

FALLING THROUGH THE CRACKS:

STORIES OF HOW HEALTH INSURANCE CAN FAIL
PEOPLE WITH DIABETES



Falling Through the Cracks: Stories of How Health Insurance Can Fail People with Diabetes

by

**Karen Pollitz
Eliza Bangit
Kevin Lucia
Mila Kofman**

GEORGETOWN UNIVERSITY HEALTH POLICY INSTITUTE

and

**Kelly Montgomery
Holly Whelan
AMERICAN DIABETES ASSOCIATION**

February 8, 2005

© 2005, Georgetown University Health Policy Institute and the American Diabetes Association

Acknowledgments

The authors express appreciation to the W. K. Kellogg Foundation, the Robert Wood Johnson Foundation, and the Commonwealth Fund for their support of this project. The authors also express appreciation to Stephanie Lewis, J.D. and acknowledge her valuable research, casework, and drafting contributions to this project while she was on the research faculty at Georgetown. In addition, the authors appreciate the efforts of Judith Feder, Robert Friedland, Cindy Mann, Linda Blumberg, Jay Hedlund, Shereen Arent, Tom Boyer, and Nathaniel Clark, who read and commented on drafts of this report. Views expressed in this report are those of the authors and do not necessarily reflect those of project funders or reviewers.

Finally, the authors express their appreciation to the ADA National Call Center staff, which fields thousands of calls daily from individuals affected by diabetes. Health insurance is just one of many topics the National Call Center staff must be ready to assist callers with. Nevertheless, they cheerfully made the extra effort to carefully screen calls and identify potential research cases for our project. Without their assistance, this project would not have been possible. Lee Barona, Director of the ADA National Call Center, and Denise Price-Brown, ADA Call Center Training Manager, deserve special thanks for ensuring that their staff members were fully prepared for the overwhelming task we asked them to undertake.

Table of Contents

Executive Summary	v
Chapter 1. Introduction	1
Chapter 2. Coverage Loss	3
Chapter 3. Individual Health Insurance	8
Chapter 4. COBRA	12
Chapter 5. HIPAA	16
Chapter 6. State High Risk Pools	20
Chapter 7. Public Programs	25
Chapter 8. Problems of the Insured	33
Chapter 9. Consequences of Insurance Problems	38
Chapter 10. Conclusion	41
Appendix. Routine Costs of Diabetes Care	43

EXECUTIVE SUMMARY

Health insurance is essential to the health and well being of people with diabetes – a chronic health condition affecting 18 million Americans in which elevated blood glucose (sugar) levels damage nerve endings and blood vessels, leading to serious health complications including

blindness, kidney failure, heart attack, and stroke. Diabetes can be effectively managed, but medical care and supplies needed to monitor and control blood glucose levels are expensive and can easily cost hundreds of dollars per month. Numerous scientific studies have found health insurance problems make it harder for people to manage their diabetes, often with

devastating consequences. Uninsured adults with diabetes are far less likely to receive needed care and effectively manage their disease, and those with health insurance have difficulty obtaining needed care when coverage is inadequate. People with diabetes need – but often cannot get – health insurance that is simultaneously available, affordable, and adequate.

As part of an initiative to train American Diabetes Association staff assisting members with health insurance problems, researchers at Georgetown University studied the experiences of 851 individuals to learn what caused their health insurance problems and what helped. For 14 months, project staff worked with people who contacted the Association’s national call center (1-800-DIABETES) because they had health insurance problems. Calls were accepted from people who were younger than age 65 and who were either uninsured, transitionally insured in coverage that was about to end, or insured with other problems. The focus of this project was on private health insurance because this is how most non-elderly Americans obtain health coverage, although some problems related to public coverage were also studied. Callers were asked if they would be willing to share their stories, and two-thirds said yes. Some are featured in this report.

Stories featured in this report are consistent with the findings of other studies and surveys demonstrating the importance of health insurance for people with chronic conditions. Serious medical complications arose among many people who were uninsured or under-insured and could not afford to pay for care out of pocket. Numerous callers struggled

Andrea (40) of Illinois

Andrea’s husband works for a fast food chain that offers health benefits. However, coverage is expensive (about \$1,000 monthly for the family’s share) and requires 25 percent coinsurance for prescription drugs. In addition to Andrea’s diabetes, her children have asthma. The family’s share of cost for the medications they need is another \$400 per month. Andrea can’t always afford all her medical expenses, so when money is tight she buys medicine for the children but does without her own. She also tests her blood sugar levels infrequently. The last time she saw the doctor, her blood glucose reading was too high.

Susan (46) of Georgia

Susan works full time at a low-wage job (\$250 per week) for an auto shop. The job offers health benefits but coverage is limited. Susan’s medical bills that would not be covered by the policy total \$400 per month. She could not afford to pay premiums on top of these expenses, so she decided not to enroll. Later, Susan was hospitalized and the bill was \$19,000. Unable to pay, she had to declare bankruptcy.

with medical debt. Some experienced job lock or moved to avoid or resolve insurance problems while others tried to make do by purchasing test strips on e-bay or prescription drugs from Canada, or other unconventional means. Several people fell victim to insurance fraud.

These case studies demonstrate what can happen to people who are sick when their health coverage breaks down. As such, they do not present a complete picture of the health coverage system. They provide little information about ways in which health insurance works well. In addition, case study data cannot be generalized to indicate how often similar problems occur among people with diabetes generally. However, they can spotlight shortcomings in the health coverage system. Just as automobile safety experts study data from car crashes for clues about how to make the roads safer, examining the health insurance problems of people with diabetes yields important clues about how to make coverage work better when it is needed most. Because the purpose of health insurance is to protect people in case of illness, it is important to study health insurance from this perspective.

Casework Overview

Between March 27, 2003 and June 27, 2004, 851 cases were opened for people who called the American Diabetes Association's National Call Center with health insurance problems. The typical caller was a middle aged woman, not working and not married, with modest income and uninsured. However, demographic characteristics, employment, income, and insurance status varied among callers. Health insurance experts at the American Diabetes Association and Georgetown University explored each caller's options for resolving health insurance problems, including consumer protections offered under federal and state law, and kept records on the outcomes of each case.

Overall, problems were resolved only 20 percent of the time. In another 60 percent of cases, people were eligible for help under some law or program, but the help was insufficient to resolve the problem. Finally, in 20 percent of cases, no help was available.

Health insurance problems studied fell into two main categories – those involving health insurance transitions and those involving coverage that was not about to change.

Health Insurance Transitions

On average, about two million Americans lose their health insurance each month. Health insurance transitions are often triggered by an ordinary life event, such as a job change or layoff, a move, divorce, graduation from college, or a change in income or health status. Some people transition directly from one health coverage to the next while others are uninsured for at least a month or longer. Roughly half of those who lose job-based coverage and two-thirds of those who lose Medicaid are uninsured for at least one month. Research also shows that people in poor health are twice as likely to encounter a lengthy spell without health insurance compared to people in good health.

About 80% of the problems studied arose because of health insurance transitions. Most people were uninsured, having already lost prior coverage. Others anticipated

transitions, such as a layoff or divorce, that would disrupt insurance coverage. For people losing job-based coverage, possible solutions explored included individual health insurance, COBRA,* HIPAA,* and high-risk pools. Although callers seeking help with public programs (Medicaid and Medicare) were screened out due to the project's focus on private coverage, issues involving these programs nonetheless arose in many cases.

Individual health insurance - In most states, insurance companies in the individual market can turn people down or charge them more because they are sick. This makes it virtually impossible for people with diabetes to buy such coverage. A few states require individual health insurance companies to sell coverage with comprehensive benefits to all residents regardless of health status (guaranteed issue) at premiums that do not vary based on health status (community rating.) However, such coverage is typically expensive. Subsidies are rarely offered to make premiums more affordable; instead, the market increasingly designs catastrophic or bare bones policies with lower premiums. However, premiums savings for callers with diabetes were offset by increased medical expenses due to high deductibles, limited prescription drug coverage, and other problems of coverage adequacy. The combined problems of availability, affordability, and adequacy of individual health insurance proved insurmountable to most callers. During the project, 395 people with diabetes needed to buy individual health insurance. Fifteen succeeded.

COBRA – A federal law known as COBRA allows certain people who would otherwise lose job-based health benefits to remain covered under their former plan for up to 18 to 36 months. However, individuals must pay the entire premium (employer and employee share), which can be difficult following job loss. Not all people who lose job-based coverage are eligible for COBRA and, among those who are, not all have heard of this option or understand how it works. Thus, COBRA protects availability of coverage in some circumstances and does not address affordability at all. During this project, 377 callers had lost or were about to lose job-based coverage and had not yet elected

Sylvia (52) of Michigan

Sylvia lost insurance a year ago when her husband lost his job and health benefits. They could not afford COBRA. Sylvia looked into guaranteed issue policies offered by Blue Cross. The premium for the least expensive seemed affordable (under \$300 per month for a couple) but the policy did not cover physician care or prescriptions. Sylvia could not afford both the premium and out-of-pocket costs for their care, so did not buy the policy. Instead she applied for charitable assistance from the company that makes her insulin. A follow up call to Sylvia two months later was answered by her daughter, Cindy. She said her mother had fallen ill and was in the hospital. She would recover, but Cindy wondered how her parents were going to pay the bills.

Henry (59) of Texas

Henry had diabetes and was on the brink of kidney failure. In July 2003, he was laid off from a job he had worked for twenty years. Unable to buy an individual policy, his only available option was to accept COBRA. Henry had enough savings to take care of rent, food, and other basic household needs, but the cost of COBRA was beyond his budget. His children agreed to contribute what they could at the outset, but, unwilling to burden them, Henry sold his home and moved in with an elderly uncle to free up funds to pay for COBRA coverage.

* COBRA and HIPAA protections are explained and discussed later in this report.

COBRA. Once informed of this option, 31 were able to elect COBRA coverage. Among those who did, many required help from family members to pay premiums.

HIPAA – Because COBRA offers only temporary continuation coverage, people with diabetes may need help buying individual health insurance once COBRA ends. Another federal law known as HIPAA requires non-group coverage to be offered to eligible individuals (usually, those who have exhausted COBRA coverage.) However, there is no limit on what insurers can charge under HIPAA. Some states regulate HIPAA premiums, but in those that do not, the cost can be prohibitive. HIPAA also does little to regulate the content of coverage, leaving the door open to insurers to offer bare-bones policies. In addition, HIPAA notice requirements are weak, making it hard for people to know about this protection. During the project 87 callers exhausted COBRA and became HIPAA eligible. Eleven successfully obtained HIPAA coverage.

High-risk pools – Thirty-two states have established programs called high-risk pools to offer individual health insurance to people who are turned down by private insurers. High-risk pools also offer HIPAA coverage in some states. Although most pools are more than 10 years old public awareness of them is low. A random survey of people with diabetes found that 73 percent living in high risk pool states had never heard of their state’s program. Tight eligibility rules and application red tape deterred some callers who learned about high-risk pools and sought help there. Because all high-risk pools surcharge premiums, most callers found coverage unaffordable. Pre-existing condition exclusions (which most high-risk pools impose on at least some applicants) deterred others, as did other coverage adequacy problems, such as high-cost sharing or benefit caps. During the project 344

Nevole (52) of Florida

Nevole lost coverage when he was laid off in 2001. He elected COBRA, using savings to pay the premiums. When COBRA expired, Nevole’s only option was a HIPAA policy offered by his former group and COBRA insurer. The HIPAA policy was subject to rating limits, but, at \$602 per month, was still about twice what he had paid for COBRA and pharmacy coverage was limited. With no other options, Nevole bought the HIPAA policy. After one year the premium increased to \$811 per month. Nevole renewed the policy and kept it another six months. By then he had almost exhausted his savings (more than \$35,000) on premiums and medical bills, so he dropped the policy. Nevole’s doctor prescribed 4 medications each month in addition to insulin, but Nevole decided to only fill those he could afford to buy. In addition, his doctor advised him to test his blood sugar 3 times per day, but Nevole could only afford to test once daily - test strips for his meter cost \$90 for a box of 100. Out of funds, with blood sugar out of control, and too sick to work, Nevole called the American Diabetes Association back in search of charitable assistance.

Walter (45) of Kentucky

Walter (45) and his wife live in Kentucky. He works full time for a Baptist church that cannot afford to provide health benefits to its employees. Walter makes less than \$25,000 annually. He had his wife have been uninsured for years and Walter has trouble affording his diabetes medication and test strips. Kentucky Access, the state high-risk pool, offered several plan options, the least expensive of which would cost Walter \$256 per month for single coverage alone. He considered this option; however, Kentucky Access excludes pre-existing conditions for one year, so in addition to the premium Walter would be required to pay out of pocket for virtually all of his health care for 12 months. Walter found this prohibitively expensive and decided not to enroll.

callers lived in high-risk pool states and were either uninsured or about to lose coverage. Only seven were able to successfully obtain high-risk pool coverage.

Medicaid and Medicare – In some circumstances, government programs offer safety net coverage for people who cannot obtain private health insurance.

Medicaid is the safety net program for some of the poor and near poor. Federal law restricts Medicaid eligibility to only certain categories of people – children, pregnant women, parents of dependent children, the elderly and the disabled. Adults who are not parents, pregnant, elderly, or disabled are not eligible no matter how poor. States administer Medicaid in partnership with the federal

government, share in its financing, and have substantial flexibility to determine covered benefits and income eligibility standards above federal minimum rules. To control program costs, many states have cut Medicaid eligibility and covered benefits, limiting the protection this safety net offers. Some callers were ineligible or intermittently eligible for Medicaid while others had difficulty accessing care in the face of state cutbacks. During the project, 109 callers had problems involving the availability, affordability, or adequacy of coverage through Medicaid.

Medicare is a federal program providing universal health coverage to the elderly. In addition, people under age 65 can qualify for Medicare if they are disabled and receiving Social Security disability income benefits. However, most applicants for disability benefits are not successful; those who do receive benefits must then wait 24 months before Medicare coverage begins. Some callers had problems obtaining a disability determination while others who were designated as disabled were uninsured during the Medicare waiting period. For the few callers with Medicare, the monthly premium and lack of prescription drug benefit posed affordability and adequacy problems. During the project, 33 callers had problems involving availability, affordability, or adequacy of Medicare coverage.

Alice (61) of Texas

Alice is a widow disabled by diabetes and other severe health problems. She is covered under the Texas Medicaid program. Texas limits Medicaid pharmaceutical coverage to only three prescriptions per month – fewer than Alice’s doctor has ordered – and does not cover test strips at all. Alice can’t afford to buy medicine and test strips are not covered by Medicaid.

Beth (55) of Kansas

Beth is disabled and covered by Medicare and her prescription drug expenses exceed \$1,500 per month. Her husband works but his job does not offer health benefits. Beth recently began purchasing her drugs from an on-line pharmacy in Canada, which reduced her cost to \$900 every three months, but even this amount is a strain on the family budget. When she called, Beth’s husband had just applied for a job with the federal government. Beth hoped he would get the job because the health benefits were excellent. Meanwhile, she sought help finding affordable medications.

Problems of the Insured

People with health insurance that was not about to change had other problems involving coverage adequacy and affordability.

Under-insured - Most often problems of the insured related to the fact that their insurance did not adequately cover diabetes care, hindering access to treatment and driving some into medical debt. Forty-six states have passed laws mandating coverage for diabetes care. Several studies have found diabetes mandates do not add substantially to the cost of health insurance and are cost effective because they prevent the onset of more expensive complications. Even so, some insured callers lived in states that do not mandate diabetes coverage. Others were in health plans exempt from state regulation. Still others had policies that cover diabetes care, but high cost sharing rendered coverage inadequate.

Margaret (55) of Kansas

Margaret takes multiple medications daily to treat her diabetes and associated complications. She has coverage under her job-based health plan, but the prescription co-pays constitute a relentless expense and the couple has trouble keeping up. Margaret says she has already “maxed out” two credit cards on prescription co-pays.

Unaffordable premiums - In addition to adequacy problems, some insured callers faced affordability problems – paying premiums was difficult, sometimes requiring great sacrifice. Cuts in employer premium contributions often precipitated these problems for insured callers. Others worked for small businesses whose group premiums had been surcharged because a member of the group had diabetes. Most problems of insured callers could not be resolved. Public and private assistance programs tend to focus on the uninsured. When problems were resolved, it was usually because the person was able to change health plans.

Patty (23) of Illinois

Patty worked for a small business. She and one other employee had family coverage under her job-based plan. The premium for the two families was more than \$3,500 per month - more than her employer could continue to afford. When Patty called, the employer was looking for cheaper options in order to continue offering health benefits.

Public policy implications

These stories demonstrate that health insurance can fail when people need it most, with devastating consequences. They also provide details to help understand more specifically the nature of health insurance problems and how they might be addressed. A common theme is the need for health insurance that is simultaneously available, affordable and adequate. When health insurance fell short on one or more of these requirements, people were hurt. Given that, several observations can be made of the cases studied during this project.

