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Eliminating Federal Protections for People with Health Conditions Would Mean Return to Dysfunctional Pre-ACA Individual Market

By Sarah Lueck

The Affordable Care Act (ACA) has enabled millions of Americans with medical conditions to obtain affordable, adequate health coverage in all states' individual insurance markets. It did this not just by barring insurers from denying coverage outright to people because of a health condition, but also by requiring insurers to charge people the same premium, regardless of their health status and to provide a comprehensive array of benefits and cost-sharing protections. Now, the law is once again under threat, as the Trump Administration and 18 state attorneys general are asking the Supreme Court to strike down the entire ACA as unconstitutional.

If successful, this would mean a return to the highly flawed individual insurance market before the ACA, when people with health conditions often found it impossible to get adequate, affordable health coverage. Insurers charged far higher premiums to people who, for example, had taken anti-depressant medications, had knee surgery, or experienced repeated sinus infections. Insurers also required people to provide detailed information about their past health issues before offering coverage. And health plans frequently lacked important benefits such as maternity care, mental health services, and prescription drugs — or charged exorbitant deductibles and other out-of-pocket costs. Repealing the ACA would cause these things to happen once again.¹

Oral arguments in the ACA case, *California v. Texas*, are scheduled for November 10, with a decision likely next spring. The ACA remains the law of the land for now, and legal experts across the political spectrum view the case against it as extremely weak. But if the courts strike down the ACA, as President Trump again urged in an executive order in September,² some 20 million people would become uninsured — likely many more when accounting for COVID-19's effects on ACA participation. In addition, if the Administration prevails, millions more could be charged more or

¹ Tara Straw and Aviva Aron-Dine, "ACA Repeal Even More Dangerous During a Health and Economic Crisis," Center on Budget and Policy Priorities, June 24, 2020, <https://www.cbpp.org/health/commentary-aca-repeal-even-more-dangerous-during-pandemic-and-economic-crisis>.

² Straw and Aron-Dine, *op cit*. The executive order states, "I have agreed with the States challenging the ACA, who have won in the Federal district court and court of appeals, that the ACA, as amended, exceeds the power of the Congress. The ACA was flawed from its inception and should be struck down."

denied coverage altogether because they have a pre-existing condition or would lose other important protections.³

Individual states could adopt ACA-style protections in their individual and small-group markets, but they were free to do this prior to the ACA and few did. Robust protections for people with pre-existing conditions weren't sustainable for states without robust premium tax credits that keep individual-market premiums affordable for both the healthy and the sick. These, too, are at risk in the Court case.

It's therefore important to understand some of the problems that consumers experienced in the pre-ACA individual market, most of which ACA repeal would resurrect.

John Craig, Utah

Insurer denials caused Utah resident John Craig, then in his mid-forties, to go without coverage for several years after starting his own software-consulting business in 2001. After Craig left an employer that provided health benefits to him and his family, he was surprised how difficult it was to find coverage in the individual market. Many insurers viewed his history of multiple sinus infections and prior treatment for depression as grounds for denying coverage.

Eventually, Craig and his wife got coverage through Utah's high-risk pool; their children had coverage through the Children's Health Insurance Program. A few years later, Craig got a high-deductible, limited-benefit health plan for himself and two of his kids, but only after he submitted extensive medical details and an insurance agent spent hours on the phone convincing an insurer to take him. His wife remained in the state high-risk pool, which cost as much as the insurance for the other three family members.

The high costs of paying for everyone's health coverage made Craig's business unaffordable. He went back to a job that provided health benefits in 2012, just two years before the ACA guaranteed that his family could access a plan and pay the same as other families, regardless of health issues. "If it had kicked in sooner, I think I might have been able to keep my business going," Craig said.

In 2015, when Craig had a gap in health benefits while changing jobs, he applied for coverage through the federal ACA marketplace and found the process hassle free. "It was like night and day," he said.

Source: Phone conversation, December 22, 2016. See also, Sarah Lueck, "Seeking Insurance, Individuals Face Many Obstacles," *Wall Street Journal*, May 31, 2005, <https://www.wsj.com/articles/SB111749120504446489>.

Higher Premiums Based on Health Status

Beginning in 2014, the ACA barred insurers in the individual market from charging people higher premiums because of their health status or health conditions. Insurers can only adjust an individual's premium by specific factors: age (within limits), geographic area, and tobacco use (also within limits).

Before the ACA, people in the individual market frequently paid much higher premiums if they had pre-existing conditions. Often, a "standard" premium rate would be established for a particular insurance product, and people could be charged a higher premium ("rated up") if they had health conditions or get a reduced premium ("rated down") if they were healthy.

