

Introduction

JESSICA M. MULLIGAN AND HEIDE CASTAÑEDA

Daniel visited the customer service center at the Rhode Island health insurance exchange close to the last day of open enrollment. He had heard about health reform, but could not figure out how to sign up. Daniel joked with the enrollment specialist about how difficult the application was: “I’m even a computer guy!” he said. The specialist was not chatty; she efficiently took his information and entered it, her screen facing away from Daniel. The waiting room was overflowing with people—some waited in their cars because the building was at capacity. The enrollment specialist would be there late into the evening.

After a few more keyboard clicks and consenting to all the required government legalese, Daniel was happy to find out that he qualified for Medicaid. As a person with Type 1 diabetes who had gone a decade without insurance coverage, Daniel was visibly relieved. He had to pick a Medicaid plan and wanted to make sure that the endocrinologist he had been paying out of pocket to see for years participated in the plan’s network. He was upbeat and asked twice about the co-pays. “It’s all free?” he asked. “All free,” the enrollment specialist assured him.

Three months after Daniel’s enrollment, he was interviewed about his experience while seated at the dining room table in his apartment in Pawtucket, a New England mill town whose industries have mostly relocated elsewhere. Daniel lived on the third floor of a triple-decker with angled walls and sloped ceilings. Daniel was single, white, and lived alone with his cat. He was 28 years old and had a high school education. He started technical schools a couple of times because he really wanted to be a computer programmer, but he was never able to finish. He accrued more than \$10,000 in student loans from these attempts and was struggling to make the payments. In March, he worked part-time

making deliveries for an auto parts store; in May he had a new job with additional hours at a warehouse.

Daniel said he was trying to unlearn some of the habits he developed when he was uninsured: He had stopped checking his glucose regularly because he couldn't afford the test strips; he didn't always have enough medication, so he skipped doses or just ate less; he didn't have enough needles, so he reused them five times or more.

Gaining access to Medicaid greatly reduced Daniel's chances of being hospitalized again in diabetic shock. He was still receiving bills from before he was covered. One thing he didn't miss, he said, was having to complete paperwork for charity care when he was slipping in and out of consciousness. Now that his supplies and medication were covered, he was back on a regular testing and insulin regimen. He was also getting help from his health plan to quit smoking.

Daniel's case shows a best-case scenario for the Affordable Care Act (ACA), a sweeping overhaul of the U.S. health insurance system signed into law in 2010. This legislation was the most dramatic reform to the U.S. health care system since the passage of Medicare and Medicaid in 1965. For some, like Daniel, the ACA represented a huge improvement in their life chances. They were incorporated into new and expanded programs that offered health coverage, including expanded Medicaid for adults in many states, which in Daniel's case gave him a real opportunity to manage his chronic health condition. As a person with diabetes, he would have been uninsurable on the individual market prior to the ACA, since insurance companies could discriminate against those with preexisting health conditions. In 2011, there were 48 million nonelderly uninsured people in the United States, roughly 18% of the nonelderly population (Kaiser Commission on Medicaid and the Uninsured 2012). By 2016, the number of nonelderly uninsured had fallen to 27 million, or 10% of the nonelderly population (Kaiser Commission on Medicaid and the Uninsured 2016). Because of the law's reforms, the U.S. uninsured rate declined by 43% between 2010 and 2015, with improvements in affordability, financial security related to health care debt, and a reduction in the amount of nonelderly adults reporting fair or poor health (Obama 2016).

Yet for others, the ACA did little to address their exclusion from health care. As the chapters in this book detail, some people, such as un-

documented and recent immigrants, were intentionally excluded from coverage under the law to establish boundaries around national belonging; others were excluded by affordability, by bureaucratic hurdles, and by choice; and still others were excluded by virtue of state policies in the wake of a Supreme Court decision, *National Federation of Independent Business v. Sebelius*, Secretary of Health and Human Services, in 2012 that made a key provision, the expansion of Medicaid, optional.¹ Thus, while the law represented an extension of social protections to some groups previously excluded from health insurance, in other ways, it created new forms of exclusion as access to affordable coverage options were highly segmented by state of residence, income, and citizenship status. This book documents the everyday experiences of individuals and families across nine states as they attempted to access coverage and care in the wake of the passage of the ACA between 2012 and 2017. It shows that people in the United States desperately wanted and needed affordable health insurance coverage; however, stratified approaches to expanding access generated resentment. Difficult enrollment processes, opaque eligibility rules, expensive premiums, and high deductibles provoked criticism from across the political spectrum. But it was conservative politicians and nativist social movements that most vehemently tapped into and fueled discontent with the law. This book illustrates lessons learned from the ambitious rise of the ACA—a law that aspired to bring affordable health care to most Americans—to its subsequent vulnerability as the political tides changed. We hope future health reforms will build on these lessons, rather than pursue health policies that increase inequality and stratification. We also hope that reformers and students of health policy will see the value in listening to on-the-ground human experience, rather than attending to statistics alone.

The ACA: An Abbreviated Overview

Unlike all other high-income and most middle-income countries, the United States has never made universal health coverage a social right. Instead, health care is delivered through a complex mix of public and private coverage with about half of financing coming from the public sector and half from private sources, which includes employer-based coverage and out-of-pocket spending. This market-based, for-profit

health system has resulted in the highest health spending per capita in the world in return for mediocre health outcomes (OECD 2014). The United States has below-average life expectancy among countries of similar economic output and scores poorly on measures of managing chronic disease and access to primary care (OECD 2015). In addition to its unrivaled expense and lagging outcomes, the major shortcoming of the U.S. health care system is its lack of universal coverage.

It is hard to overstate the degree to which the lack of health insurance in the United States was, and for many people continues to be, a humanitarian crisis that exacerbates illness and shortens lives (Kaiser Commission on Medicaid and the Uninsured 2012). For the uninsured, medical needs can quickly lead to financial catastrophe, with medical bills leading the list of reasons for declared bankruptcies (Himmelstein et al. 2009). But industry support for reform only came about because having so many uninsured and underinsured persons in the United States was exerting a drag on the entire health sector. Hospitals and other safety-net institutions strained financially to treat the uninsured because they were obligated by federal law to do so.² Insurance premiums showed double-digit increases year after year. Reeling from a deep recession with unemployment swelling, the moment had come for change.

From its passage by the Obama administration with no Republican support to its many days in court, this law was no stranger to controversy. Though the ACA resembled past Republican health proposals, opposition hardened into a scorched-earth approach galvanized by the Tea Party movement, conservative think tanks, and organizations like the American Legislative Council (ALEC) and the Koch Foundation (Haeder and Weimer 2015; Jones et al. 2014). In addition to calling President Obama a “liar” and a “socialist,” Republican opposition framed the ACA as government overreach. Anti-ACA advocates voiced wide-ranging objections to specific provisions of the law, including claims that the individual mandate was unconstitutional, accusations that the law would drive up costs, opposition to new taxes, concerns about paying for Medicaid expansion at the state level, and charges that “illegal” immigrants would benefit from the law.