1. Losing coverage was easy; regaining it was hard. People studied lost health insurance for the same reasons others do. A job change, birthday, graduation, or move automatically disrupted coverage, although illness contributed to coverage loss for some people with diabetes. Once lost, coverage was not always restored so automatically. People with diabetes encountered coverage denials, premium surcharges, and pre-existing condition exclusions. These barriers are intended to discourage adverse selection –

waiting to buy insurance until one gets sick – but they also prevented people with diabetes from remaining covered through transitions. People with chronic health conditions are disadvantaged in a coverage system that operates this way.

2. “Safe harbors” do not guarantee coverage availability, affordability and adequacy. To make it easier for people with health problems to get and keep health insurance, policymakers have created various insurance reforms, or “safe harbors,” to guarantee the availability of coverage. Most people were eligible for one or more of these safe harbors – guaranteed issue individual insurance, COBRA, HIPAA, high-risk pools – but were not helped because coverage was not simultaneously available, affordable, and adequate. Availability barriers arose when restrictive eligibility rules made people unable to qualify for coverage. The sheer complexity of understanding and navigating laws and programs, as well as simple lack of public awareness also constituted availability barriers. Once people learned about and were guided to insurance that was available, few could enroll because it was not affordable (e.g., it was not subsidized or premiums were surcharged) or did not cover needed care (due to benefit limits, high cost sharing, or pre-existing condition exclusion periods.)

3. Existing reforms could be strengthened. Hundreds of people in this study could have been helped if existing laws and coverage options were strengthened to promote availability, affordability, and adequacy of coverage.

- Coverage loss resulting from insurance transitions could be reduced by the adoption of more coverage guarantees, especially through job-based coverage, which tends to be comprehensive and heavily subsidized. For example, employer based coverage could be expanded by requiring more employers to offer health benefits, to offer dependent coverage, or to extend dependent coverage to their workers’ sons and daughters until the age of 25 or 30.
- Individual health insurance could be offered on a guaranteed issue basis, subject to community rating and comprehensive benefit standards.
- COBRA premiums could be subsidized, eligibility for COBRA expanded to small employer groups, and the duration of COBRA coverage could be extended.
- HIPAA policies could be subject to minimum benefit standards and community rating with premiums subsidized, and HIPAA notice rules could be strengthened.
- High-risk pools could expand eligibility, simplify application requirements, and conduct more aggressive outreach and marketing. Premium surcharges could be reduced and subsidies added. Covered benefits could be enhanced, cost sharing lowered, and pre-existing condition exclusions waived.

Changes like these have been opposed on the grounds that they increase government mandates, invite adverse selection, or are costly. However, in the absence of such changes, cracks in the health coverage system will persist for people with diabetes and other serious or chronic health conditions. Health insurance must be strengthened or new arrangements adopted to guarantee coverage availability, affordability, and adequacy.

4. Health insurance must be about health. A critical test of health insurance must be how it protects people who are sick. The experiences of people in these stories provide a

standard against which policy proposals can and should be measured. Availability, affordability, and adequacy of coverage must be pursued simultaneously; problems will persist as long as one is traded for another. Strengthening the health coverage system to accomplish these goals will address the needs of people in this report. And it will protect others who are healthy today but may find themselves sick and in similar circumstances in the future.

CHAPTER 1. INTRODUCTION

This report reviews lessons that can be learned about the U.S. system of health coverage from people with diabetes who had health insurance problems. For 14 months, researchers at Georgetown University and health insurance specialists at the American Diabetes Association took calls from 851 people who contacted the Association's national call center (1-800-DIABETES) because they had health insurance problems. Calls were accepted from people who were younger than age 65 and who were either uninsured, transitionally insured in coverage that was about to end, or insured with other problems. The project¹ focused on private health insurance because that is how most non-elderly Americans obtain coverage, although some problems related to public coverage were also observed. Information about people and their circumstances was recorded in a database. Callers were also asked whether they would be willing to share their stories, and two-thirds said yes. Some of their stories are featured in this report.

Case study data cannot be generalized to estimate the prevalence of health insurance problems or evaluate the effectiveness of policy interventions for the general population. However case studies are useful for spotlighting specific shortcomings in the health care system. Just as automobile safety experts study data from car crashes for clues about how to make the roads safer, examining the health insurance problems of people with diabetes yields important clues about how to make coverage work better when it is needed most. Because the purpose of health insurance is to protect people in case of illness, it is important to study health insurance from this perspective.

Background on diabetes

“Diabetes” refers to several diseases in which the body does not produce or properly use insulin, a hormone needed to convert food, such as sugar and starches, into energy. An estimated 1 million Americans have type 1 diabetes, which results from the body's inability to produce insulin.² Almost 17 million Americans have type 2 diabetes, a condition in which the body fails to properly use insulin and/or does not produce enough insulin. Poor diet, lack of exercise, and obesity are linked to type 2 diabetes. Public health experts warn of a diabetes epidemic in the U.S. Prevalence is increasing with one million new cases diagnosed each year.³

Because increased blood sugar levels damage blood vessels and nerve endings, diabetes often leads to serious health complications. People with diabetes are two to four times more likely to have heart disease or a stroke; cardiovascular disease is the leading cause of death for people with diabetes. Diabetes is the leading cause of new cases of blindness, end stage renal disease, and non-traumatic lower limb amputations. In most cases, diabetes-related complications are preventable. Studies show that by keeping blood glucose levels at normal or close-to-normal ranges, individuals can help to reduce the onset or progression of complications.⁴ The progression of diabetes therefore depends heavily on individuals' access to care and their ability to manage the disease.

Evidence suggests diabetes is not managed well on a population basis, despite the availability of state-of-the-art diabetes care and management to many in the U.S. In

2002, per capita medical expenditures for people with diabetes were \$13,243, compared to \$2,560 for people without diabetes. One in ten U.S. health care dollars is spent directly on diabetes care, but taking complications into account, one in five health care dollars in the U.S. is spent on people with diabetes.⁵

Routine costs of diabetes care – Without health insurance, the routine out-of-pocket cost of managing diabetes can be hundreds of dollars per month. (See Appendix.) Regular physician checkups are recommended to monitor blood glucose levels, blood pressure, cholesterol levels, kidney function, vision, and extremities and to administer flu vaccines and other preventive care. In addition, substantial self management costs arise from the equipment, supplies, medicine, and insulin needed to maintain proper blood glucose levels on a daily basis. People with diabetes should test their blood glucose level two to six times per day or more, depending on their circumstances. This requires a blood glucose monitor and test strips. Some 30 brands of monitors are sold over the counter, ranging in price from \$20 to \$90, although manufacturers will often provide monitors free of charge. Each monitor requires its own proprietary brand of test strips and one new strip is used for each test. A box of 50 can cost \$35 to \$50, making strips by far the most expensive component of testing. However, manufacturers do not have compassionate use programs to give free test strips to low income or uninsured patients.

Many people with diabetes use insulin to control their blood glucose levels. The price of a vial of insulin can range from \$30 to \$70, and no generic brands of insulin are manufactured in the U.S. Syringes and needles, or an insulin pump with related pump supplies, are necessary to deliver insulin. Oral medications are also prescribed, instead of or in addition to insulin, to control blood glucose levels in some patients.

Casework overview

Between March 27, 2003 and June 27, 2004, 851 cases were opened for people who called the American Diabetes Association's National Call Center with health insurance problems. The typical caller was a middle aged woman, not working and not married, with modest income and uninsured. However, demographic characteristics, employment, income, and insurance status varied among callers. Health insurance experts at the American Diabetes Association and Georgetown University explored each caller's options for resolving health insurance problems, including consumer protections offered under federal and state law, and kept records on the outcomes of each case.

Overall, problems were resolved only 20 percent of the time. In another 60 percent of cases, people were eligible for help under some law or program, but the help was insufficient to resolve the problem. Finally, in 20 percent of cases, no help was available.

Health insurance problems studied fell into two main categories: those involving health insurance transitions – people who had lost or were about to lose health coverage – and those involving coverage that was not about to change – people who were under-insured or struggling to pay their premiums.

CHAPTER 2. COVERAGE LOSS

On average, about two million Americans lose their health insurance each month. Health insurance transitions are often triggered by an ordinary life event, such as a job change or layoff, a move, divorce, graduation from college, or a change in income or health status. Some people transition directly from one health coverage to the next, while others are uninsured for at least a month or longer. Roughly half of those who lose job-based coverage and two-thirds of those who lose Medicaid are uninsured for at least one month.⁶ Research also shows that people in poor health are twice as likely to encounter a lengthy spell without health insurance compared to people in good health.⁷

About 80% of problems observed during this project arose because of health insurance transitions. Most people were uninsured, having already lost prior coverage. Others anticipated transitions that would disrupt coverage.

Many factors can trigger a loss of health insurance. In all, three-fourths of uninsured callers became uninsured as a result of an availability problem – that is, they lost eligibility for their former health plan or program. Less often, people lost coverage due to an affordability problem – they dropped coverage following an increase in premiums and/or a decline in income. Some uninsured callers surrendered coverage because it was inadequate, while a small number appear to have lost coverage due to an act of noncompliance on the part of their health insurer or employer (e.g., coverage that should have been renewed was cancelled or rescinded.) Fifty-seven percent of uninsured callers had been without coverage for less than one year when they first contacted the Association. Twenty-nine percent had been uninsured for two years or longer.

Availability

Most often, a commonplace life event – a loss or change of jobs, an illness, a birthday, or a move – ended callers' eligibility for health coverage.

Losing a job – 114 callers lost their health insurance coverage when they or their spouses were laid off from work. Job loss is the leading reason why people in the U.S. lose health insurance. According to one survey, 65% of non-elderly adults who were uninsured at some point during the past 12-months had job-based coverage before becoming uninsured.⁸ More than one-half of them (52%) lost their coverage because they lost their jobs. Most people (53%) who lose employer-sponsored health insurance end up uninsured for at least a while.⁹

Employer bankruptcy – Over the span of this project, an uncertain economy disrupted coverage for many Americans. Recent high-profile bankruptcies include Enron, WorldCom, Bethlehem Steel, and Pillowtex, although small businesses are especially vulnerable to failure in tight economies. Eleven callers lost health insurance when their employer (or their own small business) went bankrupt.

Ralph (47), his wife, and three children live in Texas. They lost health insurance three years ago when their family-owned business failed. Ralph did the best he could to manage his type 2 diabetes, but paying for test strips and medication was a struggle. Within a few months, his condition worsened and Ralph was rushed to the emergency room with severe gastric problems. He was hospitalized for five days. Ralph now has liver problems and neuropathy (numbness) in his feet. He is negotiating with the hospital to forgive some or all of his bill.

Employer stops offering health benefits - Another nine callers became uninsured when their employers dropped health benefits to save money.

Sue (20) briefly worked for a small business in Indiana that offered health benefits. However, only a few months after she was hired, the firm was purchased by another company and the new owner declined to provide health insurance. Sue's grandmother is helping her pay for her medication and other health care until she can find new coverage.

Getting sick – People with chronic conditions face an additional threat to health security. If they become too sick to work, they can lose their health insurance. Thirty-two callers lost health coverage when they, or their spouse, became too sick to continue working.

Minnie (50) lives in South Carolina and last had health insurance two years ago through her job, but got so sick she had to quit. She has had two strokes and other complications related to her diabetes. Minnie now needs food stamps and help from her children to make ends meet. Her doctor gives her free samples of medicine because she can't afford to pay for it on her own.

Illness dislodged health coverage for ten other callers who quit their jobs - and their job-based health insurance - to care for a relative who was sick.

Vivianne (42) of Illinois left her job with health benefits last year to care for her disabled mother and sister. The state of Illinois pays her \$1,000 per month to care for her mom and sister, but no health insurance is included. With rent at \$500 per month, Vivianne doesn't have much left to buy other things. She pays out of pocket for her diabetes medications and supplies when she can.

Loss of dependent status for young adults – Young adults, who comprise the largest age cohort of uninsured, often lose coverage on their 19th birthday or, if they go to college, a few years later at graduation. Almost 40 percent of college graduates and half of high school graduates who don't go on to college will experience a spell of uninsurance following graduation.¹⁰ For 23 young adults who called the American Diabetes Association, leaving college meant they no longer qualified for dependent coverage under their parents' health insurance.

Nina (19) in Michigan was enrolled in college but took a break from classes when she got too sick to manage a full time course load. When she lost her status as

full time student, she also lost dependent status under her parent's health insurance.

Move – Twenty callers lost health insurance when they moved to another state. Changing states not only disrupted coverage, it usually changed the rules governing their eligibility to find new coverage.

Karl (50) and his wife were covered under his job-based health plan in Wisconsin until he was laid off in February 2003. They elected COBRA coverage while Karl looked for a new job. His former employer even paid the premium as part of his severance agreement. By summer, he'd had no luck finding work, so the couple moved to Ohio in hopes of finding a job there. The COBRA plan didn't cover care outside of Wisconsin, however, so they dropped the policy. Karl applied for individual coverage in Ohio, but was turned down due to his diabetes.

Change in marital status - Divorce and widowhood are other life events that separate people, usually women, from their health insurance. Five callers lost coverage as a result of divorce or legal separation. In one case, a divorced mother and her 12-year old daughter with diabetes lost health insurance when the girl's father defied a court order and disenrolled them both from his job-based health plan.

Insurer leaves market – In recent years, several national insurance companies (Conseco, Mutual of Omaha, United Health Care) made business decisions to leave certain state markets or stop selling health coverage altogether. These decisions dislodged health coverage for thousands of people.

Cynthia (55) called the American Diabetes Association when her health insurance company announced it was leaving the state of Delaware. Cynthia and her husband had been covered under their individual policy for more than 12 years. Another insurer still in the market had agreed to accept applications from the people who were losing coverage, but rejected Cynthia because of her diabetes.

Fraud/non-compliance - Six uninsured callers lost coverage as a result of actions by their insurers or employers that appeared to be illegal. For example, one woman reported her insurer refused to renew her coverage after she was diagnosed with diabetes, even though federal law requires all health insurance to be guaranteed renewable. Another woman lost coverage twice, once due to fraud.

Janice (58) in Florida lost coverage the first time in 2001. Two years earlier, she had purchased an individual health insurance policy. When she was diagnosed with diabetes, however, the insurer conducted a "post claims underwriting" investigation (a commonplace and legal practice) to determine whether Janice knew or should have known she had diabetes when she applied. Based on symptoms of pre-diabetes noted in her medical record, the insurer dropped her coverage. Janice moved on, purchasing her next policy from an association that

turned out to be fraudulent. After paying premiums under that plan for one year, she was left with \$22,000 in unpaid claims.

Other less commonplace reasons – Finally, even small mistakes or unexpected events can cause people to lose health insurance.

Vicky (59) is married with two grown children and lives in Florida. She and her husband had been covered for ten years under an individual policy. In the summer of 2003, her husband became quite ill and was hospitalized for one month. Vicky was distracted and didn't always keep up with daily tasks like opening the mail. Once her husband was home, Vicky went through the mail piles and discovered a late payment/termination notice from their insurance company. Vicky and her daughter (an attorney) called the insurer multiple times to explain the unusual situation and pled to have coverage reinstated, but to no avail.

Another woman lost coverage when her husband, who had Alzheimer's Disease, noticed a bill from their health insurer in the mail, opened it, and, in a state of confusion, called to cancel the coverage. When the woman later realized her policy was no longer in force, she asked that it be reinstated, but the insurer refused.

Finally, one student's poor grades in school cost him his health insurance.

Michael (20) in Connecticut, was enrolled in college but earned grades so low he was asked to leave. He lost coverage under his dad's insurance policy once he was no longer a full time student. Unable to find other coverage, Michael is applying to pharmaceutical companies for free medications to manage his diabetes.

Affordability

Several callers dropped coverage that became too expensive for them. For example,

Belle (41), her husband, and their three children lived in Oklahoma and had health insurance through Belle's husband's job. In March of 2003, the employer decided to stop contributing to the cost of dependent coverage, then \$497 per month. Belle's family could not absorb this cost on a monthly income of \$2,300. Belle has been uninsured ever since. She's been looking for work, but has had no luck so far because jobs are scarce in their small town and Belle's health is failing. She is supposed to take Humalog (insulin) but, when she called, had not taken any for 7 weeks because she could not afford it. She also hadn't been testing her blood sugar levels because of the expense of test strips. Instead, she was simply trying to eat healthy food, though this was not entirely effective. Belle has been losing toenails, her hearing in one ear is fading, and she has difficulty breathing.

Adequacy

Three callers surrendered insurance coverage because they thought it offered insufficient protection for the premium they had to pay. For example,

Dell (25) worked full time for a company in North Carolina. His job-based health plan covered basic hospitalization and physician care, but not the test strips and supplies he needs to monitor his blood glucose levels. About a year ago, Dell's employer offered workers the option to have a pay increase if they would forego health benefits. Dell decided since his insurance wasn't covering his day-to-day diabetes care, he would take the money instead. He surrendered coverage and used the pay raise to buy testing strips and supplies.