³ Jessica Banthin *et al.*, "Implications of the Fifth Circuit Court Decision in *Texas vs. United States*," Urban Institute, December 2019, https://www.urban.org/sites/default/files/publication/101361/implications_of_the_fifth_circuit_court_decision_in_texas_v_united_states_final_121919_v2.pdf.

To understand an applicant’s health status, insurers generally required people to go through “medical underwriting,” where they would have to fill out lengthy forms and answer a variety of questions about past medical treatments and give the insurer permission to examine their medical records. After this process, many people were offered premium rates considerably higher than the standard rate. A 2009 industry survey of individual-market insurers found that 34 percent of coverage offers were at higher-than-standard rates.⁴

Also before the ACA, insurers could *deny* coverage to people with health issues in most states, which happened to 18 percent of applicants in 2013, federal data show.⁵ Insurers could also exclude people’s pre-existing conditions from coverage. The House Republican bill does not allow denials or exclusions, but it does allow unlimited amounts of premium rate-ups based on health status (for people who’ve had a gap in coverage), so it would likely lead to even greater disparities in premiums between healthier people and people with health problems than in 2009.

Jean Green, Arizona

In 2004, Jean Green of Arizona had a baby and applied for an individual-market plan for the child, as she had for her two older children. (Her employer-sponsored plan was too expensive.) One insurer rejected her application because the baby had a closed tear duct, a fairly common condition among newborns. Ms. Green tried a second company and got coverage but only after a two-week period when the baby was uninsured, as Ms. Green submitted medical records and the insurer reviewed them.

Months later, the baby was diagnosed with a rare birth defect that was causing her skull to grow abnormally, and Ms. Green was told surgery was needed. But the insurer denied a request to pre-authorize the \$90,000 procedure, saying that the problem was a pre-existing condition and was excluded from the baby’s plan for 11 months. After an unsuccessful appeal to the insurer and her state insurance department, the state of Arizona, not the insurer ostensibly “covering” the baby, picked up most of the surgery cost.

Sarah Lueck, “Having Insurance Doesn’t Guarantee Coverage,” *Wall Street Journal*, May 31, 2005, <https://www.wsj.com/articles/SB111750175890146701>.

An estimated 27 percent of adults under age 65 have health conditions — such as cancer, diabetes, obesity, pregnancy, or others — that would likely render them “uninsurable” if they had to apply for individual-market coverage under pre-ACA rules, according to the Kaiser Family Foundation.⁶ Less severe health issues could also be a barrier to getting affordable coverage. A 2001 study examined the experience of a sample of people with various types of health conditions when they applied for insurance in several states’ individual insurance markets:⁷ Emily, a 56-year-old diagnosed with depression taking an anti-depressant medication, was rejected 23 percent of the time. Bob, a 36-year-old with prior knee surgery, was rejected 12 percent of the time.

⁴ “Individual Health Insurance 2009: A Comprehensive Survey of Premiums, Availability, and Benefits,” America’s Health Insurance Plans, October 2009.

⁵ Larry Levitt *et al.*, “How Buying Insurance Will Change under Obamacare,” Kaiser Family Foundation, September 24, 2013. This doesn’t account for people who didn’t apply at all because they had a pre-existing health condition.

⁶ Gary Claxton *et al.*, “Pre-existing Conditions and Medical Underwriting in the Individual Insurance Market Prior to the ACA,” Kaiser Family Foundation, December 12, 2016. This estimate is conservative because the data it relies on don’t account for several costly conditions, such as HIV, that would cause someone to be considered uninsurable.

⁷ Karen Pollitz, Richard Soriano, and Kathy Thomas, “How Accessible is Individual Health Insurance for Consumers in Less-Than-Perfect Health?” Prepared for the Henry J. Kaiser Family Foundation, June 2001.

The extra cost for someone with a serious health condition could be eye-popping, and rate-ups for people with more common conditions such as depression or pregnancy could also be large. If insurers charged people the full expected cost of their conditions, a 40-year-old with metastatic cancer would pay an additional \$142,650 per year in premiums, according to an analysis by the Center for American Progress. Having a baby, even without any complications, would mean \$17,320 more in premiums, and having rheumatoid arthritis would mean an additional \$26,580. Even relatively common health conditions would cost thousands of dollars more in premiums per year: \$5,600 for diabetes without complications, \$8,490 for major depressive disorders, and \$4,340 for asthma.⁸

Large Gaps in Benefits

Prior to the ACA, insurers could design plans that excluded coverage of certain benefits. This left many people with gaps in their coverage. It also enabled insurers to discourage enrollment by people with costly medical needs or to require them to pay far more for the coverage they needed. In 2011, among people in the individual market:

