The Affordable Care Act as a National Experiment

Health Policy Innovations and Lessons

Harry P. Selker *Editor*

Second Edition



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Preface

Since publication of the first edition of this book, we have seen every sort of hurdle to the easy implementation of the Patient Protection and Affordable Care Act (ACA), some of which have substantially changed its very substance. But still, it endures. And as such, the ACA stands both as a major piece of a health policy innovation and as an example of what experiments in healthcare look like.

The authors of the chapters that follow address the policy, the challenges, and the necessity of such experiments. The opportunity to write this second edition emphasized that the ACA—a policy experiment now a decade from its start—is not a one-time happening, but a process that needs continual observation, feedback, revisions, and follow-up experiments. So, this second edition continues our collective efforts to improve healthcare, and thereby health, in our country. As detailed more in the Introduction, some of the chapters are updated versions of those from the first edition; others are wholly new, broadening our perspective to include more qualitative data, a discussion about the critical role of the social determinants of health, and a look toward the future and the push for universal healthcare. Our goal, as before, is to further understand the ACA and help inform future innovations so that our country can continue forward on the path to optimizing our healthcare system.

Just as we were completing this book, the COVID-19 pandemic was underway and its potential scale was looming. We were not able to address the impact of the pandemic, but we think it powerfully reinforces the importance of considering the ACA as an experiment that will need to be modified based on real-world evidence. In health policy experiments, unlike in laboratories, interventions are tested by circumstances not envisioned—in some cases dwarfing the facts that were the conditions of initial implementation. That is the case now for the ACA. Compared with conditions a year ago, there are tens of millions more people out of work, meaning many more people have no health insurance. Moreover, their access to coverage is hampered by current resistance to any expansion of the ACA. This means less healthcare and increased suffering at a time of a pandemic. Besides being deeply troubling on a human level, this is a huge societal policy challenge, and it must contribute to the dialogue initiated by institution of the ACA. While there is no national consensus about how healthcare should be paid for, there is a national

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consensus that universally healthcare should be available to all. Thus, the confluence of a terrible disease, great economic upheaval, and the loss of healthcare insurance by millions intensifies the argument of learning from the ACA experiment about how that need can be effectively addressed. We hope to that despite not explicitly addressing the COVID-19 pandemic, the content of this book will inform the ever-more pressing need for this country to solve its longstanding challenges to access to healthcare.

In assembling this book, thanks are owed to many. First, I must thank the chapter authors, clinicians, and policymakers who care deeply about patients, the public, and the healthcare system, all of whom were too busy to be expected to write their chapters, but did. They arose like a wave to complete this book based entirely on their passion for the topic and our joint appreciation of the need to support rational and informed discussion about the ACA. Yet, this would not have resulted in a book were it not for the masterful, tactful, and persistent organizing of this entire project by the indomitable Maggie Towne, nor would it have been possible without the astute and sensitive editing of Kathy Siranosian. Thanks are also owed to Miranda Finch of Springer Publishing, who invited this second edition and was always gracious and helpful in arranging publication. Also, as this was done under the aegis of Tufts Clinical and Translational Science Institute (CTSI), which is supported by the NIH National Center for Advancing Translational Science (NCATS) grant number UL1TR002544, I thank NIH and NCATS for the support for this work. Indeed, we are proud to consider this part of the work of Tufts CTSI and NCATS as, again, we believe that the ACA is the single largest translational research experiment of our generation, and its results deserve our attention.

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Chapter 1 Introduction: An Overview of the ACA as a National Experiment



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Harry P. Selker

Through the lens of medical research, by which experiments are conducted to test the effects of new treatments on patients, health policy innovations can be seen as experiments. Accordingly, the Patient Protection and Affordable Care Act (ACA) is not only landmark legislation, but also the largest health policy experiment our nation has undertaken in our generation. Like all experiments, it has led to more testing, building on positive results, and trying to correct negative consequences. However, unlike research done in the carefully controlled conditions in a lab or clinic, the ACA is an experiment being conducted in the midst of protean real-world challenges. That means its theories and logistics are not only tested, but also subject to initial and continuing challenges of many types. This point was emphasized in the first edition of this book, and is again here, because it highlights not only the importance of learning from innovation but also the importance of healthcare research in improving—indeed, perhaps saving—our nation's healthcare system.

