured did not have coverage for any of these services, compared to 5% of those with adequate insurance.[33]

Over one-third of our interviewees said they accrued medical debt because of uncovered services. It is important to remember that when people have insurance plans with deductibles, out-of-pocket payments for uncovered services do not count toward meeting the deductibles. Thus payments for these services are in addition to any amounts individuals have to expend before their insurance starts paying for services that are covered.

Interviewees cited a variety of services that were not covered under their insurance policies that caused them to accrue medical debt. Some of the most common were prescription drug coverage, dental services, and durable medical equipment. Problems resulting from uncovered services were especially severe for parents of children with special health care needs.

PRESCRIPTION DRUGS

For a number of interviewees, lack of or only partial coverage of prescription medications resulted in debt.

Peggie who had surgery for breast cancer, had insurance that did not cover any prescription medications. "[J]ust with the first two surgeries I had over a $1,000 [bill for medications], because I found that I was having a difficult time tolerating any pain medications, or tolerating any antibiotics. And they'd write a prescription, I'd take three pills and I couldn't tolerate it, that prescription would be 200 bucks, and then they'd write another prescription, and if you were having to fill those out of your pocket, and the prescription costs, they're just phenomenal." She was recently in an accident and required medications that cost another $700.

Others without prescription coverage simply did not buy needed prescriptions. Joceylne is a single mother in Florida who earns about $25,000 a year. She went to the doctor and was told she needed medication. "[T]hat's like $81, so, you know, I don't have the money,…so I'm going to still be sick until I get the drug."

DENTAL

As we have seen previously, even people who had dental insurance were not immune from debt resulting from dental care because of monetary caps on their coverage. However, many of our interviewees had insurance that did not provide any coverage for dental services. Some simply delayed or did not receive needed care because of the cost. However, six of our interviewees had insurance that did not include dental services and owed money for their dental care. These services were often quite expensive. For example, in the last two years David lost a filling and broke a tooth; the charges were $900 for one of the treatments and $600 for the other, which he said was "an amazing amount of my income." He covered the expenses by putting them on his credit card, which he had to pay off over time. Debbie, a 34-year-old mother in Florida, works in the billing office of a hospital. Her family's income is $32,400. She required dental services during her pregnancy because of side effects that made it difficult for her to brush her teeth. These bills came to about $1,000. She paid off these and other bills by refinancing her house. Other interviewees required less expensive care which they paid for, but often with difficulty.

DURABLE MEDICAL EQUIPMENT

Some interviewees mentioned lack of coverage for durable medical equipment as one source of their medical debt. For example Montye, after a hospital stay and numerous tests, was diagnosed with multiple sclerosis. Her doctor recommended that she go to a rehabilitation hospital for two weeks, but her insurer refused to approve it. She instead received a walker, which she thought the insurer was covering in place of rehabilitation. Only later did she find out that the insurance would not cover the walker either. "I mean a walker is not that expensive, but in those days, because my financial condition was so severe, it became a big problem."

"A walker is not that expensive, but in those days, because my financial condition was so severe, it became a big problem."

Donna, whose daughter has cerebral palsy, said "I was surprised they didn't cover something like an adaptive toilet chair for Grace…. And other types of equipment that she could use to help her do exercises at home or stretch her legs at home just wasn't covered through health insurance. If it doesn't, for some reason if it doesn't have a certain code as a durable medical good, it's not coded, then it's not recognized. And if it's not recognized, then there's not a chance of getting it covered by the health insurance company."

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Donna's lack of coverage for durable medical equipment represents only one of the coverage gaps facing people who have children with special health care needs. These children often require expensive and ongoing medical care, which may include treatments and equipment not traditionally covered by health insurance. In Donna's case, medical expenses ultimately forced her and her partner to file for bankruptcy.

Lisa, a 45-year-old woman in Massachusetts, has a family income of $70,000. Her son, who is three and a half, suffers from autism. She noted:

> I am paying out-of-pocket for occupational therapy services, $100 a week. In the past I have paid for speech therapy services out-of-pocket $80 a week.... I paid for the out-of-pocket speech therapy probably for three years…. Social skills classes, insurance does not cover that. That can run between $70 and $80 a week for the entire school year….

In addition, her son has gastrointestinal problems, food allergies, and metabolic issues, for which he is on a special diet. This results in higher food costs, as well as nutritional supplements, which are not covered by insurance. To cover expenses, she has had to borrow from her family and use up her savings.

Insurance Processes that Leave People at Risk

- Among people with health insurance who said that they or another family member in their household had been diagnosed or treated for cancer in the past five years:
  - Nearly one in four said their plan paid less than expected for a bill.
  - One in eight said they were surprised to find out their plan would not pay anything for a bill they thought was covered.
  - One in 12 was turned away or unable to get a specific type of treatment because of insurance issues.[34]

Health insurers, in an effort to limit their financial risk, are increasingly marketing plans containing some combination of the cost-sharing requirements described previously. These plans may also include complex provisions about when the cost-sharing requirements apply. The size of a co-payment or co-insurance may vary with the site of service or the particular medication prescribed. It may also depend on whether a provider is in or out of a plan's provider network. In addition, plans have varying provisions defining which services are and are not covered; which services do and don't count toward meeting deductibles; and which services require referrals or prior authorization. The result is often a very complicated system of coverage.

While national surveys have captured information about the features of health insurance most likely to leave policy holders at risk of financial harm, such as benefit caps, increased cost sharing, and uncovered services, it has been harder for them to show the access and financial consequences of the increasing complexity of plan designs and practices.

Many of our interviewees said they had difficulty understanding the terms of their plans. Many also complained that when they tried to clarify plan provisions or resolve insurance issues, they often received incorrect, incomplete, or inconsistent information from their insurers. Because of these difficulties, they were often unclear about exactly what their policies would cover and surprised by the amount of their medical bills for which they were liable. Some interviewees fell afoul of procedural requirements for getting claims paid.

Confusing Policy Provisions

Interviewees frequently felt they did not have a good understanding of the terms of their policies. One said, "You know, I consider myself a pretty savvy person. I have my [insurance] booklet, but it's completely Greek to me." Another said that while her employer had the insurance broker explain the policy to employees, the explanation was not in depth. "Their basic answer is…well it depends on the condition, it depends on the timing, and it depends on what the reason is the doctor orders it. You know, the only thing that was pretty clear was what would be covered on the prescription plan and the dental plan." A third commented, "It's all so confus-

ing to me. I wish I could sit down with somebody and they could go over the freaking plans with me. It's like you get this pamphlet, you want to get your insurance processed right away, and I couldn't even understand it." These feelings were perhaps best summed up by a man in California who purchased coverage himself in the individual market. "[A] lot of these plans are so complex that you would almost need to become a professional plan reader just to get a feel for if you are getting a good deal or not."

"A lot of these plans are so complex that you would almost need to become a professional plan reader just to get a feel for if you are getting a good deal or not."

For people who received coverage through their employment, few said that their employers provided education about their plan coverage. A number felt the material they did receive was overwhelming. One said, "We got pamphlets and stuff, but they were about 500 pages long and you can't read through all of that." Another commented, "[T]hey're such huge books of stuff that you just don't read the whole thing." Those who had been employed at the same company for a number of years often just received renewal letters in the mail. One woman noted, "There wasn't a real good education around [the insurance] because basically every year the insurance just gets renewed. A letter goes out and says the insurance has been renewed." Another said, "I've been there so long, I don't remember. I've been there almost fifteen years…. I think when we started working there they talked to us about the insurance."

Others had the opposite problem. Sometimes their employer changed health plans frequently, so they were faced with learning the provisions of a new policy every year or two. "[M]y current employer, which I've been with for seven years, they've changed plans I think about five times in that seven years. I remember only once going to a meeting that explained the changes." Those who frequently changed employers also had to continually deal with the provisions of new plans each time they started a new job.

Often people only really came to understand the terms of their insurance policies when they became sick and needed to use it. "You see, before [I got multiple sclerosis] I never had really had need, even though I had insurance. I never really had the need for medical treatment so it was never really an issue…. Then all of a sudden, as happens with many people, not only was I hospitalized and pretty darn sick, but to try then to navigate through all the complicated stuff, it was just too much."

"Before I got MS...I never really had the need for medical treatment.... Then not only was I hospitalized and pretty darn sick, but to try to navigate through all the complicated stuff, it was just too much."

Out-of-Network Fees

Seven of our interviewees cited increased co-insurance or deductible payments that resulted from getting care from providers not in their health plan's provider network. Often interviewees received care at hospitals that were in their network, but they did not realize that the doctors who provided care in the hospital were not in the network. In other cases, there were no in-network providers in the hospital.

Barbara, a woman living in Illinois, had a heart attack and needed to have a stent inserted. Prior to the surgery, she checked to see if the hospital was in her network. "I looked in my insurance booklet. It said that a primary provider was [my hospital] in Urbana, Illinois. And that's where I went." What she didn't know was that the clinicians who treated her, who are part of an affiliated clinic, were not in the network. "There are no brackets, no asterisks [in the booklet] saying that your doctor, your lab, and your tests will not be covered." In the end, she owed $3,500 to the hospital to cover her deductible and co-payments, but $11,000 to the clinic.

Peggie, in Florida, had similar problems.

> [Y]ou're not told when you go into a hospital and the hospital takes your insurance that not everybody they send you takes your insurance.... When I went for the x-ray, I didn't know that the people in the hospital were not hospital employees, so they're not under my insurance. Now, instead of [the insurance] paying 80 percent and me paying 20 percent, it was a 60/40, and then the person reading the x-ray wasn't in the network.

In addition, there was no anesthesiologist in the hospital that was in her provider network. Her insurer told her she would still have to pay the out-of-network fee. She asked them, "[W]ho am I supposed to get anesthesia from, if there's no one in that hospital that is under my plan? Am I supposed to walk across the street to the guy under my plan and come back?"

