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Why Americans Have a Love-Hate Relationship with Health Care Reform, So Far

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American views about the Affordable Care Act – often called Obamacare – have proved shifting and ambivalent. Polls show that more people disliked the law than liked it while President Barack Obama was in office. But once Donald Trump moved into the oval office, this trend reversed. The law's popularity has increased even as key parts of the law are being eliminated (such as the individual mandate), defunded (as with cost-sharing subsidies to insurance companies), or rolled back (including consumer protections like those for people with preexisting conditions). A recent book I compiled with my co-editor Heidi Castañeda collects the work of qualitative social scientists to help unpack these perplexing poll numbers. *Unequal Coverage: The Experience of Health Care Reform in the United States* is based on interviews with hundreds of uninsured and newly insured individuals in nine states.

This research shows that people who criticized Obamacare did so for many different reasons, and their criticisms did not come from any single ideological viewpoint. Some people, we found, were dissatisfied because they felt that "others" benefited from the law, or because they could not afford to use their coverage, or because they experienced bureaucratic and technological hurdles to enrollment. Other worries focused on limited provider networks and on the individual mandate tax to be paid by people who remained uninsured. Some of these reasons are ideological, but many relate to the design of the law, the price of coverage under it, or the law's rocky implementation Although the future remains uncertain, we learned important lessons.

People Need and Want Affordable Coverage

Again and again, the people we interviewed said they wanted insurance. Those who were uninsured felt excluded from the system and were not freely choosing to go without coverage. Insurance matters, and there remains a profound unmet need for coverage and access to care in the United States. The 20 million who gained access to coverage through the new law, often experienced life improvements by getting relief from high deductibles, copays, and unaffordable premiums. Take the example of Danny. He is a Rhode Islander with Type 1 diabetes. He had gone without coverage for ten years, struggling to pay for insulin and supplies, reusing needles, and making regular trips to the emergency room when his blood sugar reached dangerous levels. After Danny qualified for Medicaid through health reform, he was able to regularly visit his endocrinologist, obtain supplies and insulin, and work more hours at his job.

But for too many, financial barriers to coverage remain. In states that chose not to expand Medicaid coverage to the poor, many fell into the coverage gap. They were too poor to get subsidized private plans and had no realistic options for coverage. Their situations worsened when funds for charity care were reduced. High deductibles, as well as other forms of cost-sharing, proved an insurmountable barrier for many who buy plans on Obamacare exchanges. And what might seem to policymakers like small fees some states have imposed for those on Medicaid – such as a few dollars for a prescription copayment – prevent many with chronic disease from adhering to their medication regimens.

In 2018, there were still more than 27 million people without coverage in the United States – many of them immigrants. Every other economically advanced country provides universal access to health care. But currently, the United States is backsliding, because Trump administration policies weakening Obamacare have left exchange enrollments falling by 3.7% in 2018.

Stratified Approaches to Expanding Access Generate Resentment

One of the most important lessons to be learned from our research is that highly stratified approaches to expanding coverage generate social resentment. Under the Affordable Care Act, means-testing and complicated formulas for calculating the cost of coverage create multiple issues. Some people have owed penalties at tax time; others who compared their outcomes to family and neighbors and found the law to be unfair, because differences in eligibility and pricing were linked not just to income, but also age, family size and whether people smoke. A lot of differences in cost and coverage do not make sense to ordinary people.

Significant variations have always existed in the U.S. health care system, but when the U.S. Supreme Court modified the Affordable Care Act in 2012 to make Medicaid expansion optional, geography truly became destiny. Whether one lives in a state that expanded Medicaid or not could make all the difference in the availability of affordable health insurance for individuals and families of modest income. This, in turn, impacted people's abilities to get treatment for chronic health issues, recover from injuries, and stay in the workforce. Recent changes pushed by the Trump administration will exacerbate class and racial disparities and inequalities across states.

Enrollment and Accessing Coverage Should Not be So Hard

Much of the research in our book details how difficult it has been for individuals and families to get enrolled, use their coverage, and keep up with their cost-sharing obligations. Having to re-enroll annually, provide income updates, and navigate confusing plan structures and pricing is a lot to ask of tens of millions of Americans, most of them in working families raising children. Adding work requirements, premiums, and other forms of cost-sharing for low-income individuals only exacerbates barriers to enrollment, inhibits continuity of coverage and care, and creates additional administrative expenses. Stringent enrollment policies might seem like a good way to reduce fraud, but these efforts are often counterproductive and costly. If America's goal is to increase access to coverage and care, then enrollment and financing should be as simple, automatic, and long-lasting as possible.

Parts of our work also detail the adverse implications for people, communities and the country as a whole of excluding most immigrants, especially undocumented immigrants, from Affordable Care Coverage. Immigrants need health care like everyone else and making it nearly impossible for them to get covered, even at a price, reduces the effectiveness of the health care system for everyone.

Overall, our book demonstrates the on-the-ground human experience of health reform in recent years, revealing important lessons about what works and what needs improvement in future years – to ensure a more workable and equitable health care system for all.

Read more in Jessica M. Mulligan and Heide Castañeda *Unequal Coverage: The Experience of Health Care Reform in the United States* (NYU Press, 2018).