Public policy implications

For all of these callers, losing health insurance was easy. Coverage terminated automatically following a pink slip, a late premium payment, even an "F" in school. In light of these experiences, it is not surprising that almost 40 percent of Americans under the age of 65 experience a gap in health insurance coverage at some point over a 4-year period.¹¹ Diabetes added to the reasons why many callers lost coverage when they became too sick to work. To address coverage loss problems similar to those described above, policymakers could consider several strategies:

Expand definition of "dependent" coverage. Loss of dependent coverage, especially by young adults, could be addressed by expanding the legal definition of who is eligible for dependent coverage. Federal or state law might stipulate that children may remain covered as dependents under their parents' policies until age 25 or 30. Such an approach could expand coverage options for millions of uninsured young adults. If expanded eligibility for dependent coverage adds to the cost of employer sponsored coverage, additional measures might be required to address the affordability of coverage.

Subsidize premiums for employer-sponsored coverage. Premium subsidies for people with modest incomes could have helped some callers remain in job-based coverage that was available to them. Traditional premium subsidies and tax credits have been proposed by some policymakers. Others have recommended reinsurance strategies that would help employer-sponsored plans finance high-cost claims, with savings used to reduce premiums.

Avoid strategies that make insurance more affordable by having it cover less. Bare bones coverage may be cheaper, but it can also leave people with more out-of-pocket expenses than they can manage. Recent industry and political trends seem to favor the development of high-deductible health plans or the repeal of state mandates to reduce insurance premiums for employers and individuals. However, such changes can increase burdens for people with diabetes and other expensive chronic conditions, and barriers to health care can result.

CHAPTER 3. INDIVIDUAL HEALTH INSURANCE

People who do not have access to job-based health benefits and do not qualify for public programs must buy health insurance in the individual (or non-group) market. Individual health insurance is an important source of transitional coverage. An estimated one in four adults in the U.S. tries to buy individual health insurance at some point over a three-year period,¹² while most policies purchased are held for less than two years.¹³ States regulate individual health insurance. In some, insurers are required to offer coverage to all applicants (known as “guaranteed issue”) at the same price regardless of health status (known as “community rating.”) In most states, however, individual health insurance is medically underwritten, meaning applicants can be turned down or charged more for coverage based on health status. Diabetes is commonly considered to be “uninsurable” by individual market insurers.

For almost half (395 of 851) of callers, health insurance problems in some way involved individual health insurance, but in only 15 cases did individual health insurance provide callers with a workable coverage solution. The reasons why individual health insurance did not help many callers with diabetes (and often added to their problems) had to do with the availability, affordability, and adequacy of coverage in this market.

Availability

States take very different approaches to regulation. In most states, all insurers in the individual market sell medically underwritten coverage. Hundreds of people called the American Diabetes Association having just learned they were “uninsurable” in the individual health insurance market.

Alan (23) lives in Georgia and is uninsured and unemployed. He did not have health insurance through his former employer, only a supplemental policy that paid limited cash benefits during hospitalization, so COBRA was not an option when he lost his job. Alan applied for a policy in the individual market, but was turned down because he has type 1 diabetes. Because he had no access to job-based coverage and was ineligible for Medicaid, Alan had no other health insurance options. He had problems with his vision and needed immediate medical care, so he used his income tax refund to purchase medications and testing supplies, but did not know how he would afford care after that.

Lack of access to non-group coverage can also cause job-lock, forcing people to stay in employment based coverage because they have no alternative.

Phyllis (43) and her family live in California. Her husband is self-employed, so the family gets coverage through Phyllis’s job. She would like to quit in order to spend more time with her two children. Phyllis has type 1 diabetes that is very well controlled. She has never been hospitalized or had other complications. She looked into buying individual health insurance, but was surprised to learn none

would sell her coverage because of her diabetes. The high-risk pool in her state had a waiting list at the time. Phyllis decided to continue working so that she could remain insured, but told her caseworker she felt “trapped.”

Affordability

Some states require insurers to sell coverage on a “guaranteed issue” basis, meaning that people cannot be turned down based on their health status. For some callers, guaranteed issue individual policies were available, but affordability was a problem. Affordability of individual health insurance was affected by two factors: whether insurers were allowed to surcharge premiums based on health status, and whether callers had sufficient funds to pay premiums. States vary in the rating rules they apply to individual health insurance policies. (See Appendix 3.) In many states that require guaranteed issue coverage there is no limit on what insurers can charge based on health status. People with diabetes who called the project found the premiums charged for these policies were high enough to deter access most of the time.

Chuck (22) from Virginia was laid off from a small company and lost coverage in July 2003. He was not eligible for COBRA. Soon after, Chuck found a new job, but the employer required a waiting period for health benefits; he would not be eligible for coverage until the following April. Chuck tried to buy individual coverage from Blue Cross, which sells guaranteed issue policies in Virginia but charges higher premiums to people who are sick. Chuck was offered coverage for \$900 per month – half of his paycheck, more than he could afford. With no other options, Chuck applied to pharmaceutical assistance programs in the hopes of getting free or reduced-cost insulin and medications, but he was told he earned too much money to qualify for this assistance.

People in other states had access to guaranteed issue coverage that is subject to community rating. Under community rating, premium surcharges based on health status are not allowed. Even so, the price of coverage can be substantial. In New York and New Jersey, for example, a guaranteed issue, community rated individual HMO policy typically costs \$400-\$500 per month – more than people with limited incomes can afford.¹⁴ Eighty-five percent of callers who reported being unable to afford guaranteed issue, community rated coverage had monthly incomes below \$2,000. Public subsidies for private individual health insurance are usually not available. However, financial assistance from relatives solved affordability problems for some callers.

Manny (25) was a full time student in New Jersey whose COBRA coverage was about to expire when he called the American Diabetes Association. The student health plan offered was a limited benefits policy, insufficient to meet Manny’s medical needs. Manny was told about his guaranteed issue rights in New Jersey and reviewed the plans for sale. He selected an indemnity plan for about \$600 per month. Since Manny’s father was able to help him pay most of the premium, this was a workable solution for Manny.

Adequacy

Sometimes people found individual policies that were available and affordable, but inadequate. For example, compared to the comprehensive coverage Manny bought in New Jersey, several of the guaranteed issue policies offered by Michigan Blue Cross Blue Shield in 2003 were less expensive but all of the Michigan policies had significant coverage limitations. Six “traditional” policies covered inpatient hospital care and diagnostic services, but not physician office visits or prescription drugs. Three other “PPO” options covered physician office visits, but prescription drugs and vision care – important for managing diabetes – were not covered under these plans, either.¹⁵ For several callers, coverage gaps more than offset the affordability of these policies.

Sylvia (52) of Michigan lost insurance a year ago when her husband lost his job and health benefits. They could not afford COBRA. Sylvia looked into guaranteed issue policies offered by Blue Cross. The premium for the least expensive seemed affordable (under \$300 per month for a couple) but the policy did not cover physician care or prescriptions. Sylvia could not afford both the premium and out-of-pocket costs for their care, so she did not buy the policy. Instead she applied for charitable assistance from the company that makes her insulin. A follow up call to Sylvia two months later was answered by her daughter, Cindy. She said her mother had fallen ill and was in the hospital. She would recover, but Cindy wondered how her parents were going to pay the bills.

Individual policyholders may themselves choose to reduce coverage under their policies – sometimes year after year, in order to offset renewal premium increases.

Martha (60) was self-employed, married, and living in Alabama. Her husband already qualified for Medicare. She had an individual policy she bought several years earlier, before her diabetes was diagnosed. Since her diagnosis, shopping around for a new policy was no longer an option. Each year Martha elected to increase her annual deductible in order to reduce the renewal premium increase that would otherwise apply. When she called, her monthly premium was up to \$300, the annual deductible was up to \$2,500, and her co-insurance liability was another \$1,500 per year. The combined costs were an increasing strain on Martha’s budget, though she was afraid to drop coverage so close to retirement. She had asked her doctor if he would waive some of his bills and was applying to drug manufacturer charity care programs.

Public policy implications

Individual health insurance offered 15 callers a viable coverage option, meeting their test of availability, affordability and adequacy. All bought guaranteed issue policies and all had sufficient income (or help from relatives) to afford the community rated premiums. Hundreds of other callers could not qualify for or afford individual health insurance, and this made it harder for them to remain insured, change jobs, return to school, raise their children, and run their own businesses. Weaknesses in individual insurance markets could be addressed in response to these problems.

Require coverage to be sold on a guaranteed issue, community rated basis. During the course of this project, a unique coverage opportunity was offered in Alabama. Usually all individual insurance in Alabama is medically underwritten, but in the fall of 2003, Blue Cross of Alabama voluntarily offered a three-month open season during which guaranteed issue individual coverage was sold. The open enrollment policy covered all major medical (hospital and doctor) services subject to an annual deductible of \$1,000 and full prescription drug benefits subject to a separate \$250 deductible. A 12-month pre-existing condition exclusion period applied. The monthly premium was \$145 per person (\$320 per family) regardless of age or health status. At this price, four callers still could not afford coverage, but five did elect to purchase the policy. This one-time open enrollment opportunity has not since been repeated. Others from Alabama who called after open enrollment closed were not able to obtain individual health insurance.

Five states (NY, NJ, ME, MA, and VT) require all individual health insurance to be guaranteed issue and community rated and to offer comprehensive benefits. These state laws have been criticized for raising the cost of coverage for younger healthier people. On the other hand, repeal could be problematic for people with diabetes.

Provide adequate subsidies for guaranteed issue, community rated coverage. Individual health insurance is more expensive than group coverage (per dollar of covered benefits) because the administrative cost of selling policies individually is so much higher.¹⁶ Policies sold on a guaranteed issue, community rated basis also tend to be more expensive due to “adverse selection,” that is, they are more likely to be purchased by people who have health problems than are medically underwritten policies.¹⁷ Premium subsidies are rarely offered but could have helped callers in some states buy coverage. To be effective, subsidies must also be sufficient relative to individuals’ ability to pay.

Congress has considered a proposal to cover the uninsured by providing a \$1,000 tax credit to purchase individual health insurance. Advocates argue this would foster the development of low-cost policies as insurers compete to cover tax credit recipients. For three key reasons, however, this proposal would not address the kinds of problems featured in this chapter. First, a tax credit does not address the problem of availability and would not help people with diabetes buy medically underwritten coverage. Second, a \$1,000 tax credit would provide only a modest discount for the price of guaranteed issue coverage faced by most callers. Third, this subsidy does not address, and might exacerbate, problems of coverage adequacy if policies are designed to cover less in order to be priced at or near the tax credit amount.

Create alternatives that are available, affordable, and adequate. Proposals to regulate and subsidize individual health insurance have been controversial. Alternatives to individual health insurance (such as high-risk pools and COBRA) have also been created for people who can’t access individual coverage. These alternative strategies are explored in subsequent chapters. Other alternatives are also possible. For example, some Members of Congress have proposed establishing a nationwide individual market, based on their own federal employees health benefits plan (FEHBP), where people could buy comprehensive non-group coverage on a guaranteed issue, community rated basis.

CHAPTER 4. COBRA

The Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) gives certain people the right to temporarily remain covered under job-based health insurance following a qualifying event, such as a job layoff, retirement, divorce, or other loss of dependent status. COBRA offers lifeline protection to people with diabetes who face loss of job-based coverage and can't buy individual health insurance. However, only about one in five persons nationwide who are eligible for COBRA coverage elect it.¹⁸ Of 377 callers who had lost or were about to lose job-based health benefits and who had not yet elected COBRA, 31 were able to do so. Others were deterred by limits in the protection COBRA offers.

Affordability

The cost of COBRA can be prohibitive for people who have lost their jobs. People electing COBRA must pay the entire premium – employer and employee share – plus a two percent administrative fee. Based on data for average employer-based health plan costs, a typical COBRA premium would be about \$280 per month for single coverage and \$750 per month for family coverage.¹⁹ By contrast, almost half of callers who were eligible for COBRA and who provided income data had incomes below \$1,000 per month, while another 33 percent had incomes between \$1,000 and \$2,000 per month. Inability to afford COBRA was the most frequently observed problem among all callers.

Emma (48) of Michigan had health insurance through her husband's job. When he was laid off last year, however, their most reasonably priced option was to elect COBRA. Unfortunately, the COBRA premium of \$700 per month was beyond what they could afford without a salary. Uninsured, Emma sought what care she could from community based programs until she and her husband could find new job-based health coverage.

Some people who did elect COBRA received help from relatives to pay the premium. Occasionally, callers opted for COBRA, but at great financial and personal burden.

Henry (59) in Texas had diabetes and was on the brink of kidney failure. In July 2003, he was laid off from a job he had worked for twenty years. Unable to buy an individual policy, his only option was to accept COBRA. Henry had enough money saved to take care of rent, food, and other basic household needs, but the cost of COBRA was beyond his budget. His children agreed to contribute what they could at the outset, but, unwilling to burden them, Henry sold his home and moved in with an elderly uncle to free up funds to pay for COBRA coverage.

In a few cases, the financial burden of COBRA became overwhelming, and callers were forced to drop their coverage.

Jim (64) in Michigan retired a few years ago when he became too sick to work. He elected COBRA, which he could barely afford. After one year, his premium

increased to \$400 per month, which Jim simply could not pay, so he dropped coverage altogether and has been uninsured for two years. Jim's medications now cost over \$300 per month, while his disability check is only \$887. He has to borrow money from friends and family to make ends meet.

Availability

COBRA and state continuation coverage are not available to everyone who loses group health coverage. Several different types of barriers to COBRA coverage were observed.

Discontinuation of employer-sponsored health plan – COBRA and state continuation protections are contingent on the continued existence of the employer sponsored group health insurance plan. Once an employer ceases to offer health benefits, as generally occurs following bankruptcy, continuation rights also cease. For example:

Reed (48) of Texas lost his job and health benefits when his employer went out of business. Because the health plan was terminated, Reed had no COBRA continuation protection. He found a new job with health coverage within four months. However, while he was uninsured Reed developed a foot ulcer and subsequent infection that required hospitalization and intravenous antibiotics. The cost of this care was approximately \$10,000, a medical debt Reed must pay.

Firm size – Some people who lose job-based coverage are not eligible for COBRA because they worked for a company with fewer than 20 employees. While most states require similar continuation protections for policies purchased by firms with fewer than 20 workers, 12 states and the District of Columbia do not. This led to problems for several callers including Chuck (22) from Virginia, whose story appeared in Chapter 3. Laid off from a small company, ineligible for continuation coverage, and unable to find affordable individual health insurance, Chuck was uninsured for eight months until he found a new job with health benefits and had difficulty affording insulin during that time.

Notice – People leaving job-based health plans must be notified of their COBRA rights. However, many callers could not remember whether they had received notice of the COBRA option. More than a few vaguely recalled hearing about COBRA, but needed help to understand the rules and navigate the process. Occasionally, callers were given inaccurate information about their continuation rights by their job-based health plan.

Neal, a 22 year old college student from Georgia, called as he was about to lose dependent status under TRICARE – the health plan for military dependents. Although TRICARE offers continuation protection similar to COBRA, Neal said he was advised by multiple TRICARE representatives there was no such option for him. This worried him because he had been rejected by several carriers in the individual market. After Neal's caseworker verified he did have continuation rights, Neal tried once more and this time succeeded. He elected TRICARE continuation coverage for 36 months.

COBRA notice is more complicated when the qualifying event involves a change in dependent status. In these cases, an enrollee must notify the plan about a qualifying event before the plan administrator is required to provide notice of COBRA rights. People who don't understand this may never receive notice of their COBRA rights.

When Jessica (22) from California aged off her father's group health insurance plan, she had never heard of COBRA and so did not think to ask about it. Because she did not notify her father's plan of her change in status, she never received COBRA notice. After dependent coverage stopped Jessica was uninsured for 18 months. Eventually, she went to college and enrolled in student health insurance. However, because she had been previously uninsured, a pre-existing condition exclusion period applied and she had to wait six more months for the plan to cover her diabetes care.

Notice can be even more complicated for state continuation coverage. ERISA (a federal law regulating employee benefits) preempts states from imposing notice requirements on employers. For one caller, this resulted in a missed opportunity to remain insured.

Jane (43) once worked for a small employer in Maryland, but lost her job and health benefits at the end of 2002. Several months later, Jane talked to a lawyer who advised she could have elected to continue enrollment in her employer's group health insurance plan for 18 months. By this time, however, the election period for state continuation coverage had expired. Jane's caseworker called the Maryland insurance department on her behalf, but was told the state cannot require employers to give notice about state continuation rights; instead, it is up to the employees to notify the insurance company of their qualifying event.

Continuation coverage is temporary – The duration of COBRA continuation coverage can be up to 18 to 36 months, depending on one's qualifying event. However, this temporary assistance does not always offer a sufficient bridge to the next available health coverage. Of our callers whose COBRA coverage expired, two in three ended up uninsured.