The politics of reform framed the ACA as a much more radical and progressive policy than it actually was. Ultimately, the ACA was a middle-of-the-road policy that built on a legacy of public/private

solutions to social problems. It sought to expand access to coverage through two major provisions: first, by expanding Medicaid to adults making less than 138% of the federal poverty level (FPL), and second, by creating insurance exchanges (i.e., online marketplaces) to sell more affordable coverage to individuals, families, and small businesses.

Prior to the ACA, Medicaid programs varied markedly by state and only covered certain categories of low-income individuals: people older than age 65, some disabled individuals, parents, children, and pregnant women. In most states, non-disabled, childless adults were ineligible for the program regardless of their income. Before the ACA, the median eligibility level for working parents was 61% of FPL, meaning that many poor and near-poor parents also went without coverage (Paradise 2015). Medicaid programs were (and continued to be for the populations that were eligible through pre-ACA criteria or in non-expanding states) financed through a Federal Medical Assistance Percentage (FMAP), in which states and the federal government shared the financing for the program. Poorer states enjoy higher FMAPs than wealthier ones; assistance from the federal government ranged from 50% to 73.6% (Paradise 2015). In contrast, the federal government financed the vast majority of costs for the ACA Medicaid expansion; starting at 100%, this was to be gradually phased down to 90%. In other words, the ACA sought to uniformly provide low-income individuals with affordable and comprehensive health coverage through Medicaid, mostly with federal dollars.

The insurance exchanges created through the Affordable Care Act vastly expanded the non-group insurance market by removing some barriers that kept it small: It was no longer legal to bar people, like Daniel, from coverage or to charge them more because of preexisting conditions. Gender rating—which meant that women were charged more for insurance than men—became expressly prohibited. Insurance companies could no longer cancel policies after they were issued (called “excision”). And all insurance products offered on the exchanges were required to comply with the standardized minimum benefit package, meaning that they had to include a comprehensive package of basic services (Cassidy 2013). Risk-pooling strategies known as risk corridors, risk adjustment, and reinsurance were applied to the non-group market and helped to better distribute risk, thereby shielding insurance companies from high losses as well as inordinate profits (Goodell 2014).

Perhaps most important, the ACA addressed the issue of affordability on the non-group market by providing subsidies in the form of tax credits and cost-sharing reductions for households below 400% and 250% of poverty levels, respectively.³

The ACA survived multiple legal challenges, but the 2012 U.S. Supreme Court decision that states could opt out of the Medicaid expansion created new and unanticipated problems. Since subsidies were designed to help those who were ineligible for Medicaid, the law was written in such a way that those living below 100% of the federal poverty level were ineligible for help purchasing coverage. And so, in states that decided not to expand Medicaid, millions of people fell into what came to be called “the coverage gap”—they were too poor for subsidies on the exchange, and largely remained uninsured. Chapters in this volume by Mulligan, Sered, and Brunson in particular describe how people experienced falling into this gap, where they often blamed “Obamacare” for their lack of coverage rather than the state governments that opted to turn down federal Medicaid funding that in the first two years would have paid for 100% of the cost of expansion.⁴ Because some local and state governments, especially in the South, expressed hostility toward the ACA, in many places the law was only partially implemented.

Its very rocky rollout did not bolster the popularity of the law. The web-based technology platform that hosted www.healthcare.gov, the federally run exchange, encountered debilitating problems. This led to the resignation of the Secretary of Health and Human Services and the appointment of a new Chief Technology Officer (Shear 2014). The law also gave states the option to run their own exchange, default to a federally run exchange, or pursue a hybrid arrangement whereby some responsibility for exchange functions would be split between state and federal actors. Some state-based exchanges were so dysfunctional that they stopped operating and called on the federal exchange to take over. Despite these considerable challenges, millions of people managed to enroll in coverage and many of the exchange’s technical difficulties were eventually resolved. Subsequent enrollment seasons were much less controversial than the first year, but enrollment was still lower than initially predicted (Levitt et al. 2016).

In the years following its passage, the law underwent dozens of recall attempts by the U.S. House of Representatives in addition to two chal-

lenges brought before the U.S. Supreme Court. It was shielded largely by President Obama's veto power and the threat of a filibuster in the Senate. A politically divisive issue during the 2016 presidential election campaign, the ACA's vulnerability became evident with the transition in executive power. Donald Trump's rise to power was propelled by anti-ACA sentiment. In the Conclusion chapter, we reflect on how his administration radically disrupted the political landscape of the United States and what this might mean for the future of health care access and coverage. Unlike other major health reforms, such as the creation of Medicare and Medicaid in 1965 or the addition of prescription drug coverage to Medicare in 2003, the ACA never transformed into a taken-for-granted and depoliticized health care entitlement program. It remained politically contentious years after its passage. This book helps to explain why by illuminating actual people's experience with health care reform.

Why Study the ACA Ethnographically?

This book presents the stories of communities and individuals located within specific moments of time and contextualized within particular places. The themes that these stories touch upon are not limited to the ACA, but speak as well to the experiences associated with economic restructuring, multiple and overlapping forms of inequality, and the struggle of trying to care for one's self and family in a context of shifting public policy priorities that emphasized personal responsibility and the privatization of public services. This is an anthropological study of policy, and especially the "messy" work of policy implementation. It explores processes and theoretical concepts that have been at the center of social scientific studies of policy—namely, issues of power and governance (e.g., Horton and Lamphere 2006; Okongwu and Mencher 2000; Shore and Wright 1997)—and thus speaks to a wider audience than simply those interested in the recent U.S. health care reform. This book is for scholars, students, and practitioners interested in power, governance, and processes that produce inequality. Using the ACA as a lens on these issues, this book examines how social welfare policies in a multiracial and multiethnic democracy purported to be inclusive while they simultaneously embraced certain kinds of exclusions.

The contributors to this book use ethnographic methods, especially observation and qualitative interviewing, to understand how people made sense of the opportunities and responsibilities that the ACA created for gaining coverage. As researchers, we spent time with people who were providing enrollment assistance and those who were seeking health coverage. When possible, we tried to get to know people in multiple settings, including during formal interviews, at home among family, and even by accompanying them to medical appointments. The ethnographic approach that guides this book differs markedly from most academic accounts of the Affordable Care Act, where there is a strong bias toward quantitative and statistical methods. Ethnographic methods are open-ended, intersubjective, and contingent. Anthropologists follow hunches about what is important, track down as many people who will talk to them as they can, and often spend time during fieldwork simply waiting for something to happen. We do this because we understand that policy is experienced amid other everyday concerns that shape our lives and that health coverage intersects with a wide range of social responsibilities, including caring for one's self and family, seeking financial security, obtaining work, and enhancing well-being.

