

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

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.

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,¹ 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.

¹ 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.