- 62 percent had plans that lacked maternity care;
- 34 percent had plans that lacked substance use treatment;
- 18 percent had plans that didn't cover mental health; and
- 9 percent had plans that didn't cover prescription drugs.⁹

People who wanted coverage of benefits not included in their plans could sometimes pay extra to have them added, but this often meant paying substantially more each month, in addition to their monthly premiums. For example, in a 2013 *New York Times* story, a New Hampshire woman whose individual-market plan didn't cover maternity care was told she would have to pay an extra \$800 per month in premiums if she wanted to add it. She decided not to, but later became pregnant and had to pay for maternity care out of pocket.¹⁰

Beginning in 2014, the ACA required individual-market plans to cover a set of essential health benefits (EHBs) — ten categories of services such as hospitalizations, outpatient care, mental health and substance use treatment, and prescription drugs. Requiring all plans to cover a comprehensive set of benefits spreads the cost of such services across the broad group of enrollees, rather than requiring only people who need a specific benefit to pay the cost on their own. Prior to the ACA, states required insurers to cover certain benefits but did not require them to cover benefits equivalent to the comprehensive federal EHB standards.

⁸ Sam Berger and Emily Gee, "Latest ACA Repeal Plan Would Explode Premiums for People with Pre-existing Conditions," Center for American Progress, April 20, 2017, <https://www.americanprogress.org/issues/healthcare/news/2017/04/20/430858/latest-aca-repeal-plan-explode-premiums-people-pre-existing-conditions/>.

⁹ "Essential Health Benefits: Individual Market Coverage," Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, December 16, 2011, https://aspe.hhs.gov/basic-report/essential-health-benefits-individual-market-coverage#_edn2.

¹⁰ Elizabeth Rosenthal, "American Way of Birth, Costliest in the World," *New York Times*, June 30, 2013, <http://www.nytimes.com/2013/07/01/health/american-way-of-birth-costliest-in-the-world.html?hp>.

If the essential health benefit requirements were eliminated or weakened, people with health conditions often wouldn't be able to get coverage of the benefits they need or would have to pay far more — frequently at an unaffordable price — to get plans that included those benefits. Insurers could once again design plans that leave out costly benefits in order to discourage enrollment among people who cost more to cover. Many people who buy coverage in the individual market likely would not realize that their plans lacked key benefits until they got sick.

Unlimited Out-of-Pocket Costs

Before the ACA, insurers generally had free rein to establish cost-sharing charges such as deductibles, copayments, and coinsurance for the benefits they covered. In many cases, there was no limit to what a person could be charged in out-of-pocket costs if he or she needed costly care during the course of the year, and deductibles for some plans were extraordinarily high.

For example, in Ohio, a 2013 UnitedHealth plan imposed a \$10,000 annual deductible on individuals who needed any medical services other than periodic preventive visits and childhood vaccines. A person enrolled in this plan would have been on the hook for as much as \$13,000 per year in out-of-pocket costs. Another Ohio plan available in 2013 had a \$25,000 deductible.¹¹ In Colorado, a Cigna plan offered in 2012 had a \$22,500 deductible.¹² And while this paper focuses on the individual market prior to the ACA, it's worth noting that, as of 2010, almost one-fifth of people with *employer* coverage had plans that exposed them to potentially unlimited out-of-pocket costs if they had a serious illness or injury.

The ACA set a limit on annual out-of-pocket spending that applies to virtually all plans, including employer-sponsored plans. It limits to about \$7,000 per individual what individuals pay when they need very costly medical care during the year, protecting people from catastrophically high expenses, as insurance is traditionally meant to do. No individual can be required to pay more than that amount for in-network, covered benefits. The ACA also established standards for what the cost-sharing levels can be under plans in the individual market, and it required that all insurers participating in the marketplaces offer consumers at least one plan with more moderate cost sharing.

Annual and Lifetime Limits on Coverage

Before the ACA, insurers often imposed annual or lifetime limits on coverage — meaning that the insurers would pay out no more than, for example, \$1 million during a year or \$6 million over a lifetime for someone's medical needs. An estimated 105 million people with private health insurance, most in employer-sponsored plans, had policies that placed lifetime limits on coverage.¹³ The ACA barred insurers from limiting benefits in this way, ensuring that people with illnesses such

¹¹ Jonathan Cohn, "You Call This Insurance?" *New Republic*, June 11, 2013, <https://newrepublic.com/article/113440/obamacare-rate-shock-higher-prices-can-mean-better-benefits>.

¹² Sarah Lueck, "Pre-ACA Insurance Market Isn't Worth Returning To," Center on Budget and Policy Priorities, March 24, 2017, <http://www.cbpp.org/blog/pre-aca-health-insurance-market-isnt-worth-returning-to>.

