Health Insurance and Diabetes: The Lack of Available, Affordable, and Adequate Coverage

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Between March 2003 and June 2004, the American Diabetes Association (ADA) and researchers at Georgetown University's Health Policy Institute completed a project that examined through individual case studies the availability, affordability, and adequacy of health insurance for people with diabetes.[1] Over the course of the project, caseworkers and researchers took calls from 851 people who contacted the ADA national call center (1-800-DIABETES) because they had health insurance problems.

The majority of cases studied involved problems with private health insurance because this is how most nonelderly Americans obtain health coverage. Some problems related to public coverage were also studied, however. Calls were accepted from people who were younger than age 65 and who were either uninsured, transitionally insured with coverage that was about to end, or insured with other problems. Information about people and their insurance circumstances was recorded in a database. Callers were also asked whether they would be willing to share their stories, and two-thirds said yes.

The focus of this project was on diabetes because the condition is so prevalent, and health insurance is essential to managing diabetes effectively. The U.S. faces an epidemic of diabetes, a disease in which elevated blood glucose levels damage nerve endings and blood vessels, leading to serious health complications including blindness, kidney failure, heart attack, and stroke. Today, an estimated 18 million Americans have diabetes, and 1 million more are diagnosed each year.[2]

Diabetes can be effectively managed, but medical care and supplies needed to monitor and control blood glucose levels are expensive. Numerous scientific studies have found that health insurance problems make it harder for people to manage their diabetes, often with devastating consequences.[3–5] Just the routine costs of managing diabetes (to test and control blood glucose levels) can reach hundreds of dollars per month.[1] 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.[6,7]

The stories featured here are consistent with these findings and demonstrate what can happen to people who are sick when their health coverage breaks down. Case studies of health insurance problems do not present a complete picture of the health coverage system. However, 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.

Project staff worked with callers to try to resolve their health insurance problems using available resources under federal and state law. Options under employer-based coverage, individually purchased insurance, and public programs were explored. The vast majority of problems could not be resolved because there are not enough safeguards to guarantee available, affordable, adequate health coverage for all people in the United States, regardless of their circumstances. In some cases, people had tried so long without success to find health coverage that they finally gave up on the system altogether. Convinced they would never be able to find affordable, adequate health insurance, these discouraged uninsured individuals no longer sought insurance coverage, but instead only charity care.

Key Issues: Availability, Affordability, and Adequacy

Problems were resolved for one in five callers. Most often, this happened when people got new jobs with good benefits. Sometimes, other safety nets, such as high-risk pools, provided a solution. Almost 60% of callers were eligible for some assistance that was not adequate to solve their problems. For example,

- 377 people, including Reed (described below), had lost or were about to lose job-based health benefits and needed protections under the Consolidated Omnibus Budget Reconciliation Act

Reed

Reed, age 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 4 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.

of 1985 (COBRA) to remain temporarily covered under their former group health plan, but only 31 were able to do so. Most could not afford to pay the entire premium, including the former employer's contribution (an affordability problem). Others were unaware of their COBRA rights or could not claim coverage because of COBRA eligibility limitations (problems of availability).

- Almost half the people who called had problems involving individual health insurance. One-fourth of adults need to buy health insurance on their own at some point over a 3-year period if they are not eligible for either job-based coverage or public programs.[8] However, in most states, people must qualify for individual health insurance based on health status, and those with diabetes are considered "uninsurable" and so will be turned down (an availability problem). Sometimes coverage must be offered regardless of health status, but people with health problems can be charged more (an affordability problem). In other states, inexpensive individual policies are available, as in Sylvia's case (described below), but don't cover prescription drugs or do require high deductibles (an adequacy problem). Individual health insurance provided a solution for only 15 callers.
- In 32 states, high-risk pools have been established to offer individual health coverage to residents who are turned down by private insurers. More than 340 callers, including Fred (described below), lived in states with high-risk pools and needed coverage, but only 7 enrolled. Public awareness of these programs is low—only 27% of ADA members surveyed had ever heard of their state's high-risk pool—and eligibility rules can be restrictive (availability problems). All high-risk pools charge higher premiums for coverage than apply to policies in the private market (an affordability problem), and all but a handful of pools exclude pre-existing conditions for at least some of their enrollees (an adequacy problem).