Public policy implications

COBRA helped dozens of callers who lost job-based coverage and could have helped hundreds more if protections were more complete. Changes policymakers could consider strengthening COBRA protections include:

Subsidize premiums. Inability to afford COBRA premiums was the leading reason why callers eligible for COBRA coverage did not take it. Presently, only one state program and one federal program – both limited in scope – subsidize COBRA premiums. The Massachusetts Medical Security Plan pays 75% of COBRA premiums for unemployed residents. The subsidy is capped at \$217 per month for an individual, \$523 per month for family coverage. Income eligibility requirements also apply. Approximately 25,000 Massachusetts residents participated in this program in January 2003. Following budget cuts, however, only 11,000 participated in January 2004.²⁰ At the federal level, a health

coverage tax credit (HCTC) will pay 65 percent of premiums for COBRA and some other types of health coverage for certain trade-dislocated workers and early retirees. In the first year this credit was offered, more than half who claimed it used it to subsidize COBRA premiums. However, less than 10 percent of those estimated eligible for the credit used it.²¹ More generous subsidies would likely help more unemployed workers elect COBRA and could have helped hundreds of callers with diabetes.

Expand continuation rights. Some callers who lost job-based coverage were not eligible for continuation coverage because they had worked for a very small business, or because their former employer stopped offering health benefits altogether. For dozens more, COBRA worked, but then ran out before they could find other coverage. Several state continuation laws try to bridge these gaps. In California, Illinois, and New Hampshire, older displaced workers and spouses are eligible for continuation coverage until age 65, when Medicare begins. In New Mexico, all enrollees leaving small group coverage obtained through the state's small employer purchasing pool are eligible for lifetime continuation coverage.

Provide consumer assistance and education. A key task in helping hundreds of people under this project was to inform them about and help them navigate their health insurance rights and protections. Fourteen states have health insurance ombudsman programs, while Medicare funds the Senior Health Insurance Counseling Program (SHIP) to assist the elderly with their private health insurance questions in every state. Federal legislation has been proposed to provide health insurance ombudsman services for people under 65 in every state. Such assistance could help more people get and keep insurance coverage.

CHAPTER 5. HIPAA

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) guarantees protections to certain people who lose job-based coverage, elect and exhaust COBRA, and then need to buy individual health insurance. HIPAA requires individual market insurers to offer coverage to “HIPAA-eligible individuals” on a guaranteed issue basis with no pre-existing condition exclusion periods. Federal law does not limit premiums for HIPAA coverage, although some states do so to varying degrees. Among 87 HIPAA-eligible callers, 11 were able to buy HIPAA non-group coverage. Limits to the availability, affordability and adequacy of HIPAA coverage deterred others.

Availability

Lack of HIPAA notice, the short time frame for claiming HIPAA coverage, and insurer compliance problems made it difficult for callers to find and enroll in HIPAA policies.

Notice – Federal law does not provide for consumer notice about HIPAA rights to access individual health coverage. Insurers and employers are required to give consumers certificates of creditable coverage – documents that provide important proof of prior coverage and can be used to establish HIPAA eligibility. However, these certificates are not required to inform consumers about their HIPAA individual coverage rights. Consumers who do not understand HIPAA individual market protections and eligibility requirements may not successfully navigate insurance transitions.

Jacob (23) of Michigan was laid off and lost job-based insurance. He immediately elected COBRA and struggled to pay the premiums. After 17 months, with funds especially low, he decided to drop the COBRA coverage, which was going to end anyway. Jacob didn’t know about HIPAA or the need to exhaust COBRA in order to become HIPAA-eligible. Several months later, when Jacob again had money to buy health insurance, his only option was a guaranteed issue individual policy, but because he had a break in coverage, it imposed a pre-existing exclusion period for his diabetes. If Jacob had maintained the COBRA one more month, he would have been offered a HIPAA policy with no pre-existing exclusion period.

Federal rules do require individual market insurers to “exercise reasonable diligence” in determining whether an applicant for coverage is HIPAA eligible and, if so, to issue a HIPAA policy.²² In most states, however, individual market insurers do not provide HIPAA coverage; high-risk pools do. Federal law does not require insurance companies to guide applicants to other HIPAA coverage. This gap in notice requirements cost several callers an important opportunity to remain covered. This was the case for Reed, introduced in Chapter 4, who is struggling to pay a \$10,000 hospital bill he incurred while uninsured.

HIPAA eligibility is short-lived - HIPAA protections last up to 63 days. After that, a person’s prior coverage is no longer recognized and HIPAA eligibility ends. Congress

established this two-month window to allow consumers a reasonable time to secure HIPAA coverage without inviting adverse selection – i.e., incentive for consumers to wait until getting sick to obtain guaranteed issue coverage. However, people trying in good faith to find new coverage can sometimes encounter difficulty and delays.

Erek (35), a resident of Virginia, exhausted COBRA at the end of May 2003, and immediately started looking for health insurance. Erek was a member of a trade association for the self employed and thought he could buy health insurance that was offered as a benefit to members, but he was mistaken. Just as his HIPAA-election period drew to a close, the trade association informed him his insurance application was denied because of his diabetes. Erek then called the American Diabetes Association and learned about HIPAA. By this time, however, the 63-day period had passed and Erek was no longer HIPAA eligible.

Insurer noncompliance – Finally, insurer compliance is sometimes a problem, creating additional access barriers to HIPAA coverage. For example, an investigation by the Maryland Insurance Administration found high non-compliance rates with HIPAA's individual guaranteed availability requirements, especially by companies with small market share.²³ In addition, market conduct examinations by the federal government have found instances of carrier non-compliance.²⁴ One caller with diabetes had problems when an insurer failed to offer him a HIPAA policy as required.

Rick (54) in California lost his job, elected COBRA, and had exhausted it by the time he called the American Diabetes Association. His COBRA premium had been \$284 per month and, as coverage neared an end, he asked the insurance company, which also sells non-group coverage in California, whether he could buy an individual policy, but was turned down because he had diabetes. Rick applied to other individual market carriers and was turned down again. Rick called the American Diabetes Association and learned about his HIPAA rights. He then called the first insurer back to see if they would rectify their oversight and offer him coverage. However, when he learned the HIPAA policy would cost much more than COBRA, he decided not to pursue the matter.

Affordability

In 11 states, insurers are not limited in what they can charge for HIPAA policies. Five states require community rating for HIPAA policies with no adjustments allowed for health status or age. Community rated HIPAA policies can cost \$400 to \$500 per month, although premiums vary. Five other states require community rating but allow age adjustments which substantially increase the cost of coverage for older consumers. Seven states impose rating bands on HIPAA policies, permitting premium surcharges within limits, as well as age adjustments. Even with these limits, the cost of HIPAA coverage can be very high.

Nevole (52) of Florida lost coverage when he was laid off in 2001. He elected COBRA, using savings to pay the premiums. When that expired, Nevole's only option was a HIPAA policy offered by his former group and COBRA insurer.

The HIPAA policy was subject to rating limits, but, at \$602 per month, was still about twice what he had paid for COBRA and pharmacy coverage was limited. With no other individual insurance options, Nevole bought the HIPAA policy. After one year, the premium increased to \$811 per month. Nevole renewed the policy and kept it another six months. By then he had almost exhausted his savings (more than \$35,000) on premiums and medical bills, so he dropped the policy. Nevole's doctor prescribed 4 medications each month in addition to insulin, but Nevole decided to only fill those he could afford to buy. In addition, his doctor advised him to test his blood sugar 3x day, but Nevole could only afford to test once daily - test strips for his meter cost \$90 for a box of 100. Out of funds, with blood sugar out of control, and too sick to work, Nevole called the American Diabetes Association back in search of charitable assistance.

Adequacy

Federal law requires little in the way of benefit standards for HIPAA policies, and insurers in many states can and do offer very bare-bones coverage. For example,

Gerald (59) decided to semi-retire in Florida. His part-time job helped pay for COBRA coverage, and when COBRA ran out, he was offered a HIPAA policy. However, unlike his COBRA coverage, this policy did not cover outpatient care or prescriptions. Gerald bought the policy initially, but could not long afford the out-of-pocket costs for care. He went back to work full time in order to become eligible again for job-based coverage with comprehensive benefits.

Public policy implications

Loss of job-based coverage can pose a serious challenge for people with diabetes. Individual market coverage is hard to obtain in most states and COBRA does not always offer a sufficient bridge to the next job-based health plan. For these reasons, HIPAA individual coverage protections are important. However, many callers did not know about their HIPAA rights and, once informed, had difficulty pursuing them. Enhancing the availability, affordability, and adequacy of guaranteed coverage under HIPAA could help more people who lose job-based health insurance.

Strengthen notice rules. HIPAA notice requirements could be strengthened and vigorously enforced. A requirement that employer health plans and COBRA plan administrators notify people about their future HIPAA rights and coverage options could increase consumers' awareness of this law and help them navigate coverage transitions. In addition, all certificates of creditable coverage could be required to include a general explanation of HIPAA protections. The U.S. General Accounting Office recommended this change to Congress in 1999.²⁵ Because certificates are issued each time consumers leave a health insurance policy, they could serve as an ongoing reminder of why coverage continuity matters and how HIPAA can help. Insurers and employers could also be periodically audited by state and federal health insurance regulators and the U.S. Department of Labor to ensure compliance with notice requirements. In addition,

publicly funded health insurance ombudsman programs could be established to help people understand and pursue their coverage rights.

Limit and subsidize premiums for HIPAA policies. Insurers could be prohibited from charging HIPAA-eligible people more because they are sick. Premium subsidies could also be applied to make coverage more affordable. The federal income tax credit for trade dislocated workers (HCTC) that is available for COBRA can also be applied to HIPAA coverage in some states. However, the tax credit provides only a 65 percent subsidy. Laid off workers may require more comprehensive subsidies. In addition, when HIPAA premiums are substantially surcharged for people with diabetes, as they are currently in many states, it is even more likely that premiums, albeit partially subsidized, will be unaffordable.

Offer new sources of HIPAA coverage. Past proposals to limit the cost of HIPAA policies have been debated and rejected out of concern for the individual market's capacity to offer guaranteed issue coverage and still remain profitable. Accordingly, Congress might consider making HIPAA coverage available through other mechanisms, such as the FEHBP. The availability of such a national market could provide a larger pool of individuals over whom to spread risk. Additional subsidies might be required to offset adverse selection. In addition to offering a broader risk pool, most FEHBP plans offer comprehensive coverage and all plans are community rated. People who participate in the FEHBP are provided comparative information on all plans to help make coverage choices and consumers can turn to a single agency to help answer questions and resolve problems.

CHAPTER 6. STATE HIGH RISK POOLS

Thirty-two states have created high-risk pools to guarantee availability of coverage for “uninsurable” residents who need individual health insurance.²⁶ In 2003, all state high-risk pool programs combined provided health insurance to 177,038 people,²⁷ or less than two percent of individual market participants. By contrast, according to one insurance industry survey, approximately 25 percent of applicants for individual health insurance are either declined or receive substandard offers of coverage with surcharged premiums, riders excluding coverage for pre-existing conditions, or both.²⁸ More than 340 callers with diabetes lived in high-risk pool states and were either uninsured or about to lose their health insurance;²⁹ seven enrolled in high-risk pools. For the rest, coverage availability, affordability, and adequacy needs were not met by these programs.

Availability

Factors limiting access to high-risk pools included lack of awareness about these programs, restrictive eligibility standards, and red tape.

Lack of awareness - Although the first programs were established more than 25 years ago, public awareness about high-risk pools is low. A national telephone survey of 1,327 randomly selected American Diabetes Association members, conducted as part of this project, found that 73 percent of those living in high-risk pools states had never heard of their state program. Few states engage in extensive advertising or outreach to attract pool enrollment.³⁰ Many people who called for health insurance assistance first learned about their own state’s high-risk pool program from the American Diabetes Association. Lack of public awareness effectively limits the availability of high-risk pool coverage.

Eligibility restrictions - Some states have adopted eligibility restrictions that limit access to pool coverage for some who do apply. In Illinois and Louisiana, for example, high-risk pool enrollment is capped for uninsurable residents once funding limits are reached. As this report was published, the Illinois pool had just reached its enrollment cap and suspended new enrollment of uninsurable residents. In two other pools, Alabama and South Dakota, eligibility is restricted to HIPAA-eligible individuals. Residents who are uninsured and uninsurable cannot be covered by the pool.

Charles (61) of Alabama had diabetes and a history of heart problems. When he called the American Diabetes Association, he had been uninsured for four years. Prior to that, he had worked in a job with good health benefits, but his elderly parents became ill so he quit his job to care for them full time. Charles applied for individual health insurance but was turned down because of his diabetes. He was not eligible for Alabama’s high-risk pool because that program is only available to HIPAA-eligible individuals.

In Texas, uninsured residents are eligible for high-risk pool coverage. However, those who were eligible for COBRA but did not elect it may not apply to the pool until their COBRA benefits would have been exhausted.

Mona (59) of Texas was self-employed and had diabetes. She lost coverage under her husband's job-based health plan when he lost his job. They were offered COBRA, but at \$1,000 per month for family coverage, could not afford it. Mona's husband, who did not have health problems, bought an individual policy, but Mona could not, so she looked into the Texas high-risk pool. Despite meeting all other eligibility requirements, she learned she would not be allowed to apply for 18 months because she had not elected COBRA. With no other coverage options available, Mona was uninsured.

Red tape – For other callers, the process of applying for high-risk pool coverage was sufficiently complex to hinder or discourage enrollment. Most pools require applicants to first apply and be turned down for individual health insurance to prove they are uninsurable.³¹ However, obtaining this proof can take weeks, resulting in a gap in coverage that may pose other problems when people finally do enroll in coverage.

Jenny called about her son, Jason (30) who lives in New Mexico and works as a manager for a hotel chain that doesn't offer health benefits. Last year, he temporarily lost his eyesight and was subsequently diagnosed with type 2 diabetes. Jenny learned about the New Mexico high-risk pool option and encouraged Jason to enroll. He began the process by applying for individual health insurance in order to get a denial letter, which New Mexico requires as proof of uninsurability. While awaiting the letter, a serious case of flu put Jason in the hospital and his bills totaled \$20,000.

To streamline the application process, almost half of state high-risk pools maintain lists of eligible conditions so they can deem uninsurable those people who are diagnosed with a listed condition. However, of the 15 states with conditions lists, one state does not list diabetes at all and ten list only type 1 diabetes, even though 90 percent of people with diabetes have type 2.

Affordability

All high-risk pools set premiums at some multiple of standard individual health insurance rates in the individual market. Typically pool premiums are set at 150-200 percent of standard rates. In addition, all high-risk pools adjust premiums for age. Appendix 4 shows the premium for a 43-year-old under the various high-risk pool plans offered in the spring of 2004. Premiums ranged from \$129 to \$823 per month. Four out of five callers who were risk-pool eligible and provided income data earned less than \$2,000 per month. Most callers with whom high-risk pool coverage was discussed said they could not afford the premium.

Debbie (48) and her husband live in Maryland. Both are too sick to work. They live on Debbie's husband's Social Security check, which is less than \$900 per

month. Debbie can't remember the last time she had health insurance. She has applied for individual policies, but was turned down because of her diabetes. When told of the Maryland high-risk pool (MHIP), Debbie said she could not afford the premium.

Some state high-risk pools require new enrollees to pay the first three-months of premium in a lump sum. Thereafter, premiums can be paid on a monthly or quarterly basis, at the enrollee's option. This lump-sum payment requirement posed an insurmountable hurdle for one caller.

Tom (60) and his wife, Suzie, live in Indiana. Tom lost his job in the fall of 2003 and elected COBRA coverage, which ended abruptly a few months later when the employer went bankrupt. The couple then turned to the high-risk pool, ICHIA. The monthly premium (\$640) compared favorably to what they had been paying for COBRA (\$700). However, ICHIA requires new enrollees to make an initial payment that covers the first three months' premium (\$1,920). This was more cash than Tom and Suzy had. He is still unemployed and she doesn't work. The couple remains uninsured.

Eight state pools offer premium subsidies to low-income enrollees, although in most states assistance is limited. In four states (WI, NM, CO, WA) the subsidy reduces premiums to the level of standard rates offered in the individual market. Connecticut offers deeper premium subsidies, but only for a single plan option that does not cover prescription drugs. Oregon also offers a more generous pool subsidy, but the subsidy is administered by a separate program with a waiting list in excess of 12,000 people. Montana offers a 65% premium subsidy to low income enrollees and reduces the pre-existing condition exclusion period from six to four months for subsidized enrollees. Utah recently approved a sliding scale premium subsidy of 50% for enrollees with incomes up to the federal poverty level (FPL). Those with incomes from 101%-150% FPL will receive a 35% premium discount. A 20% discount will be offered to enrollees with higher incomes, up to 200% FPL.

Adequacy

The adequacy of high-risk pool coverage posed another problem for those callers who were eligible for their state pools and could afford the premium.