For those who think that generalizability should be the ultimate goal of research, ethnographic findings can appear maddeningly specific. Some anthropologists argue that we should address our lack of generalizability by reinforcing our methodological rigor, answering practical policy questions that are of interest to health researchers, and better triangulating our data (Closser and Finley 2016). We approach these recommendations with caution, because while relevance is something we strive for, we do not want to lose sight of the unique strengths of ethnographic methods. Specifically, if our methods are always already attuned to producing a list of policy recommendations, using this approach may weaken our ability to broadly contextualize our findings in social and political structures, our ability to embrace the unexpected (Taylor 2014), and our attentiveness to contradictory and subjective understandings that no amount of triangulating can resolve. An important message from this book is that differently situated individuals can have radically different assessments of whether or not a particular health policy benefits them, and these assessments *are* true from their perspective.

In critically examining the call to be useful, which health practitioners sometimes demand of anthropologists, Stacy Leigh Pigg argues that we must remain committed to a methodology that involves sitting and listening: “Whereas global public-health policy looks to ethnography solely as a source of information, pertinent to its goals, ethnographers see their task quite differently, holding that the purpose of patient ethnography is to listen and to be in situ, a practice that opens up a space for the questioning of received certainties through a responsiveness to multiple viewpoints and contested perspectives” (2013, 127). A very similar point could be made about medical anthropologists working in the United States, where there is an increasing desire for “patient-centered” research. Anthropologists have found homes on multidisciplinary research teams, but the methods that are ultimately valued are those of evidenced-based medicine and comparative effectiveness research, in which the purpose is to discover what procedure or intervention is most effective so that it can be widely implemented. Anthropologists have also been caught up in the demands of medical research infrastructures and their “fast” ways of publishing results, scaling up, and churning out programs that should be implemented uniformly in diverse settings (Adams et al. 2014). As anthropologists, we are attentive to particularities and the specificity of places. There is much to be gained by sitting and listening to the people who are involved in health policy projects, both as agents and as targets. Sometimes this listening yields policy insights (for instance, if we really want people to maintain coverage, then the enrollment process shouldn’t be so difficult). But other times, what we gain is a richer understanding of the complexities of struggling to care for each other, of political and other forms of belonging, of the reverberations of exclusion, and of the other parts of life that shape and are shaped by health policies. When we are open to the messy contradictions of health policy implementation as it is actually experienced, we see that choosing whether a policy is “good” or “bad” is an impossible task. Instead, we trace the effects of this policy, which continue to shape people’s well-being, sense of belonging, and life chances.

This volume is multi-tonal—the authors and the people interviewed are at times strident, outraged, neutral, technocratic, sarcastic, hopeful, and devastated. This is because the stakes were so high. The ACA engendered hope for improved access to care, healing, and financial security.

It also struck fear and worry in those who had coverage or made their living in the health care industry. Instead of aiming for evenhandedness, we have assembled a mix of viewpoints (though not an exhaustive or “representative” list). The chapters do not all take the same approach—some are more overtly critical, some more hopeful, some forlorn. This seems appropriate for a policy that had such diverse and differential effects depending on state of residence, income, immigration status, age, health status, type of insurance coverage, and so on.

Health care advocates have pushed us to refrain from being too critical—they have even said we should avoid emphasizing the negative, especially as the gains the law made in expanding access to coverage seem so fragile and likely to be undone. This criticism has given us pause. We do not want this work to become ammunition for dismantling the law. We would much rather provide evidence and new perspectives for those advocating for a more universal and inclusive coverage expansion policy. But we also acknowledge that our work is likely to have other impacts that we have not anticipated. Ultimately, we feel a responsibility to be honest with the material—and that means not hiding that, for many uninsured people, the law did not improve their circumstances. It means not obscuring the ways in which the law was cynically used to fan racial animus, but also structured in such a way that it created new resentments. It means remembering who the law left out. And finally, it means not shying away from critiquing the misuses of accountability talk and the commitment to market principles over an ethic of care that are enshrined in the law (Horton et al. 2014; Mol 2008). Twenty million people gained access to coverage under the ACA. For many, that access was life-altering. But our job in this volume is a more modest accounting. We seek to illuminate the contradictory effects of this policy in the world, on well-being, on belonging and exclusion, and on felt risks and responsibilities in the everyday contexts and for the ordinary people whose lives it was supposed to make better.

The ACA and Governance: Stratified Citizenship, Risk, and Responsibility

Answering calls to forge a more publicly relevant research practice (Horton et al. 2014), this book brings together ethnographic engagements

with the Affordable Care Act and explores three interrelated themes that reflect upon central theoretical concerns: stratified citizenship, risk, and responsibility. Structured under these broad themes, which are woven throughout the book and appear, to some extent, in all the chapters, this book documents how the law produced new social relations, modes of government, and experiences of care.

Stratified Citizenship

While the ACA intended to expand social rights and protections, it did not include everyone. Nor did those who received the law's benefits view it in a uniformly positive light. This book draws attention to the uneven ways in which people experienced the law on-the-ground, based on the insights provided through careful ethnographic research in communities. By talking with the people the ACA brought into coverage and those who were left out, we learned that the responsibilities and benefits of the law were distributed unequally, but in highly patterned ways. We use the term *stratified citizenship* to describe how certain social identities and demographic characteristics—such as immigration status, income, gender, race, and state of residence—mediated how people were included or excluded from health insurance coverage through the ACA.

Citizenship, at its most fundamental, refers to a complex set of practices that constitute political belonging. In this book, the concept of “citizenship” is understood not simply as legal membership in a state, but rather as practices of claims-making in various sites and scales that create political subjectivity. This broader relational definition of citizenship emphasizes that it is a dynamic institution of both domination and empowerment, governing who is citizen, subject, and abject, and how these actors relate to one another in the body politic (Isin 2009). Thus, stratified citizenship refers to the differential gradation of rights and opportunities to different groups residing within the same state. Here, we extend the concept of citizenship beyond legal belonging to a nation-state (as in holding a passport of a particular country) to also include the political, social, and affective experiences of belonging as forms of citizenship for many types of social groups, regardless of nationality. The chapters that do examine juridical statuses for immigrant groups (legal permanent residents, deferred action, undocumented, etc.) show that

stratified citizenship is experienced in complex gradations of partial inclusion that tap into feelings of aspiration, hope, and disappointment, while enacting exclusions that can range from ambiguous and incomplete to cruel and life-threatening.