Lance, also of Illinois, had even less control over where and from whom he got care. He broke his back in an accident and was taken to the only trauma center in the area. However, because the hospital was not in his health plan's network, the insurer required him to pay twice the normal deductible. He called his insurer and tried to explain that the hospital in his network did not have a trauma center or spine specialists. "I had broken my back. I was completely out of it. It is not like I could sit up and ask, where are you taking me? Oh, I can't go there because it is not in my [network]. Better go back to my

"I had broken my back. I was completely out of it. It is not like I could sit up and ask, where are you taking me? Oh, I can't go there because it is not in my [network]."

house and get my paperwork so we can figure out where I can go." However, the insurer still insisted that he pay the extra deductible. He ended up with an unanticipated bill of $4,500.

Procedural Problems

People are sometimes left with unpaid bills because they have not been informed about particular procedures they must follow in order to have their expenses covered. In some cases, they are asked to comply with requirements that may or may not actually be necessary.

Laurie, a 26-year-old woman from Illinois with employer-sponsored coverage, had problems related to the birth of her child. She had a cesarean section, which was covered by her insurer. Her son was born with some medical problems that required frequent trips to the pediatrician and use of medications. Even though he should have automatically been covered under her policy for the first 30 days after his birth, the insurer said she needed to submit documentation to prove that the child was in fact her son. Because his bills weren't being covered, she started receiving calls from bill collectors, the specialist said he would not see her son until the bills were taken care of, and the pharmacist refused to continue to extend credit for his medications.

"I had to send [the insurer] birth records. I had to send them a letter from my doctor…. And remember I just had major surgery. I can't walk, I can't move, and I'm doing all this phone work to try to keep this massive debt from piling up…. I mean, I spent hours and hours and hours and hours on this."

It took two and a half months for her to straighten out matters with the insurance company and get them to process the claims.

Luz, a 30-year-old woman from New York, also had a cesarean section and gave birth to her first child. She had family coverage through her employment, which she believed would cover the delivery. She received bills from the hospital for several months, but thought, "you know sometimes it takes time for the insurance to pay those bills." When she finally called, the hospital told her to contact her insurer. The insurer informed her that she had to file a form within 30 days of the birth to have the delivery covered and, since several months had passed, the insurance would no longer pay the bill. "[W]hen the hospital told me, 'We already called [your insurer] and will let them know that your son was born,' I thought that that was enough."

"When the hospital told me, 'We already called [your insurer] and will let them know that your son was born,' I thought that that was enough."

> [T]hey didn't send me that information that they want. They just send me a book at the beginning that was like almost two years ago…. In that book say that I have to call them and let them know. And after that say that I have to submit a form. So I didn't know that.... But…what I'm thinking right now is that they should send me something just to realize that I have to sign that information and to submit that to them. But they didn't. Nobody told me.

Luz currently owes about $5,000 for the delivery. She has appealed the claims denial to her insurer and is awaiting a final decision.

Insurance Disputes and Errors

Recent articles have highlighted how insurers' high rates of claims denials have affected providers—according to one estimate, 30 percent of physicians' claims are denied the first time they are submitted. In fact, "denial management" firms now help providers navigate insurers' systems to head off denials or negotiate with insurers over rejected claims. With respect to these firms, one hospital administrator said, "The insurers outcode us, they outsmart us, and they have more manpower. Now at least we have a fighting chance." However, less attention has been paid to the impact of these denials on patients, who have less expertise and time to challenge them, and who are often left liable for the unpaid bill.

As many of the previous stories suggest, interviewees frequently found it extremely difficult to get clear and consistent information from insurers and to resolve issues that arose regarding their coverage. Many, as Laurie above, found that dealing with insurance problems consumed an enormous amount of their time and energy. This was a common theme among interviewees and a very common source of frustration.

Peggie, who had cancer, paid her hospital deductible up front before she received services. However, when her physicians submitted bills more quickly than the hospital, the insurer said it had no record that she paid the deductible and refused to pay the physicians' claims. She tried to explain to her insurer that she had already paid the deductible, and offered to ask the hospital to call and verify this. However, the insurance company insisted that it had to receive the hospital statement before it would pay the claims. In the meantime, Peggie began getting collections letters from her physicians and worried that the bills would go on her credit record. She finally paid the bills out of pocket and then fought with the insurance company to get reimbursement for the payments. It took eight or nine months to resolve the problem. She finally wrote a letter to her insurer that said "You are worse than the cancer. The cancer I can cut out, but I have to deal with you."

"You are worse than the cancer. The cancer I can cut out, but I have to deal with you."

Robert, who lives in Florida, has chronic gastrointestinal problems that require ongoing treatment. A number of times his insurer denied claims that should have been covered. "It's almost like a game with the insurance company…. I call them up and half the time it's legitimate…. I really do owe that much because in the fine print, that's what my co-pay and deductible is. But then, the other half of the time I call them up and they say…'Oh yeah. We'll process that. I don't know what happened.' You always have to check…because they mess up a lot…. I'm a very busy person. I don't have a lot of time to go over every single bill that comes my way."

Lynnette had similar problems tracking insurance payments for her bills. Her husband was diagnosed with late stage lung cancer; he succumbed to the disease two years later. At one point the insurer refused to pay for him to go to a residential facility, so Lynnette had to care for him at home, even though she was working full time to maintain her health benefits. She was finally able to convince the insurers to cover home care. Figuring out what the insurance would cover and which claims it had paid proved to be a major undertaking.

"I don't know for sure how much the home health care costs were…. [P]art of it eventually did get covered at 100 percent…but the first part of it wasn't covered at 100 percent, and I'm not even sure why. The insurance company doesn't make it easy for a lay person to figure out how they're paying or why they're paying or what they're paying. I ended up having to [create] a spreadsheet on my computer to keep track of everything because…I didn't know who paid what when…. But there were times...when my insurance company would pay the same charge different days at 60 percent and then sometimes they'd pay it at 80 percent and then sometimes they'd pay it at 100 percent."

Confusing Provider Systems Compound the Problem

The focus of this report is on insurance policies and practices that leave people vulnerable to serious financial risk when they become ill. However, the problems resulting from complicated insurance policies and difficult to navigate insurance systems are compounded by their interaction with provider billing and collections systems, which may be equally opaque. It is not uncommon for patients to find themselves caught in between.

Barbara, for example, who was charged out-of-network rates by doctors who provided care in an in-network hospital, said "I feel like it's collusion. [The insurer] recommends the hospital, but they don't say [the doctors aren't] in the system. And when you go in the hospital, I told them three different times…'I have [insurance name], is that okay?' No one said a word…. I felt like I'm in the middle. I'm caught between the two." Lynnette, whose husband died from cancer, said "I blame the medical facilities and the insurance companies. I think the two of them are in cahoots."

> "I blame the medical facilities and the insurance companies. I think the two of them are in cahoots."

One area that posed problems for people was reconciling confusing hospital bills with confusing insurance statements; they found it difficult to understand what they were being charged for, what their insurance had paid, and what they actually owed.

Roland had surgery on his knee. He said, "You know, the diagnostic, emergency physicians, and…radiological...[they] would always show…how much the bill was, how much the insurance would allow and how much the insurance paid and then how much I owed…except for the hospital bill, which was the one for $28,000. That one, there was no detail and they wouldn't give me any detail.… I finally did get an itemized bill, but…[it just] said Operating Room, and that's all it said.… Also, it never actually told me what…the insurance would allow and what they had paid.… I could never find that out, and they wouldn't tell me that."

Joceylne's son has asthma and had to be admitted to the hospital for three days. The bill from the hospital was $15,000, but she also received bills from the providers who treated him while he was hospitalized.

> I'm getting billed from every which way. Like the doctors.… [T]ell me one person or where I need to submit my little monthly payments to, and because like every month I'm getting a bill from the doctor's for $1,000 here, $1,500 here, $300 here.… I just put into the pile, because you don't know if they're double billing.

Providers sometimes made mistakes when submitting claims to insurers, which created problems for interviewees. Lew's wife was covered by two insurance policies. She had coverage with Blue Cross Blue Shield through Lew's employment, but she also suffered a back injury at her work that was covered by Workmen's Compensation. Lew had recurring difficulties getting the hospital to correctly bill his insurers. "[T]here's times when Workman's Comp needs pre-approval for things that are done and…lots of times the hospital doesn't even bother.… They just bill the Blue Cross Blue Shield portion. We're constantly in a revolving door trying to sort that out.… I went up there in November, December and January to give them insurance forms, medical cards…and circled the one that said primary is being the Workman's Comp card and secondary is the Blue Cross Blue Shield, [but] they could never ever get [it] right."

"I went up there in November, December and January to give [the hospital] the insurance forms, medical cards..., but they could never ever get it right."

When interviewees did end up owing money to hospitals and other providers, many found themselves subject to hospitals' aggressive billing and collections processes. When Lew's wife was

still in the hospital after surgery, she was asked to sign a paper committing her to pay $2,500 for her care, even though the services should have been covered by Workmen's Compensation, which had pre-approved the procedure. The day she returned home, she found a letter from the hospital encouraging her to pay by credit card.

Victoria also found herself harassed by bill collectors. She had back problems that ultimately required surgery and, at one point in her treatment, her doctor ordered an x-ray. Prior to the procedure, she provided the hospital with information about her insurance. After the x-ray, she received a bill from the hospital, but assumed the x-ray was part of the workup for her surgery and that the insurance would cover it. She said, "I had some testing done [previously] and paid a hundred and fifty for it out of my own pocket, and the doctor was paid by the insurance company. So now, when I get a bill right away from the doctors or the hospitals, I wait to see finally what's paid in the end. And I've been told to wait. Most of the time they tell you to wait, that it's just a monthly billing cycle…." However, she was soon contacted by a collection agency. When she called her insurer to find out why her insurance had not paid the bill, they said the treatment was considered preventative, which was not a covered service. She was stunned that her account had been sent to collections after she had received only one bill. She argued with the collection agency, but they refused to send the bill back to the provider, and she finally had to negotiate a payment plan with them.