¹³ Thomas D. Musco and Benjamin D. Sommers, "Under the Affordable Care Act, 105 Million Americans No Longer Face Lifetime Limits on Health Benefits," Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, March 2012, <https://aspe.hhs.gov/basic-report/under-affordable-care-act-105-million-americans-no-longer-face-lifetime-limits-health-benefits>.

as cancer that often require expensive treatments over multiple years are not hit with very high out-of-pocket costs they cannot afford.

Wittney H., California

In 2005, Wittney H. of California, who had long had hypothyroidism, visited her endocrinologist for routine blood tests shortly after enrolling in an individual-market plan following a job change and the loss of her employer-sponsored health benefits. She was 27 years old. The insurer sent her a letter requesting all medical records from both her endocrinologist and her gynecologist. She consented because she felt she had nothing to hide — she had disclosed her health condition on her application.

A couple of months later, the insurer rescinded Wittney's coverage because she didn't disclose on her application that she had taken Glucophage, a diabetes drug that also can be prescribed for other reasons, and that she had experienced irregular menstrual periods. She had taken the drug only briefly the prior year, and her physician had told her it was to help her lose weight. The insurer, in reviewing the medical records, found the doctor had written in her notes that Wittney might have polycystic ovaries but didn't give the patient this information.

Wittney had her doctors write to the insurer explaining what happened, but it didn't do any good. When she testified before Congress in 2009, she had been rejected by other insurers due to the rescission and could only get coverage by finding a job with health benefits.

Source: "Termination of Individual Health Policies by Insurance companies," hearing before the Subcommittee on Oversight and Investigations of the House Committee on Energy and Commerce, June 16, 2009, <https://www.gpo.gov/fdsys/pkg/CHRG-111hrg73743/pdf/CHRG-111hrg73743.pdf>.

Coverage Changes After Medical Care Is Provided

Allowing insurers to once again require applicants to provide information about their pre-existing conditions and past medical treatments would open the door to what is called "post-claims underwriting." Prior to the ACA, individual-market insurers typically required people applying for coverage to fill out lengthy, complicated forms soliciting information such as medical care received during the prior year (including all doctor visits, medications prescribed, and lab results), whether or not a person had specific conditions (such as heart disease, HIV, or ear infections), and requesting authorization for the insurer to review the person's medical records.¹⁴ If the applicant were accepted and later filed a medical claim under the plan, the insurer would sometimes investigate whether the claim might be related to a medical condition the person already had — but failed to disclose — when applying.

Even unintended omissions or mistakes could cost people their health insurance, retroactively as well as going forward. An Illinois man with an immune-system cancer was about to receive a stem-cell transplant in 2005 when his insurer informed him it was revoking his coverage. The insurer claimed the patient had withheld relevant information — a CT scan from several years before that

¹⁴ Claxton, Cox, *op cit*.

showed signs of an aneurysm and gallstones. Yet the patient said he wasn't told about those findings or ever treated for those health issues.¹⁵

If some enrollees had to once again submit detailed medical information to insurers, insurers could use this information to challenge people's medical claims after care has been provided. Once again, insurers could pursue rescissions of coverage by comparing what a person said on his or her application to what medical care they had received in the past. Even if an insurer's issue with a patient didn't rise to the level of a rescission, the insurer might be able to modify the person's premium rate after the fact if the enrollee failed to disclose pertinent information during the application process.¹⁶

Many Republicans have supported maintaining the ACA's existing ban on excluding pre-existing conditions from coverage. But as discussed above, even if this protection remains, ACA repeal would undermine it, letting insurers accomplish much the same thing by failing to cover important benefits that people with pre-existing conditions need.

¹⁵ "Termination of Individual Health Policies by Insurance companies," hearing before the Subcommittee on Oversight and Investigations of the House Committee on Energy and Commerce, June 16, 2009, <https://www.gpo.gov/fdsys/pkg/CHRG-111hrg73743/pdf/CHRG-111hrg73743.pdf>.

¹⁶ Insurers are currently permitted to retroactively increase an enrollee's premium if they discover the person uses tobacco but didn't accurately report this information on the application. However, insurers are not permitted to rescind coverage on this basis. (Tobacco use is one of several factors, along with age, geographic location, and family size, on which a person's premiums may vary under the ACA.) See preamble to "Patient Protection and Affordable Care Act; Health Insurance Market Rules; Rate Review; Final Rule," Federal Register Vol. 78, No. 39, February 27, 2013. The ACA explicitly prohibited insurers in the individual and group markets from rescinding coverage except in cases of fraud or an intentional misrepresentation of a material fact.