The concept of *health citizenship* recognizes that social inclusion and marginalization are often produced through unequal access to health care, structural barriers to health, and provider attitudes. This concept helps us to understand how stratification can result in some groups experiencing higher levels of access or receiving better quality health care than others, even when all groups are purportedly included in the same system. In particular, ideologies of health-related “deservingness” (Willem 2012) can help to explain the disjuncture between formal entitlement and actual access. This book argues that, in many instances, the ACA reinforced preexisting patterns of exclusion, often by reinforcing long-standing distinctions between the “deserving” and the “undeserving.” Means testing is one way in which this occurs; long controversial in the design of poverty relief programs that are stigmatized, it is often used to sort the “deserving” from the “non-deserving” poor (Katz 2008). While addressing some existing inequalities in the U.S. health care system, the ACA also exacerbated or produced others through the differential opportunities afforded various groups, such as legal permanent resident immigrants or LGBTQ communities. In other words, “[t]he ACA aims to redress systemic inequalities in access to care, but not all populations will benefit equally” (Horton et al. 2014).

The Affordable Care Act’s impact on racial inequalities in health and health coverage has been complex. Many provisions of the law aimed to reduce health disparities, such as improving data collection on race and ethnicity, diversifying the health care workforce, and funding research on disparities and health equity (RWJ 2011). And importantly, blacks and Latinos experienced some of the biggest gains in coverage under the law (McMorrow et al. 2015). Nonetheless, these groups continued to be disproportionately uninsured: At the end of 2015, 21% of Hispanics, 11% of blacks, and 7% of whites were uninsured nationally (KFF 2016a). Because undocumented and some lawfully present immigrants were explicitly excluded from coverage, those populations remained uninsured at much higher rates than citizens (see chapters by Castañeda, Joseph, and Melo in this volume). Furthermore, the partial implemen-

tation of the ACA through non-Medicaid expansion and insufficient in-person assistance in states with governments hostile to the ACA disproportionately impacted blacks and Hispanics. One study estimated that 1.4 million more blacks would have been covered if Medicaid expansion had not been optional (Clemans-Cope et al. 2014; McMorrow et al. 2015).

As we argue in this volume, it is no accident that people of color were disproportionately impacted by the decision to exclude some immigrants from coverage and to opt out of Medicaid expansion. Repeated attempts to repeal and disrupt the implementation of the law are part of a long history in the United States of opposing programs that are perceived as benefiting communities of color, especially, though not exclusively, in the South (Haney López 2014). As of 2016, 90% of people in the coverage gap lived in the South (Garfield and Damico 2016). Voting to repeal the ACA and blocking implementation join a long list of practices (such as onerous application procedures, frequent eligibility re-verification, work requirements, and literacy tests) designed to disenfranchise people of color and thwart policies that might result in greater financial, educational, and racial equality.

The ACA both built upon but also remedied existing stratification by gender, sex, and sexuality. The law ended gender rating—the practice of charging men and women different rates for identical health plans—and protected women from higher premiums, in addition to lifetime and preexisting condition limits. Prior to the ACA, women paid up to \$1 billion more than men each year for identical insurance plans on the individual market (the practice was already banned in the case of employer-based plans) (NWLC 2012). The law also expanded access to basic women’s health services and mandated the inclusion of maternity care and coverage without cost-sharing for preventive services such as contraceptives. However, contraceptive coverage applied only to women; men using vasectomy or condoms were left with out-of-pocket costs, despite a long history of inclusion in other public and private programs. These gendered exclusions generated resentments and led to a backlash, with conservative lawmakers and media outlets objecting to and fanning outrage over the inclusion of maternity care in the individual market, since men must contribute to covering the cost for this particular service that, by definition, they do not use (Franke-Ruta 2013).

The law also remedied some heteronormative exclusions, requiring insurance plans to offer coverage to same-sex married spouses; it also extended nondiscrimination protections (KFF 2016b). For people living with HIV/AIDS, the removal of the preexisting condition bar was an important victory and allowed this segment of the population to access comprehensive insurance policies. The Ryan White HIV/AIDS Program began to transition its role to assist people in obtaining coverage through the ACA marketplaces and Medicaid expansion (HRSA 2016). However, health plans have used other means to discourage enrollment of HIV-positive people, such as discriminatory formularies that make HIV medications inordinately expensive (NH&LP 2014). The removal of the preexisting condition clause, along with the fact that the ACA prohibits discrimination based on sexual identity, also greatly benefited transgender persons. Major advocacy organizations for transgender people interpreted the law to mean that transition-related health services should be covered by ACA plans (NCTE 2016).

We link stratified citizenship to a longer history of allocating access to medical care based on notions of deservingness that were articulated in their contemporary form in the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA), which essentially repealed prior social safety net programs. Passed in 1996 by the U.S. Congress and signed into law by President Clinton, PRWORA transformed the welfare system by replacing it with state-run, block-grant programs using new criteria that included time limits for benefits, tying receipt of benefits to employment, and providing incentives for reduced caseloads. As the name suggests, it increased the emphasis on “personal responsibility” of the poor, adding a work requirement and a lifetime benefits limitation of five years. PRWORA also set the precedent of tightly intertwining eligibility for federal benefits with immigration status, denying eligibility to most legal immigrants during their first five years of U.S. residence. Through the ACA, these practices of conferring eligibility to “deserving” versus “non-deserving” immigrants and requiring that recipients of public benefits demonstrate and enact responsibility were intensified and became even more commonplace. Thus, the ACA was layered upon an existing patchwork of policies that already created exclusionary effects for some populations. This volume is attentive to the landscape of health care access already in place

when the ACA was implemented, and highlights the ways in which it emerged under already highly stratified conditions of eligibility.

A key concern that this book raises is whether—and to what extent—the ACA succeeded in including the large segment of the U.S. population that was previously uninsured or underinsured. More broadly, the chapters by Castañeda, Melo, Joseph, and Andaya each unveil the processes associated with projects of stratified citizenship by exploring who gained access and who was excluded. Because the ACA maintained many prior exclusions—such as the exclusion of “nonqualified” immigrants from Medicaid—while simultaneously creating new exclusions (such as that of DACA recipients), the law created a complex landscape of eligibility for immigrants in mixed-status families (Castañeda, this volume). Moreover, as the federal government has devolved to states the decision about whether to restore inclusion in Medicaid for certain unqualified immigrants (such as legal permanent residents who have been in the United States for less than five years) (Joseph)—as well as what services Emergency Medicaid should provide undocumented immigrants (Melo), this landscape of exclusion varied dramatically across states. Furthermore, as Andaya suggests, there is a difference between health inclusion and health equality, arguing that we must move beyond studying coverage as an either/or scenario and instead illustrate how different *forms* of health coverage can also contribute to experiences of stratification. As people were unequally included in the rights and responsibilities engendered by this law, how did that create new and further entrench earlier affective feelings of belonging and external evaluations of deservingness? Of course, ideas of deservingness are also connected with notions of risk and responsibility, as we illustrate in the following sections.