As consumers are required to shoulder a greater portion of the cost of their care, it is inevitable that many more people will end up owing large sums to providers. Many of our interviewees who were left owing money to hospitals said they were never informed about the availability of financial assistance, such as hospital charity care programs. Those who tried to negotiate with providers to get discounts on their bills had varied experiences; some hospitals agreed to discount bills while others refused to make any reductions. Some were able to get discounts from hospitals but not from physicians. Some people were offered large discounts in exchange for immediate payment of the bill, but did not have enough money to take advantage of the discount. Only seven interviewees said they had actually received charity care. Twelve said they received discounts, while another 16 were only able to negotiate payment plans.

Many interviewees expressed a desire to pay reasonable bills, but were outraged at prices they perceived as grossly inflated and unfair. Roland, who needed knee surgery, said "I had been paying my bills to the doctors…and thinking I'm paying enough, when all of a sudden I received a bill from the hospital where my portion…was about $7,000 and the total of that bill was $28,000…. I thought, this is not right. This is crazy…. And after doing a lot of research, typically that kind of surgery is not too expensive—I mean, maybe $5,000, $6,000, $7,000 max, but not $28,000."

Marco had recurring abdominal pains and his doctor recommended a CAT scan, which his insurance did not cover. The hospital billed him $5,000. He said, "I looked it up. A CAT scan generally runs about $800 to $1,200. I wasn't ready for a $5,000 CAT scan…. This was a completely illegitimate charge." Lew noted that he was billed $66.75 for a shower cap and half a bar of soap. "I still owe it. I have more important things to spend money on than an outrageous price for a shower cap and soap. I would have brought my own."

"A CAT scan generally runs about $800 to $1,200. I wasn't ready for a $5,000 CAT scan.... This was a completely illegitimate charge."

It is interesting that many interviewees, when offered substantial discounts in exchange for immediate payment, only became angrier. Many felt that the providers could only offer these discounts because they inflated prices in the first place, expecting insurers to pay only a percentage of the charges. They felt that the fact that a hospital could reduce a bill by half merely demonstrated that the original charges were grossly inflated.

Ray, whose wife experienced a series of catastrophic medical events, said, "They cut [the bill] in half, and that shows me that they probably doubled it to start with because…I know they're not going to get the whole amount from the insurance company, and maybe they'll get half, which is why they cut it in half for me, because that's probably what the bill should have maybe been to start with."

Velvet, who required surgery and radiation for breast cancer, said "The prices that they charge are outrageous…. [T]he doctor who was in charge of my radiation, when he learned that I did not have insurance, told me that he would charge me less based on what Medicare pays. And of course my first thought was, 'Why don't you charge everybody that?' But…I didn't want him to be mad at me."

Marco noted "I think that the root of the problem with underinsurance is the overcharging of the health care providers because they know they are going to be negotiated down, so they overcharge significantly, knowingly."

Purchasing Health Insurance: Do People Have Meaningful Choices?

Most Americans have group coverage through their employment—that is, insurance purchased by employers for their entire group of employees. Individuals without access to employer-sponsored coverage must purchase insurance themselves in the non-group market. In our interviews, people with both employer-sponsored and non-group insurance experienced gaps in their insurance coverage that resulted in medical debt. For both of these groups, the question arises as to why they purchased the policies they had and whether they had meaningful choices when they obtained them.

Group Insurance

- More than four in ten non-elderly adults with employer-sponsored insurance coverage said they did not have a choice of health plans.[36]
- Between 2005 and 2006, employer-sponsored premiums increased much faster than overall inflation or increases in wages.[37]
- Since the year 2000, premiums for family coverage increased by 87%.[38]

About 70 percent of our interviewees had insurance through their employment. Of these, only about half were offered a choice of insurance plans; the others were offered one plan only. Even when people had a choice of plans, interviewees generally found that from one year to the next, the plans they were offered had less coverage and higher out of pocket costs. Many said they chose their particular plan because it had the lowest premium and was the only one they could afford.

Of the 14 interviewees with employer-sponsored coverage who reported on their deductible, only about one-quarter had deductibles equal to or less than $250. Two interviewees had deductibles of $2,000 or more; both worked at firms where they did not have a choice of plans. In addition, about 60 percent of those who had insurance coverage through their employment said the premiums and/or cost-sharing had gone up in the last few years, or the coverage had gotten worse. Some noted that their wage increases did not keep pace with their increased insurance-related expenses.

Debbie lives in Florida and has insurance through her employer, a major hospital chain. She said that the cost of her insurance and the amount of her medical bills for which she is financially responsible have grown in the past few years. In 2005 her share of the premium went up $20 and then, in 2006, it went up another $80. The imposition of co-insurance has caused particular problems.

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"[W]hat they did this year, even with our insurance [premium] going up, …when you go to the doctor, they pay 80 percent and you pay 20 percent. And they try to make it like it's better. But [doctors] would have to bill $70 for that to be…better than paying a $15 co-pay. Most doctors' visits, you're looking at 200 bucks."

She did have an option to choose a policy that would have provided better coverage but, she said, "I didn't feel that we could afford what we have, let alone $50 [a month] more."

Diane, who had insurance through her husband's employer, noted that starting three or four years ago, the insurance had gotten worse every year. This year, her husband's share of the premium went up about $40 a month. They are now paying over $500 monthly. Co-payments for her prescription medications have also gone up. "My monthly meds are $70, and my husband's are $145, so I figured…$692 a month for just paying for my insurance and our medicines that we have to take. He doesn't even clear that much a week." Lauren, another woman who had seen her out-of-pocket costs rise, put it most succinctly. "Basically I am paying more for less."

> "$692 a month for just paying for my insurance and our medicines that we have to take. He doesn't even clear that much a week."

Some policy makers have promoted plans with higher cost-sharing requirements but lower premiums as a way to make insurance more affordable. As some of the stories above indicate, for many of our interviewees, higher deductibles, co-pays, and co-insurance were coupled with higher premiums. Others who did see premium reductions indicate that the lower premiums did not actually result in savings. David noted "…about two years ago…because they [changed] to a more restrictive HMO plan, my premiums went down a little bit…. I was pleased about that, but comparing that with all the additional co-pays and all the different restrictions…it doesn't really make up for it." Lauren said, "I chose the [plan] I have because the monthly premium for me is less than the more expensive one. But, in hindsight, the more expensive one has better co-pays and prescription coverage. So it's sort of like taking the lesser of two evils."

> "About two years ago... my premiums went down a little bit..., but comparing that with all the additional co-pays and all the different restrictions...it doesn't really make up for it."

Non-Group Insurance

- In 2005, nearly nine of ten people who explored obtaining coverage in the non-group market never bought a plan. Three-quarters said it was difficult to find affordable coverage. More than two of ten said they were turned down by an insurer, charged a higher price because of their health, or had a health problem excluded from the coverage.[39]
- More than half of adults with coverage through the non-group market had annual premium costs of $3,000 or more, compared with one in five covered by employer-sponsored plans.[40]
- More than one-third of those insured on the non-group market had per person deductibles of $1,000 or more, compared to 8% insured through employer-sponsored plans.[41]
- Two of five adults with non-group coverage spent more than 10% of their incomes on premiums and family out-of-pocket medical expenses, compared to one of four insured through their employer.[42]

Theoretically, anyone purchasing insurance individually on the non-group market has a choice of plans and can shop around for coverage. In some states, where many insurers have exited the non-group market, choices may in fact be limited. However, even when choices are available, in practice people are often left with few meaningful choices because the premiums for non-group policies are often prohibitively high. Research shows that most people who explore getting non-group coverage never actually purchase it because of difficulties finding affordable coverage or being turned down by insurers.[43] Those who do purchase coverage often feel forced to purchase plans with lower premiums and higher cost sharing because that is all they can afford, but then face unaffordable bills if they do get sick.

People who purchase insurance in the non-group market may also face problems to which people with group coverage are less exposed. If they have existing medical conditions, they may not be able to get insurance that covers those conditions, or they may be unable to purchase insurance altogether. In addition, unlike larger employers, individuals do not have Human Resources departments or technical consultants to advise them; they may thus be especially vulnerable to deceptive and sometimes fraudulent marketing practices.

A number of interviewees already mentioned in this report had individually purchased insurance: for example Ray, whose wife exceeded her lifetime and annual cap on coverage, and Peggie, who had breast cancer and whose insurance did not cover any of her medications. Eight percent

of Americans ages 19 to 64 who are privately insured all year, or 8.5 million people, have non-group coverage. However, almost one-quarter of our interviewees had this type of coverage. If one adds in people who shopped for coverage in the non-group market and joined associations simply to be eligible to purchase insurance, almost one-third of our interviewees purchased insurance individually.

HIGHER LEVELS OF COST SHARING

As the data at the beginning of this section shows, people who purchase non-group insurance are likely to have higher premiums and deductibles and spend a greater percentage of their income on health insurance premiums and health care expenses than those who get insurance through their employment.[44] As people with higher deductibles are more likely to have medical bill problems, one would expect people in the non-group market to be more vulnerable to medical debt than those with employer-sponsored coverage.

Of the interviewees who purchased insurance in the non-group market and reported the size of their deductibles, almost all (seven out of eight) had deductibles equal to or greater than $2,000 a year. Only two interviewees out of the 14 who had group coverage and reported the size of their deductible had a deductible this large.