Still, of all that might be said about the ACA—which has proven to be one of the most important and most controversial pieces of legislation in our nation's history—why emphasize that it is an experiment? Portraying the American public as "guinea pigs" is not exactly flattering, and dwelling on the challenges, many of which stem from partisan politics, may not seem particularly fruitful. So why advance these concepts? Because, as with any major policy implementation, the ACA must be evaluated and data collected, so that we can determine its impact. Additionally, for those who work in this area, it is worth taking a step back from the fray to remember that while, as Martin Luther King, Jr. promised, the arc of history bends toward justice [1], real-world innovations are required to ensure that arc includes universal access to healthcare. And to paraphrase Teresa of Avila, "God has no hands but ours" [2]. To create the policy experiments that force history to bend in the right way, we must be involved. Watching from the sidelines is not an option. This

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edition's continued frame of health policy innovations as experiments is intended to make explicit that all of us need to undertake and learn from such experiments.

Those of us in health policy and healthcare research must embrace this narrative, especially today, given the nation's polarized political climate. If we cannot articulate why this policy improvement is important and how it will improve the nation's health, we undermine our own objectives. After all, just as medical care is advanced by the bench-to-bedside-to-practice research that translates biological insights into effective treatments, the public needs to understand that care also is advanced by the rest of that chain of translational research, from practice to public benefit to policy. New treatments, or even established treatments, if not delivered effectively to individuals, have no impact on health [3]. We must make the case for the full spectrum of translational research—from bench to bedside to practice to public benefit to policy. Widespread understanding of the need for this entire chain will lead to better public support, including better understanding of the process of health policy innovation.

In addition to explaining and supporting the full spectrum of translational research, this second edition also strives to make clear just how challenging such an endeavor is. Its scale and cost are enormous. Yet the public, the government, and those in healthcare delivery and policy research all must understand and support it as critical for progress on one of our nation's most persistently unfulfilled obligations: to provide for the optimal health and function of all our residents.

The ACA stands as a core component of our nation's response to this mandate. Innumerable individuals and organizations, some well-known, and many anonymous, were involved with its development, passage, and over the past ten years, its implementation. That list includes the authors of this book, all of whom made contributions. Some were deeply involved in creating the preconditions that enabled the ACA, such as the Massachusetts universal healthcare experiment. Others helped write the legislation, stewarded it through Congress, or shaped (and continue to shape) its implementation. A few were involved in all of these efforts. Their perspectives and insights that follow all underscore that because policy innovations are experiments, plans and results cannot always be easily predicted, and often, incourse adjustments are needed.

The first chapters of the book lay the groundwork for the discussion. In Chap. 2, James Roosevelt, Jr. and Terence Burke reiterate the significant and groundbreaking foundations of the ACA and then update its status given the political and legal machinations over the five years since the first edition. They outline the law's successes, its unfinished goals, and how the American public's view of access to affordable healthcare has been forever changed. Kavita Patel, who helped write the ACA, takes the conversation a step further by focusing specifically on patients' rights and offering an evaluation of whether the ACA's patient protections have been effective and what specific areas need improvement. Next, Shawn Bishop, who also was deeply involved in the ACA's creation, describes the law's distinctively American features. And later, in a subsequent chapter, she reminds us that, unlike a test run in a controlled laboratory environment, this federal policy experiment can be challenged in court at any time, modified by future acts of Congress, or repealed based

on negative public sentiment. As a result, the ACA has been changed by some regulatory rollbacks and there have been over 60 repeal attempts, some of which have reached the US Supreme Court. Although Supreme Court decisions have not ended the experiment, they have significantly impacted its results. For example, as Anya Wallack explains in Chap. 5, after the Supreme Court ruled that the federal government could not compel states to undertake the ACA's Medicaid expansion, the policy fell back to a more traditional federalist relationship, whereby the federal government makes an opportunity available, and states have a choice as to whether or not to avail themselves of that opportunity. Yet another challenge to the ACA, this one involving the severability of the individual mandate, may still be heard by the Supreme Court in 2021.