Risk

The ways people assess and experience risks are deeply connected to their class positions, sense of vulnerability, and social resources. Therefore, we treat risk as an embodied, relational concept rather than an abstract property. Our focus in this volume is on how people experienced multiple forms of risk and found ways to navigate them in the new health care landscape created by the ACA. Measuring and predicting

risk is a core part of the concept of “insurance”: Insurers profit when the actual health costs of their risk pools are lower than the premiums they collect. Insurance can serve as a way to socialize risk, but it can also segment risk into smaller and more profitable pools that take precedence over broad social protection (Dao and Mulligan 2016; Ericson et al. 2003). In financial terms, more risk is not always a bad thing, since it can mean higher rates of return when risk refers to the probability that an investment will make or lose money. But risk isn’t just the product of prediction and formulas; it can be affective, too. Talking about health insurance coverage often brings up feelings of being “at risk” or in danger; people we spoke with described the sense that they were “risking” something important, such as their health or security. And risk can also refer to behavior: Risk is something we do, like drink alcohol or use drugs. And sometimes it becomes something we are. Risk is used as a label to describe a person—for example, poor pregnant women are often deemed “high risk” and subject to intense surveillance because of it (see Andaya, this volume).

Many of the chapters here show how individuals and families calculated their health and financial risks when they enrolled in coverage and attempted to access health care services. Perceived health risks, both for oneself and for family members, play a big role in shaping whether coverage is considered necessary and desirable. People who lived with a chronic condition or who experienced serious injury were more likely to view insurance as a necessity. This may be why those who signed up for coverage in the first few years of the ACA turned out to be sicker than initially predicted (Pear 2015a). Those with unmet medical needs were among the first to enroll, in part because preexisting condition clauses had prevented those with medical needs from signing up for coverage on the individual market.

Obtaining insurance to mitigate risk was a common strategy employed by the people we collectively studied, but other approaches were also noted. In a neoliberal era when many risks have been transferred from state programs onto individuals (such as indexed retirement accounts in the form of 401(k)s replacing guaranteed pensions), some individuals and families “embraced risk” (Baker and Simon 2002). They shopped extensively, calculated the cost of various disaster scenarios such as a car accident that might injure the entire family, and negotiated with

providers to obtain the maximum return on their health care investment (see Brunson, this volume). These individuals understood their decisions within a framework of being responsible risk-takers and were often ideologically hostile to government insurance or “Obamacare.” However, this risk-embracing strategy was a response to highly circumscribed conditions, where the deck was stacked against middle-income individuals and families, who chose between spending tens of thousands of dollars on insurance premiums and deductibles or risking their family’s health and financial security by gambling on remaining uninsured.

As these “risk embracers” illustrate, health insurance can both protect families from financial risks as well as generate new risks as families strain to keep up with the costs of high premiums and deductibles. As noted earlier, medical bills are the leading cause of bankruptcy in the United States (Himmelstein et al. 2009), so remaining uncovered can be financially risky for those in the middle class, who have assets to lose. But increasingly, having coverage does not provide complete protection against catastrophic medical bills. Most plans on the exchanges had substantial cost-sharing in the form of deductibles that made it difficult for people to access health services even when they were able to pay their premiums. A *New York Times* analysis found that more than half of the plans offered on exchanges had a deductible of \$3,000 or more in 2015 (Pear 2015b).

In the wider medical anthropology and sociology literature, risk has also been interpreted as a form of medicalization or diagnostic creep. Pre-disease states (pre-diabetes, obesity, or pre-hypertension, for example) signal an elevated probability of developing an illness and can come to be experienced as disease states themselves. In *Drugs for Life* (2012), Joseph Dumit argues that pharmaceutical marketing strategies explicitly seek to inculcate the idea that we are always at risk of impending illness. Risks are perceived in society in a way that naturalizes a need to always be treated, even if a person shows no actual sign of disease.

This calculable and medicalized understanding of risk as described by Dumit did not resonate with many of the people we studied who remained uncovered. They did not know their specific risk factors and biomarkers, as pharmaceutical marketers might wish, because they were cut off from consistent care and lab work is often not covered by safety net institutions. Instead, many intrinsically felt the risks of managing

their chronic conditions without insurance, of worsening health when insulin, asthma inhalers, and addiction treatment were out of reach, of sliding into disability and unemployment when their unmet medical needs made it impossible to maintain their previous levels of functioning. They weren't always already at-risk so much as experiencing the kinds of subprime risks that make being poor so dangerous to one's health.

Similar to the subprime financial instruments that made the poor profitable for payday, auto, and high-risk mortgage lenders, the health risks that poor and uninsured populations experience in the United States both worsen their health status and undermine their financial stability, all the while generating revenue for outpatient clinics, insurance carriers, hospitals, and debt collection agencies. In the financial meltdown that preceded the passage of the ACA, subprime financial instruments (like payday loans and high-interest and balloon mortgages) were aggressively marketed to low-income people. These expensive and often misleading loans undermined the ability of the working poor to achieve financial security through home ownership and exacerbated unemployment-related insecurity (Dwyer and Lassus 2015). Just as poor Americans are cut off from traditional financial instruments like 30-year fixed-rate mortgages, so too are many cut off from integrated health care and comprehensive, low-cost health insurance. The ACA attempted to address this intermingling of health and financial risks—and for those who were able to enroll in expanded Medicaid, their financial status and access to care improved (Antonisse et al. 2016; Christopher et al. 2016). Nonetheless, the ACA's exchanges provided coverage that was beyond the financial means of many. We argue that the health system itself generates new subprime risks, where health is precarious and always in danger of unraveling. And so, the chapters in this volume ask: How did individuals and families navigate the new financial and health risks created by the ACA? And how does the segmented and disjointed health system in the United States create risks for the covered and the uncovered alike?

Responsibility

The ACA created new responsibilities for individuals and families and new opportunities for providers and contractors to transform the health

care of the poor and underserved into a revenue-generating enterprise. The law's responsibilities were unequally distributed—individuals and families came under increased scrutiny and surveillance while technology and other service contractors entered into lucrative agreements and benefited from a lack of oversight at the highest levels of government. The ACA's individual mandate transformed health coverage from an employment perk and a protection into a *responsibility*. Before the ACA, health coverage in the United States was a middle-class benefit that some workers received from their employers.⁵ Coverage was also available through a mix of public programs for some protected groups: poor pregnant women, some poor children, some people with disabilities, those over 65, and some veterans. The ACA required that individuals and families obtain coverage or pay a fine. But the new responsibilities engendered by the law did not stop at coverage; they fanned out into state governments and the private sector and involved a wide range of actors and organizations in the work of implementation.