About one-third of our interviewees who purchased insurance on the non-group market and who reported the size of their premium had premiums equal to or greater than $500 a month. This compared to about one-quarter of those purchasing through employment. (The size of the premiums for people with group insurance reflects their share of the premiums only, not the amount that their employer contributes.)

PRE-EXISTING CONDITION EXCLUSIONS

People who attempt to purchase insurance in the non-group market may confront problems relating to the exclusion of pre-existing conditions. This occurs when an insurer refuses to provide coverage for a condition someone has at the time they purchase insurance.

Joe, who is 56 years old and lives in Missouri, accrued medical debt because of a pre-existing condition exclusion. In his application for a non-group insurance policy, he stated that he had osteoarthritis in his right hip. The insurer sold him a policy but excluded coverage for anything related to degenerative bone disease. Joe was not a heavy user of medical services, but in 2004 he experienced back and shoulder pain. After several weeks of pain, he saw his doctor, who referred him to an orthopedic surgeon, who recommended that he have an MRI and physical therapy a few times a week.

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After he began the physical therapy, he was notified that his treatment would not be covered because the MRI revealed some arthritis, which the insurer claimed was excluded from his coverage. Joe appealed the decision, pointing out that most people his age have some degree of arthritis and that his doctors had not determined definitively that the arthritis was the source of his pain. However, after several months, the insurer denied his appeal. Joe noted that in "talking to people who know what they're talking about, they tell me that [my insurer] is particularly diligent about looking at anything that's pre-existing, or in my case, if there is a pre-existing, they are very diligent about not…living up to what I feel is their responsibility, and that's taking care of the insurance needs of the people who pay the bills." Joe was able to negotiate discounts with some of his providers, and was offered a $600 discount on his $2,400 MRI fee if he paid it immediately, but he could not afford to do that. He is now paying $100 a month on this bill, and currently still owes about $1,100.

Victoria, who lives in Ohio, is having trouble even finding coverage because of a pre-existing condition. She was employed when she discovered she needed spinal fusion surgery. Shortly after that, her employer laid her off without providing any explanation. She was given a limited severance and six more months of insurance coverage. She is now unemployed, so her income has fallen sharply. She currently owes several thousand dollars on existing medical bills because of gaps in coverage and her reduced income. Victoria is worried about her current debt, but also wonders what she will do when her coverage ends. She investigated purchasing non-group insurance, but was told that any coverage would exclude her current health condition, and she also found prices prohibitive. "[T]hese insurance companies won't accept me even as a client, as a customer, and the ones that do want me to sign a waiver and they want me to pay five hundred to seven hundred a month for insurance.... I can't afford to do that."

In some cases insurers have denied claims or retroactively rescinded coverage altogether because they claimed policy holders had not revealed pre-existing conditions on their applications for insurance. In Connecticut, the Attorney General is currently investigating complaints that Assurant Health unfairly denied patient claims by asserting that they should have known about and disclosed medical conditions when applying for policies.[45] California Blue Cross is being sued by people who purchased its non-group products, who accuse the insurer of illegally dumping sick policyholders to avoid expensive claims.[46]

One of our interviewees, Reinhold, a 46-year-old man who lives in California, had his policy revoked. He purchased a non-group policy in early 2005. In May he needed to have a series of tests, which finally determined he had a mild case of hepatitis B. The insurer then said he had

not revealed that he had high blood pressure when he applied for coverage and cancelled his policy retroactively to the time of purchase. He currently owes about $9,000 of his $11,000 bills, and is now uninsured because he cannot afford to purchase a policy from the state's high risk pool.

DECEPTIVE MARKETING PRACTICES

People who purchase coverage in the non-group market may be particularly vulnerable to deceptive and possibly fraudulent marketing and claims processing practices because they do not have the technical expertise and support that larger employers can draw on when buying coverage for their employees. When they choose a plan, they may thus not be getting the coverage they think they are getting. We have already seen how Linda and her husband were victimized by these types of practices when they purchased non-group insurance. In fact, two other of our interviewees had policies from the same insurer and experienced similar problems.

Marco is a chemist in California. He wanted to purchase a high deductible policy that would cover catastrophic medical costs because he and his family generally try to treat themselves with herbs and naturopathic remedies. The policy he purchased, like Linda's husband through an association for self-employed people, had a deductible of $5,000 per illness, which was capped after three illnesses. Some time after he purchased the policy, he started having recurring abdominal pains and, after a relapse, his wife suggested he should see the doctor. The doctor recommended a CAT scan and some other tests. Prior to the test, he asked the hospital how much it would cost but was unable to get an estimate. The final bill for the CAT scan was $5,000.

Marco knew he would be responsible for a high deductible, but the insurance company claimed the service was not covered, so any money he paid on the bill did not even count toward meeting his deductible. As he put it, "The problem is, when the incident actually happens and you want to get something covered it seems as though data is always misconstrued. It sometimes takes two or three times…to submit the bill, to get it covered, to make sure it is properly protocoled. There are a lot of loopholes…. There is a lot of hidden information that would prevent you from getting full coverage." Since he had no coverage for the treatment, he also found himself subject to full charges rather than the discounted rates insurers negotiate. After receiving the bill for the CAT scan, he decided to discontinue treatment for fear of getting more deeply in debt. "I was considering whether I was getting value. You know, you have to weigh the evidence. Is this ailment cancer? Is it something life-threatening? Or are these bills economically threatening to bankrupt me?"

In some cases, people were so anxious to have some form of coverage that they purchased products that really cannot be considered insurance. Velvet, for example, purchased a product that essentially only covered expenses resulting from an accident. "The only insurance I was able to

afford because my employer did not offer any kind of health benefits was a poorly paying policy. It pays well on accidents, if I fall down and break my arm, it pays quite well. But on health issues, it pays quite poorly." As she put it, "It's a rinky-dink product. That's why it's cheap." Velvet later had breast cancer, and the insurance, which paid a flat amount per incident, covered very little of the bill. She ended up with bills of around $20,000, of which she's managed to pay off about half.

Does Health Insurance Provide Value?

Given their high levels of financial exposure, many of our interviewees have begun to question whether their health insurance actually provides them with anything of value.

Roland is married with three children. He is trying to start his own business and purchased a non-group plan with a high deductible and other cost-sharing, and a premium of $340 a month. He had knee surgery that did not require staying overnight at the hospital; however, he still ended up owing about $8,500. His family income of $28,000 a year would have qualified him for hospital charity care; however, the hospital did not offer financial assistance to people with insurance. One of the people in the hospital billing department told him he'd be better off if he had no insurance. He said, "I almost…canceled my insurance…. My wife and I even discussed this because I was thinking, what's the purpose of this? I mean, I'm paying $340 a month and it's not really getting me anything. It would probably be the same as not having insurance and then just paying the bill."

> "I'm paying $340 a month and it's not really getting me anything. It would probably be the same as not having insurance and then just paying the bill."

Diane had to be admitted to the hospital for almost a week because of bronchitis; as a result, she accrued medical debt of around $4,000. She said, "I don't mind if I have to pay my bills. I've always paid my bills…. But I'm angry this time…. I'm angry because we're paying so much for this health insurance, and we're getting, in my eyes, so little back. I don't understand. I just don't understand."

Many others echoed this sentiment. Joeletta said "When you think you're paying this much on insurance and you think you're safe and everything's okay and you'll be able to afford it. Well now I'm in the situation where I have insurance and I can't use it because I'm looking at all these bills." Larry said "We have hardly ever used our medical benefits in the 35 years I worked at [my company]…. Now that we are retired, when we need it, they are not there to pay for it."

Joceylne commented, "I mean it's kind of a Catch 22, because I'm working, and the main reason why people work is to get good benefits, but that's not even working for me because I still need a good plan…. I want to tell my story, because it's not really helping." Bonnie, a low income woman who works in a residential home said, "The deductible on the insurance is too high. And the price of the insurance per week is too high. Everything is too high for the benefits that are given…. [I]f you saved that money, you probably just pay off what you had to from the doctors yourself and save money…. It's just not worth it."

"Everything is too high for the benefits that are given.... It's just not worth it."

The Consequences of Medical Debt

Research clearly demonstrates that medical debt—including among people with insurance—creates significant barriers to accessing care. However, the effects of medical debt extend beyond access problems. Medical debt can also seriously affect people's financial stability and security, for example by causing them to skip paying for other necessities, drain their savings, or accrue credit card debt to cover their bills. Medical debt can also produce long term blots on people's credit records, which can make it more difficult for them to access credit, for example to buy a car or a home.

Access to Care

- In 2005, more than one-quarter of non-elderly adults who were continuously insured for the previous year experienced problems accessing care because of costs.[47]
- Insured people with medical debt act more like the uninsured than the insured without medical debt in their care seeking behavior.
  - 29% of the uninsured and 28% of the privately insured with medical debt postponed care due to cost, compared to only 6% of the privately insured without medical debt.
  - 25% of the uninsured and 30% of the privately insured with medical debt skipped a test or treatment due to cost, compared to only 8% of the privately insured without debt.[48]

Nearly nine out of ten of our interviewees said medical debt affected their ability to access care, and nearly half said reduced access had negatively affected their health. For some interviewees, reduced access meant waiting longer than their doctors recommended between appointments or not getting preventative care or screening tests. For others, it meant not getting treatment for cancer. In most cases, people postponed or did not get care because they couldn't afford the cost sharing and feared incurring more debt. In some cases, providers refused to see them because of their outstanding bills. Sometimes the failure to get care in a timely way resulted in more serious, and expensive, health problems later on.

DELAYING AND FORGOING CARE BECAUSE OF COST

Delaying or forgoing care was a major theme in our interviews. For example, people often did not follow their doctors' recommendations about when to return for follow-up care or check ups and ended up spreading their appointments out. Often they were receiving treatment for serious illnesses.