Pre-existing condition exclusion periods - The most burdensome adequacy problem was pre-existing condition exclusions. Nearly all state high-risk pools exclude coverage for pre-existing conditions when people enroll because they are "uninsurable," or are unable to buy health insurance due to a high-cost health condition.³² Pre-existing condition exclusions last 6 to 12 months. People with diabetes are effectively uninsured during this exclusion period because diabetes affects nearly all organs and systems. One high-risk pool director explained that any claims for care, "up to and including a head cold," would be investigated during a diabetes pre-existing condition exclusion period.

Almost all uninsured callers who were eligible for high-risk pool coverage would have been subject to a pre-existing condition exclusion period. Most could not afford to enroll, but had they been able to, the out of pocket expense for all medical care during the exclusion period would have constituted a substantial added expense. The pre-existing condition exclusion period rendered high-risk pool option impractical for many callers.

Walter (45) and his wife live in Kentucky. He works full time for a Baptist church that cannot afford to provide health benefits to its employees. Walter makes less than \$25,000 annually. He and his wife have been uninsured for years and have difficulty affording Walter's medications and test strips. Kentucky Access, the state high-risk pool, offers several plan options, the least expensive of which would cost Walter \$256 per month in 2004. However, Kentucky Access excludes pre-existing conditions for one year, so in addition to the premium, Walter would be required to pay out of pocket for virtually all of his health care for 12 months. Walter found this prohibitively expensive and decided not to enroll.

High cost-sharing – High-risk pools typically offer a range of cost sharing options. For example, enrollees in the New Mexico pool can choose from five coverage options, with annual deductibles ranging from \$500 to \$10,000. Co-payments or co-insurance typically apply once the deductible is satisfied. Limits on annual out of pocket spending also vary, reaching as high as \$20,000 for one of the Arkansas plan options. In some states, such as Mississippi and New Hampshire, a separate pharmacy deductible is imposed.³³ Usually, higher cost sharing options are associated with lower premiums. However, for people with a chronic condition like diabetes, trading higher cost-sharing for lower premiums does little to alleviate overall expense.

Richard (61) of Texas had worked for the same small lumber company for 33 years when his employer discontinued all health benefits. Richard didn't think he could find a new job at his age. His wife is disabled and unable to work. They tried to find coverage in the individual market, but were turned down because of Richard's diabetes. After learning about the Texas high-risk pool, Richard looked into it but was dismayed at the cost. The lowest premium then available for self-only coverage was \$437 per month, but under this option, Richard's would be liable for up to \$12,500 in cost sharing per year. Richard decided to enroll because no other coverage options were available, but he wasn't sure how he would pay for the cost sharing.

Public policy implications

High-risk pools were the only coverage choice for many callers with diabetes who could not buy private individual health insurance, but few were helped by these safety net programs. Instead, callers faced barriers that were similar to those hampering their efforts in the private insurance market. Policymakers could strengthen high-risk pool protections and help more people these programs were targeted to reach through a number of different strategies.

Reduce and subsidize high-risk pool premiums. Reducing or eliminating pool premium surcharges could make coverage affordable for more individuals. Pools would need to find funding from other sources to offset lost revenue. Premium subsidies for low-income enrollees could also make coverage more affordable. Subsidies would have to be sufficient relative to people's ability to pay.

Shorten or eliminate pre-existing condition exclusion periods. For people with diabetes, pre-existing condition exclusion periods created coverage adequacy problems. Maryland's high-risk pool recently stopped applying pre-existing condition exclusion periods for all enrollees in an effort to increase pool enrollment. Other state high-risk pools have waived exclusions for HIPAA-eligible enrollees since 1997. Since HIPAA, high-risk pool enrollment has increased substantially, reversing an earlier trend of enrollment decline.³⁴ State pools worried about adverse selection by the uninsured could nonetheless take steps to strengthen protections for enrollees with continuous prior coverage. For example, pools that currently do not give credit for prior coverage, or that limit the kinds of prior coverage that is creditable, could change their rules in order to help more people navigate insurance transitions.

Provide more comprehensive coverage of health services. The adequacy of high-risk pool coverage could be enhanced by lowering cost-sharing (deductibles and co-insurance.) In addition, pools that do not currently do so could offer full coverage for prescription drugs, as well as diabetes testing equipment and supplies. Improving the adequacy of high-risk pool coverage by expanding benefits and eliminating pre-existing condition exclusions will add to the cost of these programs. Additional outside funding would be required to prevent premiums from increasing and offsetting adequacy gains with affordability problems.

Relax eligibility barriers. Enrollment caps and other barriers could be eliminated. In addition, high-risk pools could create medical conditions lists that include all forms of diabetes to relieve applicants of the burden and time delay associated with obtaining one or more insurer denial letters.

Increase public education about high risk pools. Outreach and marketing could improve public awareness of high-risk pools, a key ingredient for improving access.

In 2002, Congress enacted new federal financial assistance to qualified state high-risk pools. States could apply for matching grants to fund up to 50 percent of net losses incurred by high-risk pools. The federal matching grant program expired after two years. Legislation to reauthorize and expand the matching grants was considered – including a provision to earmark a portion of funds for states that lower or subsidize high-risk pool premiums, expand benefits, or waive pre-existing exclusion periods – but action was not completed before adjournment. If renewed, federal support could help states take steps to make high-risk pool coverage more available, affordable, and adequate.

CHAPTER 7. PUBLIC PROGRAMS

Because private health insurance problems are the focus of this report, the National Call Center attempted to screen people whose problems obviously involved Medicare and Medicaid. Even so, in 130 cases accepted by the project, a specific Medicaid or Medicare issue was identified – 105 involving Medicaid, 29 involving Medicare, and 4 involving both programs. This chapter reviews how Medicaid and Medicare – the two largest government health programs – contributed to the health insurance problems and solutions for callers with diabetes.

Medicaid

Medicaid is the nation's safety net health insurance program for the poor and near poor, serving approximately 50 million low-income people in 2002. The program does not cover all poor uninsured people, however. To be eligible, people must meet categorical standards in addition to income and sometimes asset standards. Medicaid eligibility is restricted primarily to low income children and pregnant women; income standards for these groups range from 100 percent of poverty to as high as 300 percent of poverty in some states. Parents of children, elderly, and disabled adults are also eligible for Medicaid, although in most states these adults must have income far below the poverty level to qualify. The vast majority of uninsured Americans are low-income adults,³⁵ but less than one in four low income adults are eligible for Medicaid.³⁶

Medicaid is a state-federal partnership. Federal law established the program and overall eligibility rules, including minimum income eligibility standards. On average the federal government pays 57 percent of Medicaid expenses. States finance the other 43 percent of Medicaid costs and have significant flexibility to modify whom and what the program covers. States can expand coverage to eligible groups of people above the federal minimum standards. Most states do so for pregnant women and children but many fewer have exercised these options for parents, the elderly, and people with disabilities.

Many states have tried to cut or slow Medicaid spending in response to recent budget shortfalls. In FY 2004, 18 states implemented eligibility restrictions, 17 limited or reduced the availability of benefits, and 21 imposed new or higher cost sharing for Medicaid covered services.³⁷ In addition, the federal government can and does grant waivers to modify federal standards and increase state flexibility; a number of states have obtained waivers allowing them to require Medicaid premiums for at least some enrollees, to increase copayments, and in some cases to limit Medicaid covered services.

The 105 cases involving specific Medicaid issues included problems of availability (lacking or losing eligibility for coverage), affordability (in states where Medicaid premiums are charged) and adequacy (limits on covered benefits.)

Availability

Overwhelmingly, Medicaid problems were related to availability; uninsured callers applied for Medicaid and were turned down, or lost eligibility for Medicaid and became uninsured.

Restrictive eligibility – Many poor uninsured Americans are ineligible for Medicaid. Of the uninsured callers to the project who volunteered income data, 43 percent reported having incomes near or below the federal poverty level (\$9,310 for a single person, \$12,490 for a couple, and \$15,670 for a family of three.) However, most were not eligible for Medicaid, either because they did not meet categorical standards (e.g., they were not elderly, disabled, or pregnant) or were not sufficiently poor to meet income standards, which are below poverty in many states. One caller, an immigrant from Ecuador, met both income and categorical eligibility standards but could not enroll because of the federal rule barring lawfully present immigrants from Medicaid coverage until they have been in the U.S. five years.

Other uninsured callers had previously been covered by Medicaid but then lost eligibility. As is true for private health insurance, Medicaid eligibility can be disrupted by commonplace events.

Moving - Five callers lost eligibility for Medicaid when they moved to another state. These individuals either did not meet income/asset eligibility standards in their new state or experienced a spell of several months with no coverage while their applications were processed and they waited for new Medicaid coverage to take effect.

Change in family status – Seven callers lost or were about to lose eligibility for Medicaid as they turned 19 years old and so could no longer qualify as children. For example,

Tiffany (20) was a Medicaid recipient in Georgia for two years. While insured she was able to keep tight control of her diabetes because she had access to good medical services. However, when she turned 19 years old, she aged off the Medicaid program and was no longer eligible for medical services. The only work she could find was waiting tables in a restaurant, and the job didn't include health insurance benefits. She is currently uninsured and gets what free care and supplies she can from a community clinic and a local emergency care program for diabetes. Controlling her blood sugar is a struggle.

Medicaid can be an unstable source of coverage for parents in particular when there are changes in their child's eligibility, their work or income status, or their pregnancy status. Parents who meet the income eligibility guidelines, which are usually lower than the income levels that make the children eligible, will also lose Medicaid when their child ages off or otherwise becomes ineligible. Two divorced mothers called the Association having lost eligibility for Medicaid when they temporarily lost custody of their children. Other mothers lost eligibility when their children grew up and moved out.

Neva (59) lives in Florida and has been uninsured for 10 years since her youngest child reached majority age and ended her eligibility for Medicaid coverage. Divorced and living on an income of less than \$800 per month, Neva cannot afford private coverage (and would be turned down due to her diabetes if she could.) She relies on a local clinic for free physician visits and medications.

Change in income – Fluctuations in income can interrupt Medicaid coverage. Five people called the Association having lost Medicaid coverage when their incomes increased. One caller to the project was concerned about the instability of her daughter's Medicaid coverage. The mother worked for a small employer that doesn't offer benefits. Her 11-year old daughter qualified for Medicaid initially, but lost coverage when her mom's pay increased slightly. She later re-qualified for Medicaid, though subsequently became ineligible again after that. Over a period of years, the family incurred more than \$10,000 in medical bills during times when the child was ineligible for Medicaid. The child also had several hospitalizations for complications that could have been avoided.

Change in health status – Low-income women can qualify for Medicaid when they become pregnant. But once the child is born they will lose their eligibility for Medicaid unless they meet lower income eligibility thresholds for parents. For example,

Michelle (28) lived in Ohio and called in the fall of 2003, shortly after her Medicaid coverage ended. She qualified for Medicaid coverage when she was pregnant with their fourth child, but coverage ended two months after the baby was born. (In Ohio, pregnant women with incomes up to 150% of the federal poverty level are eligible for Medicaid, but parents of dependent children are only eligible if income is no more than 100% of the federal poverty level.) Michelle's husband worked in a job that offered health benefits, but the family could not afford the additional premium for family coverage.

People who qualify for Medicaid coverage due to disability often must have their health status reviewed periodically in order to remain eligible for the program. The eligibility re-determination process can result in people losing Medicaid coverage. For example,

Connor (24) qualified for coverage under Massachusetts' Medicaid program because he was disabled and could not work. In the spring of 2003, however, the state required him to have a physical exam and subsequently determined his disability was no longer severe enough to qualify. Even though he still did not have a job, Connor lost Medicaid coverage in June 2003. Connor lived with his girlfriend and was uninsured. The couple's only income was her workers' compensation check of \$192 per week.

State program cuts – Over fiscal years 2002-2004, all states implemented Medicaid spending cuts to help balance the budget.³⁸ Sometimes, these state cutbacks resulted in people being dropped from Medicaid coverage.

Cate (39) is currently covered under Connecticut's Husky program (the Medicaid and S-CHIP program for children and families) but has been dropped twice as eligibility rules in the state changed. When she first called in the spring of 2003, the state had elected to reduce eligibility for low income families from 150 percent of the federal poverty level to 100 percent. Cate and her family were dropped from the program. A court order restored coverage while a class action suit brought on behalf of Medicaid enrollees challenged this change. With no explanation, Cate and her family were again terminated from Medicaid eligibility. She managed to get coverage restored a second time. During periods when she was uninsured, Cate had difficulty affording her diabetes medications and had to apply to pharmaceutical companies for free drugs.

Affordability

Generally, Medicaid requires no premium for covered services. However, some states have received federal waivers allowing them to charge premiums to some enrollees. For example,

Jeff, a single, 39-year old man in Oregon, qualified for Medicaid through a waiver program that allowed the state to cover childless, uninsured adults for a nominal premium. At the outset, Medicaid's premium for comprehensive coverage was \$7 per month. Over time, however, the premium increased while the state cut Medicaid coverage for test strips and needles and increased cost sharing for other services. As a result, Jeff's out of pocket costs for covered services, uncovered services and premiums have increased to \$150-250 per month. When he called Association, he had just lost his part time job as a truck driver and, with no income, worried how he could continue to pay these expenses.

A recent evaluation of the Oregon Medicaid waiver found that 50,000 people lost Medicaid coverage because they could not afford to pay required premiums.³⁹

Adequacy

States have broad flexibility to limit the amount, duration and scope of covered benefits under Medicaid. Some limit the number of prescriptions Medicaid will cover per month. Other states do not provide Medicaid coverage for test strips. Such limits can make it harder for low income enrollees' to manage diabetes. For example,

Alice (61) is a widow whose health insurance is through the Texas Medicaid program. Her problem is that Medicaid in her state will only cover three prescriptions per month – fewer than her doctor has ordered – and does not cover test strips at all. Her caseworker helped her identify several compassionate use programs for medications offered by pharmaceutical companies. However, no manufacturers of test strips sponsor similar programs to offer free supplies to uninsured or under-insured people.

Medicare

Medicare is a federal program providing health coverage to people who are elderly, disabled, or diagnosed with end-stage renal disease. Eligibility is based on people's work history, not their income or assets. People must also be eligible to receive social security retirement, disability, or spousal benefits in order to qualify for Medicare. People can also qualify for Medicare if they have end-stage renal disease (ESRD) or require a kidney transplant.

Availability

Most of the availability problems observed arose when people tried to qualify for Medicare as disabled individuals. In one instance, a woman lost eligibility for private health insurance when her husband became eligible for Medicare.

Disability determination process - To qualify for Medicare disability coverage, people must first apply to the Social Security Administration (SSA) for an official determination that they are totally disabled and unable to work. The disability determination process can require assessment of a person's physical or mental limitations and of jobs available anywhere in the U.S. economy the applicant might be qualified and able to perform. Many callers had hired a lawyer to help them with their application or appeal. Roughly 60 percent of initial applications for disability determination were rejected in FY 2002. A substantial proportion of denials that are appealed are overturned, although this process can be very lengthy.⁴⁰ One caller whose disability application was initially denied had been waiting over one year for a court date before an SSA administrative law judge to hear his appeal.

Social Security disability income (DI) benefits do not begin until five months after the disability determination is approved. Medicare benefits become available 24 months after DI benefits begin for everyone except disabled individuals with amyotrophic lateral sclerosis (ALS). By law, the two-year waiting period is waived for this disabling condition.⁴¹ Three callers had qualified for DI benefits but were uninsured during the Medicare waiting period.

Once a determination is granted, it can be subject to future re-evaluation. Several callers lost Medicare as a result of the Social Security disability re-determination process.

James (44) in South Carolina received a disability determination in 2000. In addition to diabetes, psychiatric conditions made it impossible for him to work. His disability status was reviewed in 2003, however, and a doctor determined James was capable of returning to work as long as no more than one other person was employed at his worksite. As a result of this re-determination, James lost Medicare coverage in the spring of 2003, even though he did not have a job or health insurance. James hired an attorney to appeal the re-determination. In the meantime, he had to rely on a community health center for reduced-cost care and applied to pharmaceutical manufacturers for free medicine.

One spouse's eligibility for Medicare ends the other's private coverage – Unlike private health insurance, Medicare does not offer family coverage. Younger spouses and dependents of Medicare beneficiaries cannot enroll until they, too, reach age 65, become disabled, or develop ESRD. One 58-year old woman who called the American Diabetes Association) lost coverage when their husbands became eligible for Medicare. Research shows this is why 40% of uninsured women over the age of 50 lose coverage.⁴²

Adequacy

The most pressing problem for callers with Medicare was the lack of prescription drug coverage. Congress enacted a Medicare prescription drug benefit in 2004, but the new benefit does not take effect until 2006. Twelve callers with Medicare found it difficult or impossible to afford their medications without drug coverage.

Beth (55) of Kansas was covered by Medicare. Her prescription drug expenses exceeded \$1,500 per month. Her husband worked in a job that did not offer health benefits. Beth recently began purchasing her drugs from an on-line pharmacy in Canada. This reduced the cost to \$900 every three months, although even this amount was a strain on the family budget. When she called, Beth's husband had just applied for a job with the federal government. Beth said she hoped he would get it because the health benefits were excellent. Unless and until he did, she planned to keep ordering her drugs from Canada and hope for the best.