The ACA must be seen as part of a longer history of welfare reform that has devolved responsibility for public services onto community organizations, businesses, and individuals over the last three decades (Clarke 2004; Goode and Maskovsky 2001; Kingfisher 2002; and Horton et al. 2014). For example, following the PRWORA welfare reform in 1996, recipients of TANF (Temporary Aid to Needy Families) had to prove they were actively looking for work or enrolled in job training, and they were subject to drug testing and other forms of invasive monitoring (Soss et al. 2011). The job training programs funded through the TANF program were contracted out to private firms and community organizations. Likewise, the ACA focused on personal responsibility by requiring that individuals obtain health insurance, and famously relied on private subcontractors and partners to carry out many of its key provisions (Jain et al. 2015).

Like other government-funded social service programs in the United States, the ACA is an example of “delegated governance” (Morgan and Campbell 2011). Responsibility for carrying out the key purpose of the law—expanding insurance coverage—was placed on individuals, families, and employers with government agencies and their contractors serving as middlemen. More specifically, the ACA expanded access to health insurance by extending and adding on to existing programs,

which were largely administered at the state level (Medicaid) or by private entities like employers and insurance companies. The federal government's ascribed role was actually quite limited; it included writing regulations, enforcing the tax provisions of the law, running insurance exchanges if states opted not to, and paying for the Medicaid expansion and insurance subsidies. State governments had to decide whether to expand their Medicaid programs to poor adults or to operate an insurance exchange, and oversee and regulate insurers (Morgan and Campbell 2011).

Though this well-established model of delegated governance was employed in the ACA, it is important to point out that the law reversed a long-standing trend to cut benefits received by working-aged, non-disabled adults. Instead, the ACA established that insurance was important and necessary and provided new avenues for childless adults to access coverage through the expanded Medicaid program and insurance exchanges. Likewise, the responsibilities the law created were not always burdensome or oppressive for marginalized groups; in emphasizing collective responsibility, the ACA also provided more funding for community health centers and mandated a focus on the recording and alleviation of health disparities. For all of its flaws, the law contained a fundamental conception that the state was responsible for making health care available and affordable. Nonetheless, access to health coverage was still not considered a right, since the law obligated people to purchase insurance and did not guarantee universal coverage.

Together, federal and many state governments expanded public insurance eligibility and created new insurance marketplaces, but the actual responsibility for obtaining, maintaining, and paying for coverage fell to employers, individuals, and families, thanks to the employer and individual mandates. The mandates were one of the most controversial aspects of the law, since they required that most people get covered. Exceptions existed for religious objectors, people who were incarcerated, ineligible immigrants, those who still did not have an affordable insurance option (including millions who fell into Medicaid gaps in non-expanding states), those experiencing certain kinds of hardships, and members of certain groups including federally recognized tribes (CMS 2016). Though 26 states sued the federal government on the grounds that the mandates were unconstitutional, the Supreme Court decided in

2012 that the government does have the authority to require U.S. residents to purchase health insurance coverage as part of Congress's power to levy taxes (KFF 2012b). Penalties for not having coverage thus fell on individuals and were assessed as part of their tax filing in what the law terms a "shared responsibility payment."

While the ACA did expand government's responsibility for providing health coverage to U.S. residents, it fell short of universal coverage and asked much of individuals and families in the process. This downstreaming of responsibility meant that those with the least amount of power to affect the system had new obligations to get covered and pay for their insurance and health care costs in a health care landscape with increasingly stingy insurance plans and exorbitant cost sharing for consumers (Collins et al. 2015). Chapters by Brunson, Mulligan, and Sered explore how people made sense of their new responsibilities to get covered. Other chapters examine how coverage also promoted a responsibility to maintain health. In Susan Shaw's example of medication adherence programs for patients with chronic conditions in Massachusetts and Mary Alice Scott and Richard Wright's case study of a formerly free clinic in New Mexico, patients who gained access to coverage through health reform also experienced new pressures to maintain and improve their health status. As earlier studies of managed care have pointed out, providers commonly fill the gaps left when care is not coordinated or covered. Given their social commitment to serving the poor, many community health centers and charity providers try to buffer the impacts of disruptive policy changes, inadequate patient education, and technological snafus by simply doing more (Boehm 2005; Horton et al. 2001). Cathleen Willging and Elise M. Trott show how policymakers in New Mexico, in an example of "organized irresponsibility," used antifraud provisions of the ACA to dismantle the non-profit, community-based safety net for mental health services, thus undermining the ability of the safety net to serve poor clients.

As ethnographers of health reform, we have sought to show how people reacted to and assumed the new responsibilities created by the ACA. How were these new responsibilities socially distributed? As individuals, families, and employers were charged with the responsibility to obtain coverage, did governments and institutions face similar levels of accountability?

Overview of Book Organization and Chapters

Section I: Inclusions and Exclusions

The first section of the book explores how the ACA emerged as an extension of social protections to some groups but also created new forms of exclusion, as access to affordable coverage options were highly segmented by state of residence, income, and citizenship status. In doing so, it built upon a legacy of existing stratification that had long excluded people by class, occupation, race, ethnicity, immigration status, gender, and sexuality.

The chapter by Heide Castañeda argues that the ACA (re)produced and stratified juridical categories of immigrants with sometimes contradictory results. It highlights the fact that immigrant groups in the United States are not monolithic, but instead are stratified by many chaotic bureaucratic categories. The ACA intensified immigrants' exclusion from the health care system, exacerbating a costly spiral of disability and death. Using three case studies derived from longitudinal research in Texas, this chapter illustrates the unanticipated and contradictory effects of the law by examining how immigration categories influenced eligibility and participation. The ACA not only explicitly excluded more than 11 million undocumented immigrants from coverage, it even distinguished between "qualified" and "non-qualified" immigrants among those who were considered "lawfully present." Through three cases, this chapter illustrates the impacts of these exclusions and inclusions. We see how these distinctions produced ripple effects on U.S. citizen children in mixed-status families. In addition, the exclusion of youth holding deferred action for childhood arrival (DACA) status—produced through an unusual case of administrative rollback—created a new pattern of formal disenfranchisement, while a loophole allowed some immigrants to qualify for insurance subsidies that U.S. citizens living in the same state could not.

In "Stratified Access: Seeking Dialysis Care in the Borderlands," Milena Andrea Melo ethnographically explores a marginalized population who must negotiate exclusionary practices to access treatment to prolong their lives as they struggled with renal failure. This chapter examines the impact of the lack of health insurance coverage for low-income, undocumented immigrants who required regular dialysis to

stay alive. Undocumented immigrants were deemed undeserving of most publicly funded health care services by virtue of their “illegal” status. Those with chronic, debilitating illness struggled to navigate public and private health care institutions as indigent patients in order to locate lifesaving but substandard treatment. Since they were uninsured, receiving irregular and costly dialysis treatments in hospital emergency rooms, paid by Emergency Medicaid, was their only option. Melo demonstrates that the health system itself exacerbated health risks for dialysis patients by requiring that they come close to death before they were offered emergency services. This chapter raises questions concerning belonging, deservingness of care, and American notions of human rights in cases where those with nothing more than “bare life” are excluded.