David, who is diabetic, said "Even the time in-between my regular appointments with my diabetes specialist or a primary care doctor, I just don't go as often as I'm supposed to." He also found out recently that he may have glaucoma, a serious eye disease. "I put off getting a follow-up appointment with my ophthalmologist, even though I got notices reminding me that I'm supposed to get it." Dorothy, whose daughter has scoliosis and severe flat feet, said "Because of the bills, sometimes it holds me back from taking her to her visit to the hospital…. This past summer, she was supposed to go and have her feet looked at and, because of the amount of expenses, I hold back from doing that. What I have to do now is save money for her to get…the inserts for her shoes. Podiatry is going to cost me at least $500, and the insurance will not pick that up." Peggie, who had two bouts with breast cancer, said, "When someone says, 'Let's do this scan or…this might give us more answers,' you hesitate to do that because you know that you can't afford it…and say, 'Why don't we do this mammogram in two more months, or this scan later, because I just can't afford to do it.'"

Delaying dental care was especially common. Connie, for example, noted that even though she had dental insurance, the last time she had gone for care it cost her $800. She commented, "I haven't gone to the dentist. I actually prolonged it for two years. I just went back and I have three cavities." Lew noted that his major delay in receiving treatment was for dental care. "I have a partial plate and I need another one. The one that I got has wires on it that have rubbed my teeth and caused some enamel to wear away…. I chew with my front teeth instead of my back teeth. I don't have five or six hundred dollars to have that done." Kathleen said she had to have major dental work two years ago, which was difficult for her to pay for even though she has dental insurance. She has skipped going to the dentist for check-ups since then because of the cost.

Delaying or not filling prescriptions was also a common occurrence. Joeletta, a blind and disabled woman in Ohio, for a time had insurance that provided very limited coverage for prescription medications, so, she said, "we were living all that time without medicine." She currently needs medicine for sinus problems, but because of the cost, she hasn't purchased any in three years. David needed a drug that was no longer on his health plan's formulary. Although his doctor prescribed it, it was still not covered by his insurance. He said, "I still haven't filled that prescription because I checked at pharmacies and it's over one hundred dollars…just for a couple of months."

People often delayed or did not get preventive care, which could potentially result in the failure to diagnose and treat illnesses. Diane, a married woman in Missouri, said her husband's family has a history of cancer and he needs to have a colonoscopy, but has held off because of the cost.

"It'll cost the $2,500 deductible. It's about $3,000 for that procedure, and then you get other charges on top of it…. It really worries me that he hasn't gone…and his doctor is very upset with him for not doing it." Connie has an enlarged heart and high blood pressure. Her doctors ordered tests, which determined that her heart was all right but, as she said, "something is causing chest pain…. I'm not going to tell [my doctor] and say, hey I still have this occasionally. She'll say, well let's run tests…and I'd go, no way." Bonnie needs a pap smear, but cancelled her appointment because "[they would send] me the whole bill, and I can't really afford it."

"It's about $3,000 for that procedure, and then you get other charges on top of it.... It really worries me that he hasn't gone...and his doctor is very upset with him for not doing it."

HEALTH CONSEQUENCES OF REDUCED ACCESS TO CARE

Frequently, people were in pain or had other symptoms but tried to wait things out because of the cost. Caitlin had ripped quadriceps, but said she delayed going for care because she feared owing more money. "I was limping for a month before I went because I was afraid that they were going to charge me."

Sometimes delaying needed care resulted in a worsening of people's conditions that eventually required more expensive treatment. Lauren got sick for a month with the flu and a sore throat. "I kept thinking that I was going to get over it…. I don't want to go to the doctor and then pay $25 for them to tell me that it's just a virus." When she could no longer speak and finally did seek care, she found out she had strep throat that had gone on so long that it required treatment with a very strong, and more expensive, antibiotic. Marie has asthma, but didn't fill three prescriptions because, with $30 co-pays, it would have cost her $90. She also avoided going to the doctor because of the cost. "[I] ended up sick and going to the emergency room and paying the $30 co-pay at the emergency room and then went to get an antibiotic filled and paid a $50 co-pay for that."

PROVIDERS REFUSING CARE

In a few cases, interviewees were denied care by their providers because of unpaid bills. Samantha had insurance through her employer, a hospital in Illinois. The only physicians in her provider network worked in an affiliated clinic. Samantha is diabetic and had accumulated $12,000 in debt because of unaffordable co-insurance, which required her to pay 20 percent of her bills. She was paying $25 a month on the bills, but last year the clinic told her she could not come back for care until all the bills were paid off. Before services were cut off, she was diagnosed with

cancer. She said, "I didn't get a chance to go back to try to find out what type." In addition, her heart rate was elevated and her doctors had scheduled a test to determine the cause, but that was also cancelled. Sometimes she now goes to the emergency room, because it is the only way she can get test strips and medicine for her diabetes, but the cost is very high. At one point she was taken to the hospital in an ambulance because her blood sugar was so high she was almost in a coma.

Janet experienced the same problem with the same insurer and providers. She suffered from a series of serious medical problems. As a result, because of accumulating co-insurance and co-pays, she owed about $15,000 to the hospital and clinic. She only found out while meeting with her doctor that the clinic had said she could no longer receive services until the bill was paid. She felt lucky that she learned about this two weeks prior to open enrollment at her employment, so she was able to switch to another insurance plan.

A ROCK AND A HARD PLACE

Again and again, interviewees described living in fear of getting ill because, even though they had insurance, they could not afford to get care. Laurie said, "The joke [in our family] is 'Nobody get sick any more.'…. We've spent so many thousands this year so far that we just can't financially afford to pay any more this year." Lew noted, "Right now, we're very tenuous about going to the doctor for anything other than what we absolutely have to." Joeletta commented, "[Y]ou think you have insurance and…with insurance I think I can go and afford [care], but now I'm finding out that it's not true." Robert perhaps expressed these feelings best. "I am in fear of having to go [for care]…. You feel caught between a rock and a hard place. You don't want to increase your debt, but at the same time, it's your health. That shouldn't be the case."

> "I am in fear of having to go [for care]…. You feel caught between a rock and a hard place. You don't want to increase your debt, but at the same time, it's your health."

Financial Consequnces

- Nearly one in ten non-elderly adults who were continuously insured for the previous year had to change their way of life to pay medical bills.[49]
- Nearly one in five was unable to pay for basic necessities, such as food, heat, or rent, because of medical bills.[50]
- One in three used up all their savings to pay medical bills.[51]

It is perhaps not surprising that almost all of our interviewees said they had experienced negative financial consequences as a result of their medical debt. These problems ranged from tight budgets to bankruptcy.

EFFECTS ON FAMILY BUDGETS

For some with moderate incomes who experienced catastrophic medical events, enormous medical expenses required them to take out very large loans, usually borrowed against their homes. In these cases, financial problems were almost completely the result of their medical debt. Ron, who was profiled at the beginning of this report, has a family income of about $60,000. After the hospital threatened to put a lien against his home because of his hospital bill, he borrowed over $80,000 against his home to pay it off. Ray, whose wife exceeded lifetime and annual insurance caps before she died, is retired; his income comes from Social Security, veteran's benefits and some stock dividends. He refinanced his home for $150,000 to cover her medical expenses. Both Ron and Ray said they had to reduce their standard of living to cover the loan payments. Ron said, "There is no cushion like there used to be. You wouldn't have to worry in a couple of years are we going to need a new roof…we can take out of savings…. Now…is there going to be something to take it out of? So, it just takes some of the security out a little bit." Ray said, "I'm very tight on budgeting. I figured out my budgets…. The income I have in relationship to outgo just includes food and…utility bills. I just barely break even with paying these two bills to [the hospitals]."

> "The income I have in relationship to outgo just includes food and...utility bills. I barely break even with paying these two bills to [the hospitals]."

For lower income people, medical debt added to the existing difficulties of living on a limited budget. These interviewees, who were already juggling bills to cover living expenses, found their financial burden seriously aggravated by the medical debt.

Debbie is married with three children; her household's income is about $32,400. She currently owes about $2,300 for medical bills resulting from a pregnancy, dental care, and medication co-payments. She said, "We just basically don't have a lot of extra money. We don't really have anything for savings. We kind of live paycheck to paycheck…. My insurance…you get a three percent raise, but your insurance goes up five percent, ten percent. I don't know how much longer I'll be able to keep insurance if it goes up again, which I'm sure it will in January." She and her husband refinanced their house for $40,000 to pay off medical bills and other debt.

Over one-third of our interviewees said they had used up their savings or were unable to save for retirement because of their medical bills. Bonnie laughed when asked if she had used her savings to pay her medical bills. "I don't have any savings. It eliminates all possibility…to save money. That's what it does."

> "I don't have any savings. It eliminates all possibility...to save money."

IMPACT ON EMPLOYMENT

Almost three-quarters of our interviewees said medical problems and unaffordable medical bills had affected their employment. Sometimes people were forced to reduce their work hours or stop work altogether because of their illness or that of a family member. Sometimes accruing medical debt coincided with other life events that seriously affected their income, such as being laid off from a job or losing a well-paying job and having to take a position with a much lower salary. The need to have adequate health insurance also affected people's employment choices in a variety of other ways.

Victoria was laid off, without explanation, when she needed spinal fusion surgery. As severance, her employer continued to provide health insurance for six months, but after that she became uninsured. She had been making about $60,000 or $70,000 a year, but currently has no income. She said, "I don't want to get to the point where I start tapping into my 401K and whatever else I rolled over into my IRA…. I'm fifty…. I've got less than the average person to retire on already, so why would I depend on that?... So I'm motivated to go out and work, but I can't find a job…. If there was a state program or something that would keep me healthy until I found employment and other coverage, I wouldn't be so upset. But for a full year I won't be covered on any insurance."