Affordability

Medicare coverage for outpatient services requires a monthly premium of \$66.60 in 2004 that will increase to \$78.20 in 2005. For low income individuals, this can be difficult to afford. Medicaid pays Medicare premiums and provides wrap-around benefits for poor beneficiaries and pays Medicare monthly premiums for near-poor individuals with incomes up to 135 percent of the federal poverty level.

Michelle (34) lived in Colorado. She and her four children were covered by Medicaid and, because she was disabled, Michelle was also enrolled in Medicare. Then Michelle got married. Her husband's annual income of \$30,000 disqualified her from continuing in Medicaid and, without Medicaid's help, she also could no longer afford to pay Medicare's monthly premium of \$58. Michelle became uninsured and made do on the free care she could obtain from local clinics.

Public policy implications

Medicare and Medicaid were established to fill substantial gaps left by the U.S. employer-based system of health coverage, but some gaps remain.

Simplify and expand Medicaid eligibility. Medicaid covers some, but not all poor uninsured Americans. Expanding eligibility to include all adults with incomes below the poverty level could substantially reduce the number of uninsured. Efforts to streamline eligibility, such as eliminating asset tests or requiring less frequent eligibility re-

determinations, have been adopted by some states to make it easier for low income uninsured people to get and keep Medicaid coverage.⁴³ Other changes could further promote continuity of coverage. For example, states currently have the option of guaranteeing children continuous Medicaid eligibility for 12 months, regardless of intervening changes in family income or status. Expanding continuous eligibility to adults could have helped some callers with diabetes.

Increase federal financial assistance to states. In the past, Congress has offered states higher matching payments to encourage expansion of Medicaid eligibility and benefits. The State Children's Health Insurance Program (S-CHIP) increased the federal matching rate and lowered state costs by as much as one-third and successfully prompted all states to expand coverage for low income children. The Vaccines for Children Program, adopted in 1994, provides states 100 percent federal matching payments to purchase childhood vaccines through Medicaid for uninsured children. Even so, states have long struggled to finance their Medicaid programs. Recently many have restricted Medicaid eligibility and cut benefits to reduce costs. A temporary increase in the federal Medicaid matching rate that ended in June 2004 helped forestall eligibility rollbacks in many states, but state budget problems persist and further changes in Medicaid are likely. Policymakers might consider whether increasing federal matching payments generally or for specific aspects of the program (for example, for target expansion populations or to streamline administrative burdens) might provide needed support for the program.

Extend Medicaid eligibility for uninsured people with diabetes. In 2000, Congress created a special Medicaid eligibility option for uninsured women with breast and cervical cancer. The Breast and Cervical Cancer Prevention and Treatment Act, or BCCPTA, (P.L. 106-354) was somewhat controversial because it created a condition-specific eligibility category; yet it was enacted with overwhelming support. Because federal funds were already being spent to screen uninsured women for these cancers, funding treatment of cancers that were detected seemed a logical next step. Policymakers might consider whether this model makes sense for uninsured persons with diabetes. In light of the high health care costs associated with complications of diabetes, expanding Medicaid eligibility could help more low income uninsured people manage their diabetes more effectively with possible cost savings overall to the health system.

Streamline Medicare disability determination process. Medicare promises health coverage to non-elderly people who cannot work because of a disability. However, the disability determination process can be lengthy and complex, deterring many who apply. To expedite this process, a time limit for consideration of all applications and appeals could be established. Additional Social Security workers and administrative law judges would probably be needed to process all cases in a timely manner.

End two-year waiting period for Medicare disability coverage. Upon receiving a disability determination, a two-year waiting period is required before Medicare coverage begins. However, Congress has already exempted one group – those with ALS – from this delay. Legislation has been introduced to gradually eliminate the Medicare waiting period for all disabled individuals.

Extend Medicare eligibility for people with diabetes – Since 1972, people with end-stage renal disease (ESRD) have been eligible for Medicare. The program spent \$4.5 billion last year on health care for approximately 400,000 enrollees with ESRD.⁴⁴ Because diabetes is the leading cause of kidney failure (in addition to other complications that are expensive to the Medicare program) policymakers might consider opening eligibility for Medicare to uninsured people with diabetes.

The ESRD and BCCPTA programs have created high-risk pool-like features in Medicare and Medicaid, respectively. Expanding either or both programs to cover diabetes would build on this feature. In light of the limitations facing state high-risk pool programs, these national programs offer some advantages. Both programs have broader funding bases, are better known, and could potentially reach many more individuals. Strengthening safety net coverage for people with diabetes could expand access to health coverage and health care and help prevent the onset of serious health complications.

CHAPTER 8. PROBLEMS OF THE INSURED

Another 165 case studies involved insured people with coverage problems unrelated to transitions. Most of these cases involved people who were under-insured, with coverage inadequate to secure needed care. A smaller number had difficulty affording their health insurance and had no other options for less expensive coverage.

Adequacy

Research on the under-insured suggests that tens of millions of insured Americans have coverage that is inadequate to secure access to needed care while protecting against financial catastrophe.⁴⁵ A single catastrophic event, such as a heart attack or a premature birth, might precipitate a financial catastrophe. Chronic conditions such as diabetes require ongoing care with mounting costs that can also reach catastrophic levels.

The term “under-insured” relates in part to the absolute level of coverage. For example, a policy with scant or no coverage for hospital care or prescription drugs could leave people with ruinous financial exposure in the event of a serious illness and hinder access to care. The definition of under-insured must also take into account the policyholder’s income and resources. A high-deductible policy might be adequate for a wealthy person but create financial and access-to-care burdens for someone of modest means. One study found that high medical bills are the leading reason why families in the U.S. file for personal bankruptcy; further, 80 percent of such filers have health insurance.⁴⁶ Another study reported that 20 million American families – representing 43 million individuals – had problems paying medical bills in 2003, and two-thirds of these families had health insurance. Families burdened with medical debt also have trouble paying for other necessities, such as food and rent.⁴⁷ As employers and insurers increase cost sharing and limit covered benefits in an effort to slow premium growth, more insured people with chronic conditions are finding coverage inadequate. Between 2001 and 2003, the percentage of privately insured, low-income, chronically ill Americans who spent more than 5 percent of their income on medical expenses increased from 28 to 42 percent.⁴⁸

Limited benefits and high cost sharing – Fifty-eight callers reported problems because their insurance policy either did not cover basic benefits, such as prescription drugs, or imposed burdensome cost sharing, or both. Most (42) of these callers were covered under job-based health plans. In recent years, employers have cut health plan coverage, most often by increasing cost sharing, in an effort to hold down the cost of health benefits.⁴⁹

Cathy (33) in Pennsylvania was happy with her husband’s job-based coverage until the employer decided to drop coverage for all brand name prescriptions. No generic equivalent for insulin exists. Cathy applied to the manufacturer for free insulin but was turned down because she had health insurance and her husband, a truck driver earning about \$40,000 per year, made too much money. At one point, the couple considered disenrolling from coverage so Cathy could qualify for free insulin. The health plan also dropped coverage for syringes and needles, prompting Cathy to re-use her needles until they were so dull they hurt.

Tiered formularies, which require higher cost sharing for more expensive or brand name drugs, are also being used increasingly by insurers to hold down pharmaceutical benefit costs with some success.⁵⁰ However, callers with diabetes ran into trouble when lower cost substitutes for their insulin and other medications were not available.

Rita (54) in Ohio is insured under an employer-sponsored plan that charges modest co-pays for generic drugs but requires people to pay up to \$100 per prescription for brand name drugs. Rita takes several brand medications, including insulin, and feels the monthly co-pays are more than she can afford. Sometimes her doctor can provide free samples, but most months she must sacrifice buying other things that are important to her health, like test strips for her blood glucose monitor.

Even modest cost sharing was problematic for some people with diabetes who take multiple prescriptions on an ongoing basis.

Margaret (55) of Kansas took a variety of medications daily to treat her diabetes and associated complications. She had coverage under her husband's job-based health plan, but the prescription co-pays were a relentless expense and the couple had trouble keeping up. Margaret said she had already "maxed out" two credit cards on prescription co-pays.

Lack of coverage for diabetes-specific supplies and services – Some insured callers lacked coverage for diabetes-specific supplies and services. Lack of coverage for test strips, in particular, was a problem for 50 callers. The price of strips varies and dozens of brands are sold. However, each brand of blood glucose monitor requires its own, proprietary test strip, preventing people from swapping strips between meters. Depending on the monitor, test strips can cost almost \$1 apiece. Most doctors recommend people with diabetes test at least two to four times per day, making the cost of strips a significant monthly expense. Scant or no insurance coverage for strips, therefore, poses a serious adequacy issue, especially for people who use insulin. Someone who cannot afford to monitor glucose levels cannot correctly adjust their insulin doses at injection time. One study observed a decrease in self-monitoring among individuals with higher cost sharing requirements for test strips.⁵¹

Janet (62) of Minnesota only checks her blood glucose once a week because her insurance policy does not cover test strips. Although she understands more frequent monitoring is recommended, she cannot afford it.

Diabetes advocates have lobbied at the state level for laws requiring health insurance to cover diabetes management services and supplies. Although opponents of mandated benefit laws in general are concerned they will raise premiums, several studies have demonstrated the cost effectiveness of diabetes mandates. An evaluation by the Utah Insurance Department found that diabetes mandates increased claims costs by no more than 0.1 percent, or about \$2 per policyholder per year.⁵² Another study, conducted by the Louisiana Department of Insurance, estimated the cost associated with that state's

comprehensive diabetes mandate was less than .006 percent of the total cost of benefits paid by insurers.⁵³ A report by the Maine Insurance Department found that most carriers surveyed did not believe that there would be a significant increase in premiums due to implementing a diabetes mandate because they already provide coverage for diabetes. Two insurers that did not cover diabetes at the time of the mandate estimated premiums could go up \$6 to \$6.90 per year. The Maine report also noted that overall claims due to diabetes could be reduced in the long term due to better disease management.⁵⁴ Today 44 states and the District of Columbia have enacted mandated benefit laws requiring health insurance policies to cover diabetes management services and supplies. Two other states require insurers offer policyholders the option of coverage for diabetes supplies and services.⁵⁵

Not all health insurance policies are subject to state mandates. People covered under self-insured employer plans, for example, are not subject to state mandated benefit laws. In 2003, most (52 percent) employees with job-based coverage were in self-insured health plans.⁵⁶

Lynn (56) of Kansas was covered under job-based health plan. Her doctor recommended she check her blood glucose three times daily but her health plan didn't cover test strips. Kansas' diabetes mandate requires group insurance policies to cover test-strips. However Lynn's health plan appeared to be self-insured, and so was exempt from the state mandate. Without coverage for strips, instead of following the doctor's orders, she could only afford to test once a day, or every other day. Sometimes, she asked her daughter to help her buy strips.

States sometimes exempt policies from mandated benefit laws. In 2003, legislatures in at least nine states considered allowing insurers to offer products that do not have to comply with some or most state mandates.⁵⁷ Most of these initiatives failed. In Colorado, where a bill did pass, the "mandate free" policy was nonetheless required to cover mandated diabetes services and supplies.⁵⁸ However, in Arkansas, insurers are now permitted to market policies free of most state benefit mandates, including diabetes mandates.

Sometimes policies exempt from state mandates can be marketed through associations. Millions of individuals and small employers purchase health insurance through associations. Health insurance sold through an association is often regulated differently than health insurance purchased directly from an insurer, and in some states association policies are exempt from state mandates.

Affordability

Twenty-eight insured callers had difficulty affording their coverage. Sometimes this was because their employer did not contribute much of the cost. Others were in small group plans whose premiums had been surcharged due to their diabetes. Sometimes a decline in income changed what people could afford.

Limited employer premium contribution – On average, employers that provide health benefits contribute 70-80 percent of the premium.⁵⁹ Sixteen callers were in job-based

health plans where employers contributed a lower share of the cost, especially for dependent coverage.

Dave (41) is an unemployed social worker in Texas. He has health insurance through his wife's job. However, her employer only pays about half of the \$1,000 monthly premium for family coverage, leaving Dave and his wife to pay the rest. In addition, the policy requires a co-pay of \$45 per prescription. Dave takes five medications, adding another \$225 per month to their costs. The couple has trouble affording these expenses on a single income, although Dave's wife earns too much to qualify for public assistance. Dave can't afford to be uninsured, either, so they go deeper into debt and hope he will find a new job soon.

Small group premium rate-ups based on diabetes – Thirteen states require small group health insurance policies to be community rated – that is, premiums are not allowed to vary based on the health status of people in the group. All other states permit at least some premium variation based on risk in small employer policies with a few states imposing no small group rating limits at all.⁶⁰ Although insurer pricing practices vary widely, one study quoted an insurer in Virginia that would increase premiums for an 8-person business by 37.5 percent if one person in the group had diabetes.⁶¹ Similar rating practices appear to have contributed to coverage affordability problems for some callers.

Patty (23) worked for a small business in Illinois. She and one other employee had family coverage under her job-based plan. The premium for the two families was more than \$3,500 per month - more than her employer could continue to afford. When Patty called, the employer was looking for cheaper options in order to continue offering health benefits.

Limited income – Six insured callers with affordability problems were in unsubsidized COBRA coverage. Twelve callers had non-group coverage. Four others were in public programs that charged premiums. Some had trouble affording basic necessities after paying for health insurance.

Hannah (53) and her husband live in Illinois and elected COBRA when he had to quit his job due to illness. Hannah, who has diabetes, stays home full time to care for her husband, so they live on his disability retirement and some savings. Their monthly income is less than \$3,000; their COBRA premium (\$609 per month) requires more than 20 percent of that. Co-pays for medications, obtained via mail order, are another \$170 every three months. Hannah knows things would be worse with no insurance, so they pay these bills first, but some months, there is not enough money left to buy food. When Hannah called she had already tried just about every place she could think of for help, with no luck. She was going to turn to her church to see if they might help.

Public policy implications

To mitigate rising premiums, employer health plans increasingly have raised deductibles and other cost sharing and limited covered benefits.⁶² In line with this trend, some

policymakers have advocated strategies to make health insurance more affordable by having it cover less. They argue the health care system will be more efficient if consumers will become more cost-conscious users of health care.⁶³ However, this approach fails to recognize the chronic health care needs of people with diabetes. The ongoing cost of managing diabetes is significant, so much so that when faced with financial barriers, some people have no choice but to manage their diabetes less well. Trading coverage adequacy for affordability can be harmful to people with diabetes and, ultimately, is self-defeating. Instead, adequacy and affordability must be pursued in tandem.

Subsidize health insurance for small employers and their workers. Small businesses can be especially sensitive to the rising cost of health insurance and so may need financial assistance to provide good health benefits to their workers. Several state programs help make health insurance more affordable for small employers. For example, the Insurance Partnership in Massachusetts encourages small employers to offer health benefits by subsidizing premiums up to \$400 per year for single coverage (\$1,000 for family coverage) for qualified small businesses that employ low income workers. The Partnership also helps low income workers pay their share of premiums. The program helps approximately 4,900 small businesses provide coverage to 13,000 workers and their families.⁶⁴ In New York, subsidized coverage is offered to low-income people and small employers through a program called “Healthy NY.” A state-funded reinsurance program helps to reduce the cost of coverage faced by small businesses and individuals by paying 90 percent of the cost of claims in the range of \$30,000 to \$90,000 for each enrollee.⁶⁵ As of December 2003, enrollment in Healthy NY totaled approximately 40,000 persons.⁶⁶

About 20 percent of uninsured workers are in firms that offer health benefits. Several states coordinate with Medicaid to subsidize premiums for low wage workers whose employers offer health benefits. The Family Health Insurance Assistance Program (FHIAP) in Oregon, for example, currently helps over 3,700 low income workers obtain job-based coverage they would not otherwise be able to afford.⁶⁷

Require health insurance to adequately cover diabetes care, equipment, and supplies. Health insurance coverage for diabetes care, equipment and supplies makes it easier for people to manage their disease. Adequate coverage must also ensure that financial barriers (such as deductibles) to effective diabetes management are minimized. Proposals to promote more widespread sale of high-deductible health plans and other policies offering less comprehensive coverage should be reexamined for their impact on care of diabetes and other chronic health conditions.

CHAPTER 9. CONSEQUENCES OF INSURANCE PROBLEMS

Health insurance problems have severe consequences for individuals, their health, their families, and their community. The Institute of Medicine recently reported the lack of universal health coverage costs the U.S. results in the death of 18,000 people each year and costs the economy \$65 billion to \$130 billion annually in preventable disease and lost productivity.⁶⁸ Unpaid medical bills have long been the leading cause of personal bankruptcy for American families, both uninsured and under-insured.⁶⁹ People with health insurance problems may become more vulnerable to exploitation and fraud. Others simply give up, resigning themselves to living as best they can without the care they need.