Other hurdles to the execution of the ACA experiment have been somewhat more predictable, but not less important, such as the need to create a national health information technology infrastructure, as laid out by Peter Embi and Umberto Tachinardi in Chap. 6. And another obstacle, in common with any major policy innovation, has been the need for public messaging and engagement. The challenge of this is illustrated by Ceci Connolly, who details how anti-ACA messaging contributed to the 2016 defeat of Hillary Clinton, cost Democrats seats in Congress, and paved the way for significant substantive policy retrenchment in the Trump era.

Even so, the vast majority of the ACA remains in force, thanks in large part to our system of checks and balances and the role of the courts in reviewing actions by the federal government.

The next chapters of the book explore a few of the ways healthcare in our nation has changed (or not) over the past five years, and they do so by presenting an intriguing juxtaposition of quantitative and qualitative data. First, Purva Rawal reviews the Center for Medicare and Medicaid Innovation (CMMI), including its major models, results, and the challenges and opportunities that lie ahead. The CMMI is itself an innovation, with a directed channel to implementation via the Secretary of Health and Human Services rather than requiring Congressional intervention. This unusually direct pathway allows the contributions of experimentation to improve healthcare delivery, and the quantitative data outlined in this chapter provide important insights for future improvements. Then, Sarah Matousek and Niko Lehman-White explore the social determinants of health, explaining that though for decades, starting long before the ACA, Americans have been part of a separate, long-term, largescale social experiment that shows us the results of healthcare delivered on a patient-by-patient basis, isolated from other health-related factors. However, as health is determined by far more than care delivered in healthcare facilities, our nation's focus on healthcare, rather than on health, and the social determinants of health, has missed many avenues for improved health. The evidence from this experiment is that we must shift our attention more toward prevention, public health, and wellness, and ultimately, must adopt a "health in all policies" approach. Such strategies are needed to stem our country's rising levels of un- and underinsured, as Rosemarie Day and Lehman-White illustrate with real-world examples in Chap. 11, because barriers like unstable employment and low levels of education and literacy continue to impede healthcare access.

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Day and Lehman-White continue the discussion in Chap. 12 by exploring some of the specific policy levers that states can use to promote stability in health insurance markets and thereby to improve insurance affordability to the currently in insured residents. In doing so, they illustrate how the ACA serves as a catalyst for healthcare reforms at the federal, state, and market levels. Day closes this second edition by reiterating that while the ACA is a major step, it is only one step on a longer path of optimizing our healthcare system so that it is more on par with the rest of the developed world in its fairness, efficiency, and outcomes. After careful reflection on the various paths to universal coverage, she concludes that our country does best in implementing major policy changes when we agree on a common goal and then take incremental steps to accomplish it—an approach that gives us a chance to experiment, make adjustments, and keep moving forward.

Taken altogether, these chapters make it clear that while the ACA may be the largest healthcare experiment in our history, it is far from being complete or being the last. In addition to furthering understanding of this landmark legislation, the aim of this updated edition is to advance the dialogue and inform future innovations as we work toward the crucial, but still distant, objective of a more perfect healthcare system.

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Chapter 2 A Decade of ACA: The Successes, Unfinished Work, and Impact of the Affordable Care Act



James Roosevelt Jr. and Terence Burke

Since being signed into law on March 23rd of 2010 by President Barack Obama, the Affordable Care Act (ACA) has prevailed as one of the most transformative pieces of social and economic legislation in history. As the definitive and defining piece of public policy in Obama's presidency, it stands alongside Social Security, Medicare, and Medicaid in applying the powers of the government to increase equity in our society while ensuring that the American people can now rightfully expect to have access to quality affordable healthcare.

While there is a long history of attempts to create a government-backed health-care option – going back to President Franklin Delano Roosevelt – there were several mounting pressures that made the passage of the ACA possible. These pressures included rising numbers of uninsured and underinsured people, rapidly rising healthcare costs, an increase in the impact of chronic disease, and the realization that the costs of healthcare and the state of health of the American people can have a major impact on our economy.

Despite all of this, the ACA has faced considerable political opposition. It was bashed and trashed in its development and passage into law, weaponized through the 2016 presidential campaign, and described as in a "death spiral," right up until the high drama moment when late Senator John McCain (R-AZ) rescued it from the brink of extinction with his late night thumbs-down vote on a bill that would have killed it.

After almost a decade of highs and lows, we now know that the ACA has benefitted people's health and our economy, that there is still unfinished work to be pursued to achieve full access and equity, and most importantly, that the American

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