People with children with special health care needs, who usually faced very high medical expenses, also frequently had to alter their employment in order to care for their children. Donna, whose daughter has cerebral palsy, had a well-paying job that required her to work long hours. When their daughter was born, Donna and her partner decided they could not both work full time and take care of the child, so Donna took a less well-paying part-time job. She said, "Between the lifestyle changes and the changes in income, it just kind of snowballed. The medical issues that would come up with the co-payments and the deductibles, the durable medical goods that for the most part were covered by the insurance but sometimes were not, it just snowballed and got way ahead of us." She and her partner finally had to file for bankruptcy.

Other people found they had to work longer hours to help pay their medical expenses. Peggie's husband tried to make up for the loss of her income when she was disabled with breast cancer by working more. "[He was] concerned about a wife that is unable to even get food out of a microwave and leave me alone when it's almost impossible to get down the stairs, but he needed to work so we could pay these bills. So, yes, there's a lot of working extra hours." Ray put off his retirement so he could pay off the medical debt that resulted from his wife Cindy's long illness. Some interviewees had children and wanted to reduce their work hours so they could spend more time at home, but were unable to do so because they needed the income to pay health care insurance and other out-of-pocket medical expenses.

"[My husband was] concerned about a wife that is unable to even get food out of a microwave and leave me alone when it's almost impossible to get down the stairs, but he needed to work so we could pay these bills."

A number of interviewees felt that they needed to look for new jobs in order to get better insurance. Diane, who is self-employed, is covered under her husband's employment-based health insurance, but they have to pay the full cost of the additional family coverage. She said she might need to quit her job as a bookkeeper and look for a full-time position that included benefits. "I'm basically mad because…the people that I work for, the people that I'm doing books for, have immense trust in me, and that takes years to build." Bonnie said, "I'm looking for other work. As soon as I get [another] job with good health insurance, I am going to quit this. And I will have no [regrets] after all the time I've been there."

Health insurance costs also affected people's ability to start their own businesses. Because he was trying to start a business, Eric faced a cut in income. He currently has a household income of about $30,000. He has diabetes, which requires ongoing medication and care, and the only insurance policy he could purchase in the non-group market that provided adequate coverage has

premiums of $1,000 a month. He said, "We can't go out and buy a new pair of sneakers. We have to shop with coupons at food stores. We have to think twice before we drive long distances, because of the price of gas. The whole lifestyle has turned around dramatically 180 degrees. There's no more fun in the daily life." He's also had to stop saving for his children's college education. Roland, who is also trying to start a business, said, "We've chosen to be self-employed. I realized there's some sacrifices [that we're going] to have to do. The thing that I did not anticipate is not being able to afford health care. And that's where we're at right now."

> "We've chosen to be self-employed. I realized there's some sacrifices [that we're going] to have to do. The thing that I did not anticipate is not being able to afford health care."

IMPACT ON CREDIT

- 21% of all non-elderly adults had been contacted by collection agents about medical bills in the past year.[52]
- More than one-quarter of non-elderly adults who were continuously insured for the previous year took on credit card debt to pay medical bills.[53]
- 29% of low- and middle-income households with credit card debt reported that medical expenses contributed to the debt.[54]
- Average credit card debt was 46% higher for low- and middle-income medically-indebted households than for low-and middle income households with credit card debt but no medically related debt.[55]

We have already seen that for some interviewees, medical bills were a factor that contributed to their decision to file for bankruptcy. Even in less extreme cases, however, unaffordable medical bills can create long term problems by damaging people's credit.

In a number of the stories already described in this report, interviewees reported that they had medical bills that were sent to collection agencies. In fact, nearly half of our interviewees said they had been contacted by collection agencies because of unpaid medical expenses. Some only found out they had unpaid bills when they started receiving calls from collectors. Others were told that if they did not pay their bills, the bills would be turned over to collectors. Barbara commented "The letters [from the providers] come. And at the bottom it said that if I do not pay by this time, it will be turned over to a collection agency. I don't know if that's threatening, but it sure does make you sit up and pay attention."

> "[The bill] said that if I don't pay by this time, it will be turned over to a collection agency. I don't know if that's threatening, but it sure does make you sit up and pay attention."

Lance, who broke his back in an accident, reported more aggressive threats:

> I started making payments [to the clinic] in July, when I went back to work. They contacted me in October…and told me that my payment was not sufficient and that they needed me to pay $400 a month. They wanted me to fill out a sheet that said they could determine how much I could pay, or they could decide whether I could put it on a credit card or take out a loan to pay it off…. I continued to pay the $40 or $50 per month that I had been paying. And then two months ago they called me back and said that if I did not pay more that they were going to send the bill to a collection agency or an attorney. And then last week I got a letter that said if I did not pay the full bill today they would send me to an attorney or to a collection agency.

Several interviewees said their providers encouraged them to pay their bills with credit cards. Some did so to avoid damaging their credit record or to ensure that they could continue to receive services. In fact, nearly half of our interviewees said they had used credit cards to pay their bills. Credit cards are an expensive way to pay for care, as they charge interest on unpaid balances and often impose large fees for late payments.

Many of our interviewees reported that their credit had already been damaged by medical debt, which then affected their ability to get needed loans or forced them to take out loans at higher interest rates. Dorothy, a single mother whose daughter has scoliosis, said "Right now I cannot get a loan, because my credit is so badly messed up…. I was trying to get a loan to help pay off the medical bill, and also trying to get a loan to help with the kids going off to college. Either one doesn't work out."

"Right now I cannot get a loan, because my credit is so badly messed up...."

Samantha, also a single mother, said she was denied a loan to help pay for her daughter's school because of a bad credit record. Peggie was denied a car loan. Lynnette was able to get a loan to purchase a car but, she noted, "I was not able to get the best interest rate…because of this collection agency." Lew noted that his wife had a credit card with a 15 percent interest rate and applied for one with a 9.9 percent rate to try to save a little money, but because of their credit record her application was turned down.

Psychological Consequences

- Among adults who said they or a family member had been diagnosed with or treated for cancer in the past five years:
  - Nearly half said the costs of cancer care were a burden on their family, and one in six said they were a major burden.[56]
  - One-third said the cancer experience caused someone in their household to have emotional or psychological problems.[57]
  - One-quarter said the experience caused severe strains with other family members.[58]

A less tangible consequence of medical debt is its psychological impact on families. Most of our interviewees said that their unpaid medical bills contributed to increased stress and tension in their families.

For lower income families who are trying to live on tight budgets, medical expenses added to the overall stress of trying to make do with limited resources. Joceylne is a single mother with two children and an income of $25,000; she has medical debt of about $2,700. She said "I lay down, I'm thinking about how am I supposed to get out of debt and manipulate what I need to do…. I'm always counting change and making sure you can eat, and do what you have to do, and survive." Lew previously earned about $80,000 but, after he lost his job in a bank because of a company merger, he now earns about $20,000. His current medical debt is around $2,500, and he has considered filing for bankruptcy. He said, "After working in the credit banking industry for most of my life, it's a bitter pill. It went against everything I had ever spoken to anybody about or preached to anybody about."

> "After working in the credit banking industry for most of my life, [considering bankruptcy] is a bitter pill. It went against everything I had ever spoken to anybody about or preached to anybody about."

Eric, who is married and has two children, has a family income of about $30,000. He refinanced his home to help cover his family's health insurance premiums. He said, "There's a lot of stress in the family [because of these healthcare costs]. A lot of ill feelings. Some of us have gone to substance abuse to try to relieve our pressure. You know it's not good." David, a single man who has an income of $24,000, said "It's just stressful being in debt. I don't like being debt. I don't like having to make decisions about not being able to do something because I can't afford it. That happens a lot."

Even in families with higher incomes, medical debt can create serious stress. Lynnette has an income of $40,000 and accrued $9,000 in medical debt when her husband was dying of cancer. She said, "I tried to shoulder the load myself, so that played a big part in my own stress level. We have a post office box. I would routinely stop and get the mail and not even take it in the house. I'd bring it here to work. I did not want my husband to see the bills. The doctor had been emphatic with me to keep [his] stress level down…. The only way I knew to do it was to keep it to myself…. The kids had no idea."

Peggie has a family income of about $100,000, but accrued $40,000 of medical debt because of treatment for cancer. She said, "[The stress and tension] were worse than the cancer…. The cancer you could deal with and that you could go and cut out or zap,…but knowing every day when you're going to the mailbox, it's like, 'Oh my God…. What's going to come in that mailbox today is going to throw us over or we're going to lose the house.' It's an enormous stress, and I think it did not help me heal well to know that I had to deal with that all the time."

A number of interviewees similarly commented that that the increased stress and tension affected their health and ability to heal. Linda noted that her husband had a medical setback during his recovery from heart surgery, which she thought was affected by his worries over his medical bills. For others, the stress over medical bills was added to the stress of being seriously ill. Janet, who suffered a series of serious medical events, including breast cancer, said she became depressed from being sick for so long, and was admitted to a mental health facility. "I was feeling depressed because of my body. I lost my breast. I was young. I was 45." She said her medical bills increased her depression, and the treatment for depression only added to her medical bills.

Discussion

Findings

Many studies have documented that people with insurance are being forced to pay increasing percentages of their income on health care as a result of rising insurance premiums, deductibles, and other forms of cost-sharing. One symptom of this phenomenon is the high percentage of insured people facing medical bill problems and medical debt, along with the attendant problems of reduced access to care and serious financial hardship. Research has also identified some of the features of insurance that leave people at greater risk of experiencing these consequences—high premiums and deductibles, less comprehensive coverage, and limits or caps on what plans will pay.