The experiences of callers illustrate the variety, severity, and scope of problems people face when they lack health security. In 71 percent of cases, people reported significant burdens as a result of their health insurance problems.

Difficulty accessing medical treatment – Forty percent of callers (341 people) had difficulty accessing medical treatment, including diabetes medications and supplies. Test strips were especially problematic; 213 people had difficulty accessing blood glucose testing strips. Problems affording insulin and prescription drugs were also common.

Andrea (40) and her family live in Illinois. They have health insurance through her husband's job at a national fast food chain. The coverage is expensive (about \$1,000 per month) and Andrea's pharmaceutical coverage requires 25 percent coinsurance. In addition to Andrea's diabetes, her two children have asthma. The family's share of total cost for the medications they need is another \$400 per month. Andrea can't always afford all these medical expenses so when money is tight she buys medicine for the children but does without her own. She also tests her blood sugar levels infrequently. The last time she saw a doctor, her blood glucose reading was too high.

Deteriorating health - Forty-four callers reported serious deterioration in their health status because health insurance problems impeded their access to care. For example,

Mamie (54) is an uninsured widow living in Florida. Uninsured, she has great difficulty accessing health care. She has not tested her blood glucose level or taken her oral diabetes medication for months. Mamie has an ulcer on her leg that is getting bigger and deeper. The closest free clinic is too far for her to travel, so she has sought no medical treatment.

Bankruptcy/medical debt - Medical debts incurred as a result of health insurance problems can devastate family finances, driving some to bankruptcy. One national survey found two in five adults (41 percent) in the U.S. have problems paying medical bills, meaning they had been contacted by a collection agency about outstanding medical bills, they had significantly changed their lives in order to meet their medical bill obligations, or they were currently paying off medical debt that they had incurred in the

last three years. While uninsured adults were most likely to experience such problems, continuously insured people also experienced medical bill problems at significant rates (29 percent.)⁷⁰ Other research shows that medical bills are the single leading factor contributing to personal bankruptcy in the U.S.⁷¹

Susan (46) works full time at a low-wage job (\$250 per week) in an auto shop in Georgia. Her employer offers health benefits, but coverage is limited. The policy would leave her with uncovered medical bills of approximately \$400 per month. Susan could not afford to pay premiums on top of her uncovered medical expenses, so she decided not to enroll. She was later hospitalized and the bill was \$19,000. Susan had to declare bankruptcy.

Family burdens - Many uninsured and under-insured callers needed to ask for help from relatives, placing an additional burden on the family.

Bill (39) was unemployed and uninsured in California. With no income, he could not afford his insulin, testing supplies, and other medications, which cost \$400-\$500 per month. He had to ask his grandfather to pay these bills for him.

Other burdens from trying to make do - Callers with health insurance problems did the best they could to obtain needed health care, sometimes resorting to unorthodox strategies. Some imported drugs from Canada because they could not afford U.S. prices. More than a few were uncomfortable knowing this practice is against the law. One caller regularly purchased test strips on e-bay. Prices at this auction website were, indeed, much cheaper than in pharmacies, although quality and authenticity could not always be guaranteed. In 2004, the FBI uncovered a \$1.5 million stolen test strip scam operated by thieves on e-bay.⁷²

Others who could not obtain health insurance sought some protection from discount medical plans. These plans help consumers secure price discounts from networks of hospitals, doctors, and pharmacies that would otherwise only be available to insurers and other large health care purchasers. However, consumers are still liable to pay the full, discounted fee for any health care they receive. Discount medical plans are not health insurance and so are not regulated by state or federal health insurance laws. Plans vary in price, though most are far less expensive than traditional health insurance. Almost all discount plans advertise that they are available regardless of pre-existing conditions, making them particularly attractive to people – like those with diabetes – who seek coverage and may have been turned down in the past.⁷³

While discount policies typically include a disclaimer that such coverage is not health insurance, many callers nonetheless thought their discount policy provided insurance protection. One caller had dropped insurance coverage in favor of a less expensive discount plan.

Susan (38) of Colorado decided to quit her job after her baby was born in order to stay home full time. Her husband's job did not offer health benefits, so the couple

elected COBRA coverage from Susan's former employer. At just over \$1,000 per month, however, it was very expensive, especially now that the family had only one income. A few months later, Susan found a different policy for a much lower premium, bought it, and surrendered her COBRA coverage. Only later did she realize the difference, but by then she was uninsured.

As discount medical plans proliferate, so do concerns that these products may mislead or exploit consumers.⁷⁴ The Federal Trade Commission has issued consumer alerts about discount medical plans⁷⁵ as have attorneys general or insurance regulators in Iowa, New York, Vermont, Colorado, Delaware, Kentucky, Louisiana, Oklahoma, Washington, and Florida.⁷⁶

Discouraged uninsured - Finally, 147 uninsured callers reported they had given up on seeking health insurance. Most had searched for coverage and found nothing available or affordable. They called for help finding free care and supplies, not health insurance. Most of these discouraged people had been uninsured for more than one year. Two thirds who reported income data were in poverty. One-third worked in low income jobs or lived on limited retirement income. Forty percent of the discouraged uninsured were unmarried and living alone; the rest were either married or single parents.

Fred, 60, is a minister in Wisconsin. His church pays him a salary of \$20,000 annually, which supports him and his wife. No health benefits are offered. Fred hasn't had health insurance in over ten years. Recently he was diagnosed with diabetes. He pays out of pocket to see his physician. Test strips are his biggest ongoing expense – those that fit his meter cost \$85 for 100 strips. The closest free clinic is more than two hours away – the trip requires more time away from his parish than Fred feels he can take. The caseworker suggested the Wisconsin high-risk pool, but after learning what it would cost and cover, Fred said he was not interested. Convinced he would never be able to obtain insurance, he hoped to find free or low-cost test strips, but his manufacturer, like all others, does not offer them.

CHAPTER 10. CONCLUSION

The experiences of people in case studies demonstrate that health insurance can fail people when they need it most, with devastating consequences. Stories of hundreds of individuals are generally consistent with broader research findings on the importance of health insurance and provide detail on the nature of health insurance problems and how they might be addressed. A common theme is the need for health insurance that is available, affordable and adequate. When health insurance fell short on one or more of these requirements, people were hurt. Given that, several observations can be made of the cases studied during this project.

1. Losing coverage was easy; regaining it was hard. Most people with diabetes lost health insurance for the same reasons others do. A job change, birthday, graduation, or move automatically disrupted coverage, although illness contributed to coverage loss for some people with diabetes. Once lost, coverage was not always restored so automatically. People with diabetes encountered coverage denials, premium surcharges, and pre-existing condition exclusions, in addition to general problems of affordability. These barriers are intended to discourage adverse selection – waiting to buy insurance until one gets sick – but they also prevented people with diabetes from remaining covered through transitions. People with chronic health conditions are disadvantaged in a coverage system that operates this way.

2. “Safe harbors” do not guarantee coverage availability, affordability and adequacy. To make it easier for people with health problems to get and keep health insurance, policymakers have created various insurance reforms, or “safe harbors,” to guarantee the availability of coverage. Most people were eligible for one or more of these safe harbors – guaranteed issue individual insurance, COBRA, HIPAA, high-risk pools – but were not helped because coverage was not simultaneously available, affordable, and adequate. Availability barriers arose when restrictive eligibility rules made people unable to qualify for coverage. The sheer complexity of understanding and navigating laws and programs, as well as simple lack of public awareness also constituted availability barriers. Once people learned about and were guided to insurance that was available, few could enroll because it was not affordable (e.g., it was not subsidized or premiums were surcharged) or did not cover needed care (due to benefit limits, high cost sharing, or pre-existing condition exclusion periods.)

3. Existing reforms could be strengthened. Hundreds of people in this study could have been helped if existing laws and coverage options were strengthened to promote availability, affordability, and adequacy of coverage.

- Coverage loss resulting from insurance transitions could be reduced by the adoption of more coverage guarantees, especially through job-based coverage, which tends to be comprehensive and heavily subsidized. For example, employer based coverage could be expanded by requiring more employers to offer health benefits, to offer dependent coverage, or to extend dependent coverage to their workers’ sons and daughters until the age of 25 or 30.

- Individual health insurance could be offered on a guaranteed issue basis, subject to community rating and comprehensive benefit standards.
- COBRA premiums could be subsidized, eligibility for COBRA expanded to smaller employer groups, and the duration of COBRA coverage could be extended.
- HIPAA policies could be subject to minimum benefit standards and community rating with premiums subsidized, and HIPAA notice rules could be strengthened.
- High-risk pools could expand eligibility, simplify application requirements, and conduct more aggressive outreach and marketing. Premium surcharges could be reduced and subsidies added. Covered benefits could be enhanced, cost sharing lowered, and pre-existing condition exclusions waived.

Changes like these have been opposed on the grounds that they increase government mandates, invite adverse selection, or are costly. However, in the absence of such changes, cracks in the health coverage system will persist for people with diabetes and other serious or chronic health conditions. Health insurance must be strengthened or new arrangements adopted to guarantee coverage availability, affordability, and adequacy.

4. Health insurance must be about health. A critical test of health insurance must be how it protects people who are sick. The experiences of people in these stories provide a standard against which policy proposals can and should be measured. Availability, affordability, and adequacy of coverage must be pursued simultaneously; problems will persist as long as one is traded for another. Strengthening the health coverage system to accomplish these goals will address the needs of people in this report. And it will protect others who are healthy today but may find themselves sick and in similar circumstances in the future.

APPENDIX. ROUTINE COSTS OF DIABETES CARE

The ongoing cost of managing diabetes is substantial, more so as complications of the disease arise. Clinical guidelines recommend people with diabetes should see an endocrinologist or other physician trained in diabetes management for a quarterly checkup. During these exams, a glycated hemoglobin test, or HbA1c (A1C) – a test that measures average blood glucose levels over the previous three months – is performed to determine how well the patient is managing the disease. A pre-prandial (before meal) test result of 90-130 mg/dL is considered an acceptable blood glucose level. Blood pressure and cholesterol levels will also be checked. Feet will be examined for any potential problems with neuropathy (numbness), and urine will be tested for increased amounts of protein, an indication of kidney damage (nephropathy) due to diabetes. An annual eye exam is also recommended due to increased risk of retinopathy, the leaking or breaking of blood vessels in the eye that can lead to blindness. Flu vaccine is recommended annually and pneumonia vaccine once with re-vaccination as recommended, as well, as diabetes increases the complications of these illnesses.⁷⁷

In addition, patients can incur substantial costs from the equipment, supplies, medicine, and insulin that are needed to control blood glucose levels on a day to day basis. People with diabetes should test their blood glucose level anywhere from two to six times per day, and so require a blood glucose monitor and test strips. Many people with diabetes use insulin to control blood glucose levels. Some take medications instead of or in addition to insulin to control blood glucose levels.

To illustrate the cost of diabetes care, and the importance of health insurance, the following two profiles have been constructed portraying typical health care needs. The first profile – Jeff – is an example of somebody who manages his diabetes effectively with no complications. As shown in Table 12, the cost of his diabetes care would be roughly \$350 per month.⁷⁸ The other profile – Elisabeth – is an example of somebody who has developed several serious complications of diabetes. As shown in Table 12, the cost of her diabetes care would be roughly \$800 per month.

Jeff (effective self-management) – Although Jeff, 30, was diagnosed with type 1 diabetes 20 years ago, he exercises regularly, eats well, and manages his diabetes effectively, and has not developed any serious complications. Jeff gives himself multiple insulin injections to help keep his blood glucose levels in check. He takes 20 units of Lantus, a long-acting insulin injected once per day at bedtime. He also takes 3 pen-style insulin injections of Humalog (total dose 20 units), one before each meal. Finally, Jeff also takes an ACE Inhibitor, Altace – 10 mg one time per day.⁷⁹ This drug, generally used to treat high blood pressure or kidney disease, is also prescribed to prevent the onset of these conditions.

In addition to these three prescriptions, Jeff needs a variety of supplies to both deliver his insulin, and help monitor his blood glucose levels. These supplies include:

- An insulin pen to deliver the Humalog
- Syringes to deliver the Lantus
- A blood glucose meter and lancing device to measure his blood glucose levels
- Test strips used to collect blood that will be measured by the blood glucose meter
- Lancets to prick his finger to test blood glucose levels
- Alcohol swabs
- Glucagon emergency kit (purchased once per year) to be used if blood glucose levels drop dangerously low

Elisabeth (diabetes with complications) – Elisabeth, 57, was diagnosed with type 2 diabetes 15 years ago. She is seriously overweight and has developed several health complications that increase her monthly medical costs substantially. Elisabeth takes two oral diabetes medications – 1,000 mg of Metformin (a generic version of Glucophage) twice per day, and 8 mg of Avandia once per day – to help control her blood glucose levels. In addition, she takes insulin – 40 units of Humulin N once per day.⁸⁰

In addition to these three diabetes prescriptions, Elisabeth needs a variety of supplies to both deliver her insulin, and help monitor her blood glucose levels. These supplies include:

- Syringes to deliver the Humulin N
- A blood glucose meter and lancing device to measure her blood glucose levels
- Lancets to prick her finger to test blood glucose levels
- Test strips used to collect blood that will be measured by the blood glucose meter
- Alcohol swabs

Elisabeth also has developed high blood pressure for which she takes 10 mg of Altace and 12.5 mg of Hydrochlorothiazide, each one time per day. In addition, she has high cholesterol for which she takes 40 mg of Lipitor once per day. Elisabeth also takes 900 mg of Neurontin three times per day to treat neuropathy in her feet. And, because she is starting to have cardiac problems, Elisabeth takes 300 mg of Diltiazem (generic version of Cardizem CD) and 120 mg of Inderal LA, each one time per day.

The prices shown in the following table are not necessarily what an insurer would pay for diabetes self management supplies, equipment, medications, and services. Prices shown for medications and testing equipment and supplies reflect retail prices charged by a national chain drug store. Whenever possible, generic medications and equipment were chosen over brand names. Prices shown for physician services and laboratory tests are based on Medicare fee schedules.

**Approximate monthly cost of routine pharmaceutical and medical care for diabetes,
with and without complications, for two typical patients⁸¹**

Item/ Service	Jeff		Elisabeth	
	Unit/dosage	Price (30 day supply)	Unit/dosage	Price (30 day supply)
Insulin	Lantus (20 units 1x per day = 600 units/month). (\$65.99/bottle = \$.0660/unit)	\$39.60	Humulin N (40 units 1x per day = 1200 units/month). (\$29.19/bottle = \$0.0292/unit)	\$35.04
	Humalog pen (20 units 3x per day = 1800 units/month) (300 units per pen = 5 pens per month at \$25.19 per pen)	\$125.95		
Oral diabetes medication	n/a		Metformin (generic for glucophage) - 1000 mg 2x per day (60 count)	\$66.59
			Avandia (8 mg 1x per day)	\$162.99
Blood glucose testing equipment and supplies	Lancets – BD Ultra Fine II – 4 used per day (100 count @\$7.98 - \$.0798 per lancet)	\$9.58	Lancets – BD Ultra Fine II – 2 used per day (100 Count @ \$7.98 - \$.0798 per lancet)	\$4.79
	Syringes – _ cc BD Micro Fine Needles – 1 per day (100 count = \$0.2499 each)	\$7.50	Syringes – _ cc BD Micro Fine Needles – 1 per day (100 count = \$0.2499 each)	\$7.50
	CVS Brand Blood Glucose Meter (\$14.99 - purchased every 2 years)	\$0.625	CVS Brand Blood Glucose Meter (\$14.99 - purchased every 2 years)	\$0.625
	Blood glucose test strips – CVS Brand (100 count @ \$44.99/box) – 4 strips used per day - \$0.4499/per strip	\$53.99	Blood glucose test strips – CVS Brand (100 count @ \$44.99/box) – 2 strips used per day - \$0.4499/per strip	\$26.99
	Alcohol swabs – BD brand (100 count @ \$2.49/box - \$0.0249/swab) 4 per day	\$2.99	Alcohol swabs – BD brand (100 count @ \$2.49/box - \$0.0249/swab) 2 per day	\$1.49
	Glucagon Kit (\$90.60 purchased one per year)	\$7.55	n/a	
Other medication	Altace (10 mg 1x per day)	\$60.59	Altace (10 mg 1x per day)	\$60.59
			Hydrochlorothiazide (12.5 mg 1x per day)	\$12.89
			Lipitor (40 mg 1x per day)	\$109.99
			Neurontin (300 mg 3x per day) (\$43.59 per 30 count)	\$130.77
			Diltiazem (generic for Cardizem CD) - 300 mg 1x per day	\$71.59
			Inderal LA (120 mg 1x per day)	\$65.59
Physician visits	Endocrinologist visit (4 per year @ \$82.15 per visit; includes blood pressure test and foot exam) plus lab tests: HbA1c test (\$13.56), cholesterol test (\$16.26 – once per year) ^a	\$33.26	Internist visit (4 per year @\$82.15 per visit; includes blood pressure test and foot exam) plus lab tests: HbA1c test (\$13.56), cholesterol test (\$16.26 – once per year) ^a	\$33.26
	Ophthalmologist visit (1 per year @ \$52.65 per visit) ^b	\$4.39	Ophthalmologist visit (1 per year @ \$52.65 per visit) ^b	\$4.39
			Podiatrist visit (2 per year @ \$52.65 per visit) ²	\$8.78
Total avg. monthly cost		\$346.03		\$803.87

^a Medicare fee schedule, CPT code 99214 (established patient, level 4 office visit) = \$82.15; HbA1c test uses Medicare fee schedule, HCPC code 83036 = \$13.56; cholesterol test HCPC code 83719 = \$16.26; total cost = \$111.97 per visit when a cholesterol test is performed; \$95.71 per visit when a cholesterol test is not performed.