Sylvia

Sylvia, age 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 option seemed affordable (under $300 per month for a couple), but that 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 pharmaceutical assistance from the company that makes her insulin. A follow-up call to Sylvia 2 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 worried about how her parents would manage to pay the resulting bill.

Fred

Fred, age 60, is a minister in Wisconsin with an annual salary of $20,000 and no health benefits. He paid out of pocket to see his physician. Test strips were his biggest ongoing expense; those that fit his meter cost $85 for a box of 100 strips. Fred had been uninsured > 10 years and no longer sought coverage, convinced none was available that he could afford. But he agreed to look into the Wisconsin high-risk pool, which has premium subsidies for low-income residents. However, for someone of Fred's age, the annual cost of single coverage under Wisconsin's high-risk pool would have been $7,692, or almost 40% of his gross income. The pool subsidy program would have reduced this by roughly 15%. In addition, had he enrolled, Fred would have had to pay premiums for 6 months before his diabetes would have been covered because of the pool's pre-existing condition exclusion period.

For another one in five callers, no help was available at all. Most often, this was the outcome for people who were underinsured, such as Andrea (described below). Very few government laws or programs exist to help people who have health insurance that is inadequate to cover their medical needs. As a result, an increasing number of insured Americans are underinsured. High medical bills are the leading cause of personal bankruptcy in the United States, and 80% of the people who file for bankruptcy for this reason have health insurance.[9]

Public Policy Implications

Several key observations emerge from these case studies.

First, it can be easy to lose health insurance. Most often, commonplace events, such as a job loss or change or a divorce, led to callers losing their health insurance. Because health insurance in the United States depends on a person's employment status, family status, income, age, health status, and state of residence, a change in any of these fac-

Andrea

Andrea, age 40, of Illinois, is married, and her 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% coinsurance for prescription drugs. In addition to Andrea's diabetes, her children have asthma, so the family's share of costs 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 glucose levels infrequently. The last time she saw her doctor, her blood glucose reading was too high.

tors can and often will automatically change or disrupt health coverage. On average, 2 million Americans lose health insurance every month.[10]

Second, regaining health insurance can be difficult. People with diabetes who applied for individual health insurance were usually denied. Many could not qualify for Medicaid or Medicare. When new coverage was available, callers often found it unaffordable or inadequate. Access, affordability, and adequacy barriers were redundant, creating layers of difficulty people could not overcome. Studies show that when health coverage is lost, people in poor health are more likely to experience lengthy spells of uninsurance compared with people in good health.[11]

Third, policymakers must act to make health insurance available, affordable, and adequate for people with diabetes. The mere presence of health insurance options does not guarantee health security. Too often, policymakers have tried to patch cracks in the system of health insurance by creating safety net protections that turn out to be too expensive or too obscure and complicated to find or that offer coverage inadequate to help people effectively manage diabetes. More effective protections are possible, but they require greater expense or government regulation than policymakers have been willing to support to date.

The stories shared here of these people with diabetes remind us that the consequences of health insurance problems are also unsupportable. Real people are struggling with financial and medical complications that could have been prevented had access to test strips, insulin, prescription drugs, and other medical care been assured.

It is time to take a hard look at what we value in our health care system. The stories of people with diabetes and their health insurance problems reveal ways in which the U.S. coverage system is failing those who need it most. Their experiences provide a standard against which policy proposals can and should be measured.

To address the needs of people when they are sick, policymakers must promote and expand coverage that is available, affordable, and adequate. Failures will persist as long as one of these key features is traded for another. Strengthening the health coverage system to accomplish these goals will address the needs of the people in this report and others like them throughout the country. And it will protect individuals who are healthy today but who may find themselves sick and in similar circumstances in the future.

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