Our interviews showed the impact of these developments on patients and their families. For low-income people and those with chronic health needs, even modest levels of cost-sharing saddled them with debt and made care unaffordable. For people with moderate incomes, plans with higher cost-sharing and more limited benefits often had the same result. Even those with relatively comprehensive coverage incurred enormous debt if they become seriously ill, especially if their health plans included caps on coverage. The interviews showed that these costs and resulting debt created serious barriers to accessing often desperately needed care. Rather than feeling secure because they had insurance, people lived in fear that they might become ill and not be able to pay for care. When they did seek care, the bills often created serious financial problems for families already struggling to stay economically afloat.

Our interviews also suggest that people's assumption of increased financial risk—either in the form of reduced benefits or higher deductibles—is usually not by choice. In practice, people often had few alternatives when they tried to obtain insurance. When they had access to employer-sponsored coverage, they often did not have a choice of plans and, when they did, their options were often severely limited by what they could afford. When people purchased insurance on their own, they faced even greater problems; they were often forced to choose between plans with unaffordable premiums or plans with such high levels of cost-sharing that they provided little financial protection. In some cases, if people had pre-existing conditions, they were not able to purchase insurance at all.

The interviews also revealed problems with our health insurance system that have been harder to capture in previous survey research. Our interviewees faced an insurance system so complicated and confusing that it was virtually impossible for them to understand. The complexity of insurance products made it difficult for people to compare and evaluate them with respect to covered services and financial exposure, which left them vulnerable to deceptive marketing practices.

When they had coverage, it was hard for them to ascertain what their insurance covered or why claims had been denied, which in turn made it hard to identify errors or resolve problems when they arose. The frequency with which people received incomplete, inaccurate, or inconsistent information from their insurance companies suggested that the insurers themselves (or at least their staff) found it difficult to keep track of the various provisions of their products.

In many ways, this confusion is a result of the proliferation of methods that insurers have used to increasingly shift financial risk to policy holders, either through enhanced cost-sharing or the application of techniques designed to limit utilization. These mechanisms place on patients the burden of complying with a complex web of requirements and procedures. In some cases, they place patients in situations where it is impossible to comply with these rules. In others, they subject people to financial penalties that are irrational or result from situations that are completely out of their control.

The stories our interviewees told include many examples. People who went to hospitals in their network only had access to clinicians who were not in their network, and thus were forced to pay higher levels of co-insurance. People who got sick at the end of one year and required treatment that extended into the next year had to pay deductibles twice; if they had become ill at the beginning of the year and completed treatment by end of the year, they would only have had to pay once. People were denied coverage for services clearly covered by their insurance policies simply because they did not know they had to file a particular form. And people whose policies included annual and lifetime caps who experienced truly catastrophic medical events became liable for enormous bills, precisely the situation that insurance is designed to prevent.

As we also saw, this insurance system interacted with an equally confusing and opaque provider billing and collections system that made tracking medical expenses and resolving mistakes an almost impossible task. When people found themselves liable for charges not covered by their insurance, many expressed a willingness to pay reasonable bills or set up payment plans that were within their means, but were often outraged by prices they considered grossly inflated. Many believed providers set unreasonably high prices so they could maintain desired levels of reimbursement when they negotiated percentage discounts with insurers. In the end, many people felt they were caught between insurers and providers—two large systems over which they had little control.

Policy Environment

Much attention has been directed in the last few years to hospitals' lack of transparent pricing, their aggressive billing and collections practices, and their frequent failure to inform people about the availability of financial assistance programs. Congress has held hearings on these issues and in some states legislation has been passed to try to mitigate these problems. These are steps in the right direction, although our interviews suggest there is a long way to go before the problems are eliminated.

What is striking, however, is that similar attention has not been paid to the policies and practices of the insurance companies that provide people with coverage. Our interviews suggest that states are not seriously monitoring benefit packages and premium rates to ensure that customers are being offered real value in exchange for their premiums. And they indicate that insurance companies are not being held accountable for inadequate customer service systems and error-prone claims handling processes that often leave consumers liable for expenses that they should not have to bear. And they reveal that some insurance products are being marketed deceptively and possibly even fraudulently.

These issues assume particular importance because state and national policy-makers, faced with rising rates of uninsurance, are increasingly turning toward the private insurance market as the mechanism for expanding health care coverage and restraining health care costs. Their proposals have taken a number of forms.

Under the rubric of "consumer driven health care," some policy-makers have advocated increased consumer cost sharing as a way to restrain health care costs. They identify inappropriate utilization of services as the major cause of spiraling health care costs in this country and maintain that because some health care costs are covered by insurance, policy holders do not have enough of a financial stake in choosing appropriate over inappropriate care. The head of the Washington-based Center for Health Transformation, testifying before a Missouri state commission studying health care reform, said "People would behave differently in the health care marketplace if it were their dollars at stake."[59]

Others support eliminating state mandated benefits and allowing the sale of insurance policies with limited coverage, maintaining that this will reduce premiums and make insurance more affordable or allow people to choose the level of health coverage that best meets their needs.

Our interviews, combined with data from national surveys, show that the assumptions behind both of these approaches are deeply flawed. Few of the people we interviewed are choosing plans with limited benefits and/or high deductibles in exchange for low premiums; rather, they feel they have no choice and often find that the plans they have do not meet their needs. They understand that the affordability of health insurance cannot be measured solely in terms of the cost of the premiums; the accumulation of deductibles, co-payments, other cost-sharing fees, and the costs of uncovered services can make health care unaffordable even when premiums are relatively low. Most of our interviewees, rather than "frivolously" seeking inappropriate care, have exhausted their savings and gone deeply in debt to obtain needed care or are delaying or forgoing necessary care to avoid falling further in debt. Sometimes delaying care results in more serious illness later on. Many are beginning to question whether the money they are paying for premiums is worth the coverage that their insurance provides.

Along with these "consumer-driven" proposals, many states are now considering mandates requiring people to purchase private insurance as a route to universal coverage. Massachusetts has led the way, passing a law that requires all residents to purchase insurance or face financial penalties, with premium subsidies for people with lower incomes. Many states are currently investigating similar approaches. However, it is not yet clear whether private insurers will offer policies that are truly affordable when all consumer costs are considered, and whether states will offer subsidies adequate to achieve this goal.

Finally, both the federal government and some states are looking to the private market to provide benefits for publicly funded programs. Most notably, Medicare prescription drug coverage is now being offered through private insurance companies, although many question whether this is the most cost-effective way to provide this benefit.

Before relying on the private insurance market as the vehicle for expanding coverage for the uninsured, it is important to understand how well it currently functions in achieving its primary purpose—offering affordable and quality products to its customers and providing them with reliable customer service. Where problems exist, they must be rectified. Otherwise, we will simply replace the problems related to lack of health insurance with the problems related to inadequate insurance, with its similarly devastating health and financial consequences for individuals and their families.

Recommendations

According to economic theory, insurance has value because it allows people to mitigate the financial risk associated with illness, and because it allows those who become ill to afford care they would otherwise not be able to purchase. Our findings indicate that for insurance to fulfill these goals and provide real value to policy holders, it must meet three criteria:

1. It must be comprehensive.

Comprehensive insurance must provide coverage for services that are medically necessary and shown to be effective. It must include coverage for prescription drugs, which are an essential component of medical care. It must also provide coverage for preventive care and disease management that can prevent more serious illness later on.

2. It must be affordable.

Affordability must take into account not only the cost of premiums, but also all of the other out-of-pocket expenses, such as deductibles, co-payments, and out-of-network fees, for which consumers will be liable.

3. It must be accessible, including to people who have pre-existing medical conditions or health risk factors.

Health insurance is of little value if the people who most need it cannot purchase it, either because they are denied coverage or because they face prices that are prohibitive. Meaningful insurance must be accessible to everyone, including those who have been ill and those who are viewed as being at higher risk of becoming ill.

The insurance problems we have identified in this report are multiple and systemic, and comprehensive solutions will necessarily require methods for lowering the costs of health care in the system as a whole. In the meantime, however, states can take actions that will mitigate these problems, and insurers can also take steps to improve their products and practices.[60] The following recommendations describe some measures that could be implemented in the short term to provide better protections to people who are or hope to become insured.

Set standards for what constitutes comprehensive, affordable insurance. Standards must include both the range of benefits covered and the out-of-pocket amounts for which consumers may be liable.

Rather than reducing covered benefits, states should set requirements to ensure that any insurance products sold provide value to their purchasers. Consumers could be protected from excessive risk both by requiring coverage for a comprehensive set of services and by including features to prevent excessive out-of-pocket costs. These might include limiting plan deductibles, requiring that plans include out-of-pocket maximum amounts based on consumers' income, and prohibiting the inclusion of annual or lifetime caps on coverage.

Creating standards does not need to restrict innovations designed to make good coverage more affordable. Some employers are experimenting with insurance policies that target patients with particular clinical diagnoses and lower or eliminate cost sharing for specific high-value services—for example, beta blockers for patients with congestive heart failure.[61] Others are creating tiered premium systems that charge lower-wage employees less than those with higher incomes.[62]

Ensure that people are provided with information that allows them to be informed consumers when they try to purchase health insurance.

In order to make wise decisions when purchasing insurance, consumers need information that allows them to clearly understand their options. Setting standards for insurance policies would in itself contribute toward this goal by reducing the incomprehensible number of options that consumers currently face and by making it easier for customers to compare plans to one another.

Insurance companies could also be required to provide consumers with standard disclosure forms that clearly detail the services products cover and the out-of-pocket expenses for which consumers are liable. These forms should be common across insurers to further support comparison of products and prudent purchasing. They should also provide consumers with clear and simple information about their rights and protections under the terms of their health plan and under state law (for example, the right to an independent appeal process).

As states are now beginning to publish data on hospital and physician performance, such as rates of hospital infections or percent of patients who receive appropriate screening tests, they should also consider devising measures to assess insurance company performance and collect and disseminate data showing how well plans are providing services.