^b Medicare fee schedule, CPT code 99213 (established patient, level 3 office visit) = \$52.65.

Notes

¹ The authors would like to express their thanks to the W.K. Kellogg Foundation, the Robert Wood Johnson Foundation, the Commonwealth Fund, and the American Diabetes Association for their generous support for this project. The views presented in this report are those of the authors and do not necessarily represent those of the funders.

² American Diabetes Association. "Type 1 Diabetes," cited April 2004. Available from <http://www.diabetes.org/type-1-diabetes.jsp>. Until recently, type 1 diabetes was referred to as "juvenile diabetes."

³ National Center for Chronic Disease Prevention and Health Promotion, "Fact Sheet: A Diabetes Report Card for the United States" U.S. Centers for Disease Control and Prevention, cited 24 August 2004. Available from <http://www.cdc.gov/diabetes/pubs/pdf/reportcard.pdf>.

⁴ American Diabetes Association. "American Diabetes Association Complete Guide to Diabetes," 3rd Edition. 2002.

⁵ American Diabetes Association. "Economic Costs of Diabetes in the US in 2002," *Diabetes Care*, Volume 26, Number 3, March 2003, 926: 917-932.

⁶ Short, P. F., Graefe, D., and Schoen, C., "Churn, Churn, Churn: How Instability of Health Insurance Shapes America's Uninsured Problem," The Commonwealth Fund, November 2003.

⁷ Haley, J., Zuckerman, S. "Is Lack of Coverage a Short- or Long-Term Condition?" Report to the Kaiser Commission on Medicaid and the Uninsured, Kaiser Family Foundation, June, 2003.

⁸ Edwards, J. N., Doty, M. M., and Schoen, C., "The Erosion of Employment-Based Health Coverage and the Threat to Workers' Health Care," The Commonwealth Fund, August 2002.

⁹ Short, P. F., Graefe, D., and Schoen, C., "Churn, Churn, Churn: How Instability of Health Insurance Shapes America's Uninsured Problem," The Commonwealth Fund, November 2003.

¹⁰ Collins, S., et.al, "Rite of Passage? Why Young Adults Become Uninsured and How New Policies Can Help," The Commonwealth Fund, May 2004.

¹¹ Short, P. F., Graefe, D., and Schoen, C., "Churn, Churn, Churn: How Instability of Health Insurance Shapes America's Uninsured Problem," The Commonwealth Fund, November 2003.

¹² Duchon, L., et. al., "Security Matters: How Instability in Health Insurance Puts U.S. Workers at Risk," The Commonwealth Fund, December 2001.

¹³ Kaiser Family Foundation and ehealthinsurance Inc., "Update on Individual Health Insurance," August 2004. Publication # 7133-02. Menlo Park, CA.

¹⁴ New York State Insurance Department, cited 26 August 2004. Available from <http://www.ins.state.ny.us/hgintro.htm>; New Jersey Department of Banking and Insurance, Health Insurance Programs, cited 26 August 2004. Available from <http://www.nj.gov/dobi/reform.htm>.

¹⁵ <http://www.bcbsm.com>, downloaded June 20 2003. By state law, all plans in Michigan are required to cover diabetes supplies, such as blood glucose monitors and test strips. In 2004 Michigan Blue Cross Blue Shield began offering a new PPO policy with limited prescription coverage, subject to an annual cap of \$2,500. See <http://www.bcbsm.com>, downloaded September 1, 2003.

¹⁶ Gabel, J. R., et. al., "Individual Insurance: How Much Financial Protection Does It Provide," *Health Affairs* Web Exclusive, 17 April 2002.

¹⁷ Monheit, A.C., et. al., "Community Rating and Sustainable Individual Health Insurance in New Jersey." *Health Affairs*, Volume 23, Number 4, July 2004: 167-175.

¹⁸ Lambrew, J., "How the Slowing U.S. Economy Threatens Employer-Based Health Insurance," The Commonwealth Fund, November 2001.

¹⁹ "Employer Health Benefits, 2004 Annual Survey," The Henry K. Kaiser Family Foundation and Health Education and Research Trust, September 2004.

²⁰ Massachusetts Hospital Association, "Crisis in Health Coverage: A Call to Leadership," 16 March 2004.

²¹ U.S. General Accounting Office, "Health Coverage Tax Credit: Simplified and More Timely Enrollment Process Could Increase Participation," Report to the Committee on Finance, U.S. Senate, GAO-04-1029, September 2004.

²² 45 CFR Part 148, Subpart B, Sec. 148.126 (a) and (b). Federal Register Vol. 62, No. 67, 8 April 1997, p. 17000.

23 Brenda Wilson, Chief, Managed Care, Maryland Insurance Administration, presentation at the CMS (formerly HCFA) HIPAA Meeting, 22 August 2000.

²⁴ Center for Medicare & Medicaid Services, HIPAA Insurance Reform: Direct Enforcement, cited 26 August 2004. Available from <http://www.cms.hhs.gov/hipaa/hipaa1/content/enforcement.asp>.

²⁵ U.S. General Accounting Office, "Private Health Insurance, Progress and Challenges Implementing 1996 Federal Standards," GAO/HEHS-99-100, May 1999.

²⁶ Number of states does not count Florida, Idaho, or Tennessee. Florida is sometimes counted among states with high-risk pools, although this program has been closed to new enrollment since 1991. Idaho requires licensed, private insurers to sell guaranteed issue products, which are called "high-risk pool products," but which are not financed or governed like other state high-risk pools. Tennessee also has been considered a high-risk pool state, although its program was merged with Medicaid (TennCare) in 1994. West Virginia recently enacted high-risk pool legislation; its pool is expected to open in 2005.

²⁷ Communicating for Agriculture and the Self-Employed, "Comprehensive Health Insurance for High-Risk Individuals, Eighteenth Edition, 2004/2005," Fergus Falls, Minnesota, 2004. Count includes enrollment in Florida and Idaho.

²⁸ Tooman, L., "Real People, Real Coverage," Council for Affordable Health Insurance, Issues and Answers, No. 103, May 2002.

²⁹ This number excludes callers from Florida, Tennessee, Idaho, and South Dakota (whose high-risk pool became operational after our project began.)

³⁰ Achman, L. and Chollet, D., "Insuring the Uninsurable: An Overview of State High-Risk Health Insurance Pool," The Commonwealth Fund, August 2001.

³¹ Applicants who receive other adverse underwriting actions – i.e., an offer of coverage with a surcharged premium or exclusion rider – can use this as proof of uninsurability in most state high-risk pools, as well.

³² High-risk pools in Alabama and South Dakota are only open to HIPAA-eligible individuals or other enrollees who, by law, cannot be subject to pre-existing condition exclusion periods.

³³ Moreover, in the Mississippi high-risk pool program, all enrollees must wait 180 days before pharmacy benefits are provided.

³⁴ Communicating for Agriculture and the Self-Employed, "Comprehensive Health Insurance for High-Risk Individuals, Fourteenth Edition, 2000," Fergus Falls, Minnesota, 2000.

³⁵ The Kaiser Commission on Medicaid and the Uninsured, "Health Insurance Coverage in America: 2002 Data Update," The Henry J. Kaiser Family Foundation, December 2003.

³⁶ Davidoff, A., et. al., "Medicaid and State-Funded Coverage for Adults: Estimates of Eligibility and Enrollment," Henry J. Kaiser Family Foundation, April 2004.

³⁷ The Kaiser Commission on Medicaid and the Uninsured, "State Fiscal Conditions and Medicaid," Kaiser Family Foundation Fact Sheet. April 2004.

³⁸ The Kaiser Commission on Medicaid and the Uninsured, "State Fiscal Conditions and Medicaid," The Henry J. Kaiser Family Foundation, April 2004.

³⁹ Mann, C., et. al., "The Impact of Recent Changes in Health Care Coverage for Low-Income People: A First Look at the Research Following Changes in Oregon's Medicaid Program," The Henry J. Kaiser Family Foundation, June 2004.

⁴⁰ In addition, the majority of denials are upheld on appeal. See Employment Support Institute, Virginia Commonwealth University School of Business, "Flow of Cases Through the Social Security Disability Determination Process," cited September 22. Available from http://www.workworld.org/wwwwebhelp/ssa_disability_determination_process.htm

⁴¹ 42 U.S.C. § 426 (h) (2000)

⁴² Lambrew, J., "Diagnosing Disparities in Health Insurance for Women: A Prescription for Change," The Commonwealth Fund, August 2001.

⁴³ Ross, C., et. al., "Enrolling Children and Families in Health Coverage," The Henry J. Kaiser Family Foundation, June 2002.

⁴⁴ Centers for Medicare & Medicaid Services, "2004 Annual Report of the Board of Trustees of the Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds," cited 17 August 2004. Available from <http://www.cms.hhs.gov/publications/trusteesreport/2004/>.

⁴⁵ Short P.F., Banthin J.S., "New Estimates of the Underinsured Younger than 65 Years," *JAMA*. Volume 274, Number 16, 25 October 1995, 1302-6.

-
- ⁴⁶ Jacoby, M. B., Sullivan, T. A. and Warren, E., “Rethinking the Debates over Health Care Financing: Evidence from the Bankruptcy Courts,” *New York University Law Review*, Volume 76, Number 2, May 2001: 375 – 415.
- ⁴⁷ May, J., Cunningham, P., “Tough Trade-offs: Medical Bills, Family Finances and Access to Care,” Center for Studying Health System Change, June 2004.
- ⁴⁸ Tu, H., “Rising Health Costs, Medical Debt, and Chronic Conditions,” Center for Studying Health System Change Issue Brief No. 88, September 2004, accessed at www.hschange.org.
- ⁴⁹ “Employer Health Benefits, 2004 Annual Survey,” The Henry K. Kaiser Family Foundation and Health Education and Research Trust, September 2004.
- ⁵⁰ Percentage of workers facing three-tier cost sharing formulas for prescription drug benefits has increased from 27% in 2000 to 63 % in 2003. “Employer Health Benefits, 2004 Annual Survey,” The Henry K. Kaiser Family Foundation and Health Education and Research Trust, September 2004.
- ⁵¹ Karter, A., et. al., “Self Monitoring of Blood Glucose: Language and Financial Barriers in a Managed care Population with Diabetes.” *Diabetes Care*, Volume 23, Number 4, April 2000: 477-483.
- ⁵² “2003 Diabetes Mandate Report,” Utah Insurance Department, 28 October 2003.
- ⁵³ “A Study of the Costs Associated with Healthcare Benefits Mandated in Louisiana,” Internal Report, Louisiana Department of Insurance, 28 February, 2003
- ⁵⁴ “Proposed Mandated Health Insurance Benefit for Diabetes Supplies and Self Management,” A Report to the Joint Standing Committee on Banking and Insurance or the 117th Maine legislature, Bureau of Insurance, March 1996.
- ⁵⁵ Mississippi and Missouri have mandates to offer coverage for diabetes services and supplies. Four states – Alabama, Idaho, North Dakota, and Ohio – do not have diabetes mandate statutes at all.
- ⁵⁶ “Employer Health Benefits, 2004 Annual Survey,” The Henry K. Kaiser Family Foundation and Health Education and Research Trust, September 2004.
- ⁵⁷ “State Health Care Policy, First Quarter of 2004,” State Health Policy Brief, NCLS Health Policy Tracking Service, Volume 5, Number 1, April 2004.
- ⁵⁸ H.B. 1164, Leg., 64th Gen. Assem., Reg. Sess. (CO.2003)
- ⁵⁹ “Employer Health Benefits 2004 Annual Survey,” Kaiser Family Foundation and Health Resources Educational Trust, September 2004. Available at www.kff.org.
- ⁶⁰ The District of Columbia, Virginia, Michigan, and Pennsylvania do not limit risk-based rating in small group policies, although Michigan and Pennsylvania do impose separate rating limits on plans sold by Blue Cross Blue Shield insurers.
- ⁶¹ “A Guide to Health Insurance Options for Small Businesses in Northern Virginia,” Healthcare Leadership Council, September 2003.
- ⁶² Mays, G. P., Hurley, R., E., Grossman, J. M., “An Empty Toolbox? Changes in Health Plans' Approaches for Managing Costs and Care,” *Health Services Research*, Volume 38, Number 1, February 2003: 375-393.
- ⁶³ See for example, “Economic Report of the President, Transmitted to the Congress February 2004,” H-Doc 108-145, at 189, 199, (2004) which states, “Over reliance on health insurance as a payment mechanism leads to an inefficient use of resources in providing and utilizing health care...Reforms that lead to more direct interaction between consumers and health care providers, relying less on third-party payers such as insurance companies, have the potential to increase the efficiency and therefore the cost-effectiveness of health care markets.”
- ⁶⁴ Telephone discussion with Nancy Kealy, Director , The Insurance Partnership (20 September 2004). For more information regarding the program, see <http://www.insurancepartnership.org/flash.asp>
- ⁶⁵ Swartz, K., “Healthy New York: Making Insurance More Affordable for Low Income Workers,” The Commonwealth Fund, November 2001.
- ⁶⁶ “Report on Healthy NY Program, 2003,” A report prepared for the New York State Insurance Department, Prepared by the Lewin Group in partnership with Empire Health Advisors, December 2003.
- ⁶⁷ The Family Health Insurance Assistance Program, “Summary Enrollment Information,” 13 September 2004. Available from http://www.ipgb.state.or.us/fhiap/snap/9_13_04.pdf
- ⁶⁸ “Insuring America’s Health Principles and Recommendations,” Institute of Medicine, January 2004.
- ⁶⁹ Jacoby, M. B., Sullivan, T. A. and Warren, E., “Rethinking the Debates over Health Care Financing: Evidence from the Bankruptcy Courts,” *New York University Law Review*, Volume 76, Number 2, May 2001: 375 – 415.

-
- ⁷⁰ Sara Collins, et. al., “The Affordability Crisis in U.S. Health Care: Findings from the Commonwealth Fund Biennial Health Insurance Survey,” The Commonwealth Fund, March 2004.
- ⁷¹ Jacoby, M. B., Sullivan, T. A. and Warren, E., “Rethinking the Debates over Health Care Financing: Evidence from the Bankruptcy Courts,” *New York University Law Review*, Volume 76, Number 2, May 2001: 375 – 415.
- ⁷² Kim, R., “FBI arrests couple in diabetic-test-strip theft and scam, Joint FDA probe shows illegal EBay sales hit \$1.5 million,” *San Francisco Chronicle*, 22 April 2004.
- ⁷³ “Be Wary of Health Discount Cards,” *Consumer Reports*, May 2002, cited 17 August 2004.
- ⁷⁴ Britton, G., “Discount Medical Plans and the Consumer: Health Care in a Regulatory Blindspot,” *Loyola Consumer Law Review*, Volume 16, Number 2, 2004, 97-118.
- ⁷⁵ “Bogus Medical Discount Plans: A Bitter Pill,” Federal Trade Commission Consumer Alert, Bureau of Consumer Protection, February 2003. Available from www.ftc.gov/bcp/online/pubs/alerts/medplanalrt.htm.
- ⁷⁶ Britton, G., “Discount Medical Plans and the Consumer: Health Care in a Regulatory Blindspot,” *Loyola Consumer Law Review*, Volume 16, Number 2, 2004, 97-118.
- ⁷⁷ American Diabetes Association, “American Diabetes Association Clinical Practice Recommendations, 1999.” *Diabetes Care*, Volume 22, Supplement 1, 1999. “Standards of Medical Care in Diabetes,” *Diabetes Care*, Volume 27, Supplement 1, January 2004.
- ⁷⁸ This amount was determined by using pricing data from major online pharmacies (CVS and Eckerd Drug Stores) and Medicare payments for physician services and lab tests.
- ⁷⁹ Based upon the dosage of Jeff’s medications, he weighs approximately 180 lbs.
- ⁸⁰ Based on the dosage of her medications, Elisabeth weighs approximately 250 lbs.
- ⁸¹ Costs are illustrative and do not necessarily reflect what private insurers would pay for the same items and services. Pharmaceutical prices quoted are taken from www.cvs.com. Cited May 13, 2004. Physician and lab prices are based on the 2004 Medicare fee schedule published in Federal Register, Vol. 69, No. 4, 7 January 2004.