In “Stratification and ‘Universality’: Immigrants and Barriers to Coverage in Massachusetts,” Tiffany D. Joseph examines how stratification of access by immigration status effectively undermined a “universal” health policy. While the ACA only extended coverage to U.S. citizens and eligible documented immigrants, Massachusetts pursued a universal health care system at the state level and offered coverage to all residents regardless of documentation status. Despite this policy that aimed for inclusion, immigrants in Massachusetts were still more likely than non-immigrants to remain uninsured. Joseph interviewed Brazilian and Dominican immigrants, health care professionals, and immigrant/health organization employees to find out why immigrants remained uninsured. She identified immigration-related, health care system, and bureaucratic barriers that prevented individuals from effectively accessing care. She found that bureaucratic disenfranchisement processes tied to applying for coverage and re-enrollment created major difficulties for immigrants who were unfamiliar with the U.S. health care system and who had limited English proficiency. As Joseph argues, Massachusetts served as both a model and a cautionary tale for ACA implementation, with barriers exacerbated for immigrant, low-income, and minority populations.

“Stratification through Medicaid: Public Prenatal Care in New York City” by Elise Andaya focuses on Medicaid-covered prenatal care in New York State to illustrate how health care for low-income people after the passage of the ACA has reconstituted preexisting patterns of exclusion and reinforced long-standing moral divisions between the “righteous”

and the “undeserving” poor. Given that Medicaid expansion accounted for more than half of the population newly insured under the ACA, this chapter investigates how the long-standing division between “consumers” of private health insurance and Medicaid “recipients” had effectively been maintained. Those covered under Medicaid faced a cultural landscape in which public aid was inextricably entangled with judgments about “proper” citizenship and moral worth. Stratification was especially evident in pervasive beliefs about the disposability of poor people’s time and the disciplinary power of waiting for services that were viewed as “free” or “charity.” In addition, poor women were singled out as medically and socially high-risk patients, justifying increased state-medical oversight in the name of risk that sharply underscored the interplay between discipline and nurturance by the state. Finally, their inclusion in the body politic was only temporary; shortly after pregnancy ended, women and their infants were reincorporated into society through new or existing categories of stratified health citizenship, including non-citizenship. Andaya suggests that the experiences of Medicaid-covered pregnant women reveal the difference between health inclusion and health equality, and the consequences of this distinction for the ACA. This chapter suggests we must go beyond understanding lack of coverage to also take account of how different *forms* of health coverage can also contribute to experiences of health inequality. The failure to dismantle the public/private division places into question the degree to which health reform has transformed ideologies of health citizenship in the contemporary United States.

Section II: Implementation along the Red/Blue Divide

This section examines how the larger politics of the “red/blue divide”—that is, partisan political divisions that led to profound geographic differences in the law’s implementation—shaped both understandings of the ACA and how those affected negotiated the risks of being or not being covered. The chapters in this section show that people made sense of the divisions created by the ACA by using the language of deservingness, individualism, dependence, and responsibility.

Drawing on the concepts of “dog whistle politics” and white resentment, Jessica M. Mulligan illustrates how repeated attempts to repeal

and disrupt the implementation of the ACA must be understood as part of a long history of strategic opposition to programs that are perceived as benefiting communities of color. This chapter examines the different meanings and impacts of the law for differently situated individuals and families, which derive from three overlapping sources. First, they emerge from the contradictions of using means-tested, actuarially rated programs to increase insurance access rather than universal access. They are also the result of the move by some states to reject the expansion of Medicaid and therefore deprive millions of access to medical insurance. Finally, they derive from racial politics that structure how many people make sense of the law. She concludes that there is no shared sense of the social created through the law, which has impacted its success. Instead, people's experience of health care reform, and potentially enhanced health care access, is mediated by a politics of resentment, eligibility and actuarial categories, past experiences with insurance and illness, and attempts to care for loved ones.

Susan Sered, author of the seminal work *Uninsured in America: Life and Death in the Land of Opportunity* (2005), revisits the American health care landscape following the implementation of the ACA and in her chapter returns to the same communities to learn how the people she originally interviewed are faring now. The ACA, she argues, was never designed to overhaul the U.S. health care landscape; rather, it was a political compromise in a health care "system" made up of a chaotic multitude of financing and delivery mechanisms. Of the people she met on her return trips, not a single person had remained in the same coverage status and situation for more than a few years at a time. Even with insurance, she notes, health care is hardly affordable for most Americans. The return visits made it clear that health and access to health care greatly depend upon where one lives. Geographically driven health disparities have been exacerbated by the 2012 Supreme Court ruling, leaving large numbers of people to fall into the "coverage gap." The existence of these gaps, together with the inconsistent nature of coverage and the absence of a human rights ethos, created barriers and hostilities, with many people feeling that other categories of people received greater benefits.

In "Texans Don't Want Health Insurance': Social Class and the ACA in a Red State," Emily K. Brunson examines how the ACA has unfolded

in Texas, a state with significant popular and political sentiment against the law despite being home to the highest percentage of uninsured persons in the nation. State leaders introduced numerous road blocks to coverage, including the decision to not expand Medicaid coverage as well as other less successful efforts to undermine ACA implementation. This has increased the number of *underinsured* persons, who cannot afford health care because of the high costs associated with their expensive and inadequate insurance plans. Providing a deep analysis of longitudinal case studies of three previously uninsured women—some of whom were able to access insurance coverage following the ACA—Brunson shows how each person struggled with issues of choice, responsibility, and risk in relation to their health care. The chapter also considers how social class and gender affected these women's experiences and their understandings of health, health care, and the ACA. Brunson concludes that while the ACA improved health care access and health outcomes for some Texans, it also deepened inequalities by increasing stratification based on social class. Those who were better off economically could use their social capital to navigate the decision to buy coverage or remain uninsured, while the working poor remained without options and continued to live uncovered.

Section III: The ACA's Accountability Contradictions

The final section of the book examines the social distribution of new responsibilities under the ACA and how people responded to the call to get enrolled, improve their health, and pay for coverage. Collectively, these chapters demonstrate that the accountability, responsibility, and transparency that were demanded of patients, clients, and providers were not equally expected from lawmakers, administrators, and insurance companies.