Enact guaranteed access, guaranteed renewability, and community rating laws in states where they are not already in place, to ensure that people who have been ill are not shut out of the insurance market.

Guaranteed access means that insurers must sell their insurance products to customers regardless of their health status. Guaranteed renewability prohibits cancellation or non-renewal of coverage because of people's medical claims or diagnoses of illness. Many states have enacted these types of laws in the small group insurance market. Such laws should be enacted in both the small group and the non-group markets.

While these types of laws guarantee that insurers cannot refuse to sell insurance to individuals, they do not guarantee that prices for those who have existing medical conditions will

not be prohibitively high. For this reason, a number of states have enacted community rating laws that require insurers to set rates based on the aggregate medical claims of everyone with the same health insurance policy, and not on the claims history or risk factors of individuals. (Some states have adjusted community rating, which means that premiums may be adjusted based on factors such as age or geographic location, but not based on medical history.) Community rating laws should be applied to both the small group and the non-group markets.

While these types of laws can result in somewhat higher average premiums, they prevent insurers from pricing people at higher risk of needing medical care out of the market.

Conduct oversight to ensure that health insurance premiums are reasonable.
The Commonwealth Fund recently noted that insurance-related administrative costs per person in the U.S. are the highest in the world, currently comprising 14 percent of private insurance expenditures. In addition, as the private insurance market has consolidated, the profit margins of commercial insurers have soared.[63] States need to provide oversight of insurance premium increases to ensure that they are reasonable and to protect consumers from price-gouging. They should require insurers to file requests for premium increases with the state insurance department and hold public hearings on the requested increases. The appropriateness of premium increases should be evaluated with respect to insurers' efficiency (the amount of each dollar they spend directly on covering health insurance claims) and resources (profits, surpluses, and reserves).

Develop public/private partnerships to help share the cost of comprehensive, affordable coverage for people with limited resources.
Some states have implemented, or are considering, programs that would combine state and private funding to provide comprehensive coverage for groups that otherwise could not afford it. The Massachusetts Fishermen's Partnership, for example, worked with a local health system and federal and state officials to develop a comprehensive insurance product for Massachusetts fisherman. The product is offered by a private health plan, with premium costs subsidized using both state and federal funds.

Other types of partnerships are also possible. Some states have offered public insurance for people with extraordinary medical expenses that "wraps around" their private insurance coverage, and others have set up emergency relief funds to assist people with medically-related expenses that their insurance does not cover. The West Virginia Small Business Plan gives a participating insurer access to the provider rates negotiated by the state agency that provides health insurance coverage for all state employees. This has allowed the carrier to offer an insurance product for small employers at a rate 20 to 25 percent below retail rate. As a condition for participating, the insurer was required to reduce its administrative margin. Ohio is considering a similar plan.

Create mechanisms to help consumers resolve insurance-related problems.
States need to create and staff strong customer service departments to record and investigate customer complaints about health insurance contracts and practices. Some states have appointed independent ombudsmen who assist consumers when they have insurance-related problems and intercede with insurance companies to help resolve them.

States could also work with insurers to develop clear and easy to understand Explanations of Benefits (EOB) forms. These forms, which are provided to consumers when their claims are processed, should include easy to understand explanations of what services a plan has covered, how much the plan has paid, what claims the insurer has denied and why, and what amounts consumers still owe to their providers.

Set rules that prohibit unfair insurance practices. Monitor insurance industry compliance with existing laws and require corrective actions when necessary.
For example, the Department of Managed Health Care in California is developing rules that would prohibit insurers from canceling insurance policies after people file claims unless they can show that policy holders deliberately lied on their applications. Insurance Departments could also consider rules that would prevent insurers from charging consumers out-of-network provider fees when they receive care in in-network hospitals, or when no in-network providers are available.

States should also do regular audits of insurers to identify operational problems, such as failure to pay claims fairly or promptly or comply with any state laws, and require corrective action when necessary.

Ensure that hospitals and other providers offer appropriate discounts and financial assistance to patients with unaffordable medical bills.
Insurance reforms are essential for addressing some of the problems people encounter when they interact with the health care delivery system, but patients will still feel "caught in the middle" unless changes are made in provider financial assistance, billing, and collections practices.

California recently passed legislation that requires hospitals to provide information on their charity care and financial assistance options and limits the prices they can charge for patients with limited resources. The legislation also sets rules for when providers can send bills to collection agencies; for example, it prohibits forwarding bills to collections while patients are attempting to settle, negotiate, or make payments on the bills, or while appeals with their insurance companies are pending.[64] Other states could consider similar legislation, and should ensure that those with inadequate insurance, as well as the uninsured, are covered by its provisions.

Conclusion

With health care costs and the number of people without insurance rising out of control, health care analysts and state and federal policy-makers are again focusing on ways to repair our health care system. Some of the proposals that have been offered are based on theoretical notions of what ails our system and what will fix it—people do not pay enough of their medical costs to become informed consumers, state mandates require insurers to provide too much coverage, people should be allowed to purchase only the health insurance they need. However, serious proposals should be based not only on theory, but on the real experiences of real people.

Numerous surveys have clearly documented that, in fact, many uninsured and insured people face unaffordable medical bills and crushing medical debt that undermines both their health and their long-term financial security. This report has attempted to put a face on these numbers. It has tried to show the often devastating effects of medical debt on individuals and families who thought they were secure because they were insured, but found out that their insurance did not protect them when they needed care. As we look for ways to decrease the number of uninsured, we should not replace one problem with another. People need coverage, not the illusion of coverage. We must guarantee that they have access to quality, affordable insurance that provides real protection when they are most in need.

Endnotes

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Partner Organizations

The Access Project (TAP) has served as a resource center for local communities working to improve health and healthcare access since 1998. The mission of The Access Project is to strengthen community action, promote social change, and improve health, especially for those who are most vulnerable. TAP conducts community action research in conjunction with local leaders to improve the quality of relevant information needed to change the health system. TAP is affiliated with the Heller School for Social Policy and Management at Brandeis University.

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The Champaign County Health Care Consumers (CCHCC), founded in 1977, is a non-profit grassroots citizen action organization dedicated to the mission of health care for all. CCHCC is founded on the premise of participatory democracy and the belief that meaningful change in the health care system will come only with the active involvement of consumers. CCHCC works to bring a consumer voice and consumer-driven changes to the health care system through education, advocacy, and community organizing. CCHCC is a community-based organization with over 7,000 members working locally on issues of national importance.

44 Main Street • Suite 208 • Champaign, IL • 61820 • (217) 352-6533 • www.prairienet.org/cchcc/

Florida CHAIN (Community Health Action Information Network) is a statewide network of organizations dedicated to improving the health and wellbeing of Floridians, especially disenfranchised constituencies. Florida CHAIN works by linking and building the capacity of communities for national, state, regional and local advocacy. Priorities include: promoting access to health care at the local, state and national levels; supporting local healthcare reforms; and building community leadership through the empowerment of those most affected by these issues by providing timely information, policy and skills training, and structures for collaborative strategy development.

6600 Cypress Road • Suite 508 • Plantation, FL • 33317 • (954) 791-7314 • www.floridachain.org

Health Access California is a statewide health care consumer advocacy coalition of over 200 organizations working for the goal of quality, affordable, health care for all Californians. Since 1987, Health Access has played a significant role in leading the movement for health care reform in California. Health Access has promoted universal health care proposals and advocated for specific incremental reforms that promise to provide immediate health care services to California's most vulnerable populations.

414 13th Street • Suite 450 • Oakland, CA • 94612 • (916) 497-0923 • www.health-access.org

Health Care For All is building a movement of empowered people and organizations in Massachusetts with the goal of creating a health care system that is responsive to the needs of all people, particularly the most vulnerable. It is dedicated to making quality care the right of all people, and supports a health care system that is universal, comprehensive, and equitable.

30 Winter Street • 10th floor • Boston, MA • 02108 • (617) 350-7279 • www.hcfama.org

Missouri Citizen Education Fund (MCEF) is a statewide labor-community coalition that mobilizes the grassroots through non-partisan voter registration, issue education, and training. MCEF unites constituencies in Missouri and works with allies "to promote more progressive public policy in the areas of health care, public education and fair taxes."

5585 Pershing • Suite 150 • St. Louis, MO • 63112 • (314) 531-2288 • www.missouriprovote.org

The New York Immigration Coalition (NYIC) is a policy and advocacy coalition with 200 member groups in New York State that work with immigrants and refugees. As the coordinating body for organizations that serve one of the largest and most diverse newcomer populations in the United States, the NYIC has become a leading advocate for immigrant communities on the local, state, and national levels. With its multi-ethnic, multi-racial, and multi-sector base, the NYIC provides both a forum for immigrant groups to share their concerns and a vehicle for collective action to address these concerns.

137-139 West 25th Street • 12th Floor • New York, New York • 10001-7277 • (212) 627-2227 • www.thenyic.org

St. Louis Area Jobs with Justice (JwJ) is a coalition of 80 labor, community, student and religious organizations committed to protecting and improving the lives of workers. JwJ members take a pledge, "I'll be there five times a year for someone else's fight as well as my own, because when enough of us are there we all start winning." St. Louis Area Jobs with Justice is one of 40 JwJ coalitions throughout the country.

2725 Clifton Ave. • St. Louis, MO • 63139 • (314) 644-0466 • www.stl-jwj.org

Universal Health Care Action Network of Ohio (UHCAN Ohio) is a statewide organization working throughout Ohio for high quality, accessible, affordable health care for all Ohioans and to re-shape the health care system. We build coalitions, provide policy analysis, train advocates, and mobilize grassroots action. UHCAN Ohio has offices in Cleveland, Columbus, and Cincinnati.

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