Susan J. Shaw examines the management and regulation of low-income residents' access to and coverage for medications in Massachusetts, the "canary in the coalmine of U.S. health care reform." In this chapter, she shows how Medicaid patients experienced accountability in health care as they struggled to pay out-of-pocket costs for their medications and endured frequent eligibility re-certifications for insurance coverage. Their physicians were subject to insurers' cost-

savings measures that included changing lists of covered medications. Finally, patients received monthly statements from their insurance companies detailing the patients' share compared to the actual costs of their medications. Shifts in medication benefits intersect with complex pharmaceutical beliefs that shaped low-income patients' adherence to biomedical care for chronic disease. Utilizing insights about the importance of "audit culture" to regimes of accountability, she argues that the Massachusetts experience of health care reform serves as a cautionary tale of the diverse costs of health care reform in neoliberal moral economies of care.

In "Outsourcing Responsibility: State Stewardship of Behavioral Health Care Services," Cathleen E. Willging and Elise M. Trott argue that politically driven processes of the past have shaped the current context of mental health care delivery in New Mexico. New Mexico is an economically challenged, mostly rural state, where mental health care disparities, a product of structural violence and of contemporary efforts to privatize, corporatize, and outsource public sector services, disproportionately impact Hispanic, Latino, and Native American citizens. Provisions of the ACA, including the expansion of Medicaid and outreach to underserved populations, offered the possibility of improving access and services for New Mexicans struggling with unmet treatment needs. However, as the authors argue, public stewards manipulated key ACA provisions to propagate unsubstantiated allegations of waste, fraud, and corruption against safety-net service providers. This chapter shows how public-private partnerships in the Medicaid arena, discourses of transparency, and technologies of accountability can engender truthiness claims, obscure vital information, destabilize a behavioral health care safety net, and deny low-income citizens care. They argue that scholars have the responsibility to attend to the "total bureaucratization" of government-funded health care systems that also allows such abuse of authority.

The chapter by Mary Alice Scott and Richard Wright explores the intersections of seemingly opposing understandings of health—as a "right" or a "responsibility"—in health care professionals' commentaries on ACA implementation in a formerly free clinic in southern New Mexico. In doing so, it challenges an often-unexamined moral framework that obscures structural barriers to achieving health. The concepts

of co-responsibility and of patient engagement—increasingly central to health care and other social programs globally—were reflected in staff framing of health care problems, clinic activities, and conceptualizations of patients. Patient engagement relies on “shared responsibility” among patients, providers, health care administrators, and communities; it requires motivating patients to increase participation in their own health care, empowering patients to develop self-efficacy, and improving health literacy so that patients can be more fully informed in making health care decisions, along with other processes to increase patient accountability. As this chapter shows, there is often a mismatch between provider expectations of shared responsibility and the highly constrained actions of patients, who in this study confronted structural barriers including being unhoused, lack of regular transportation, undocumented immigration status, competing priorities including work, and missing important identification documents that were necessary for obtaining coverage.

* * *

This book guides readers through the tumultuous U.S. health care system through the lens of the Affordable Care Act. Using ethnographic methods, the contributors provide up-close, intimate portraits of individuals who gained coverage and remained uninsured as well as the providers tasked with delivering health care to the newly insured. We see the moral, financial, and health stakes of a sweeping social policy as it touched down in people’s lives. The volume answers the question of whether or not the Affordable Care Act worked, arguing that it unevenly expanded access to care and in so doing, the ACA addressed some inequalities and stratification, sustained or exacerbated others, and created new ones.

NOTES

- 1 *NFIB v. Sebelius* considered the constitutionality of the individual mandate and the Medicaid expansion. The Supreme Court maintained the constitutionality of the individual mandate under Congress’s power to tax. The individual mandate is the provision of the Affordable Care Act that requires most residents of the United States to obtain health insurance coverage or pay a fine. However, the Court found that the Medicaid expansion was “unconstitutionally coercive” because states could be penalized for not expanding Medicaid by losing all of their Medicaid funding (which also covers long-term care, coverage for children,

pregnant women, parents, poor seniors, and people with certain disabilities). Instead, states had to affirmatively opt in to expand their Medicaid programs to adults at 138% or below the federal poverty level (KFF 2012). This decision created “the coverage gap” wherein many adults in non-expanding states were ineligible for both Medicaid and ACA subsidies that made coverage more affordable.

- 2 The Emergency Medical Treatment and Labor Act (EMTALA) of 1986 requires that people with emergency conditions be treated and stabilized in emergency rooms regardless of ability to pay (CMS 2012). While some politicians have construed this law to mean that nobody goes without coverage in the United States, in fact, the law is quite limited since it only covers emergency care and patients are still billed for services used (Carroll 2012). See Melo (this volume) for an account of the deadly consequences of relying on emergency care to manage chronic illness.
- 3 The ACA is a long and complicated law that includes many other provisions, such as requirements for improved data collection on health disparities, funding for more primary care graduate training, and rules for employers offering coverage. These provisions are not discussed at length in this book. Instead, we focus on the coverage expansions that were at the heart of the law.
- 4 Throughout the book, we employ the term Affordable Care Act or ACA to refer to the health reform legislation. Sometimes we also use “Obamacare,” as this was the nomenclature often used in the press and was also the name that many of the people who we interviewed responded to and recognized. As discussed in the chapter by Mulligan, the term Obamacare was initially used derisively and was part of efforts to racialize the law. However, the Obama administration then tried to reclaim the term by putting a positive spin on it: Obama cares. When referring to the legislation, we use the term ACA. When appropriate to the context of the discussion, we also occasionally use Obamacare throughout the text.
- 5 Employer-based health insurance expanded rapidly in the United States after World War II in part because employer contributions to insurance were tax-exempt. Employer sponsored insurance coverage has been declining since its peak in the 1980s (Enthoven and Fuchs 2006).

REFERENCES

- Adams, Vincanne, Nancy J. Burke, and Ian Whitmarsh. 2014. Slow Research: Thoughts for a Movement in Global Health. *Medical Anthropology* 33 (3): 179–197.
- Antonisse, Larisa, Rachel Garfield, Robin Rudowitz, and Samantha Artiga. 2016. The Effects of Medicaid Expansion under the ACA: Findings from a Literature Review. *Kaiser Commission on Medicaid and the Uninsured* (November 30). kff.org.
- Baker, Tom, and Jonathan Simon. 2002. *Embracing Risk: The Changing Culture of Insurance and Responsibility*. Chicago: University of Chicago Press.
- Boehm, Deborah A. 2005. The Safety Net of the Safety Net: How Federally Qualified Health Centers “Subsidize” Medicaid Managed Care. *Medical Anthropology Quarterly* 19(1): 47–63.

- Carroll, Aaron. 2012. Why emergency rooms don't close the health care gap. www.cnn.com.
- Cassidy, Amanda. 2013. Essential Health Benefits. *Health Affairs*. Health Policy Briefs. www.healthaffairs.org.
- Christopher, Andrea S., Danny McCormick, Steffie Woolhandler, David U. Himmelstein, David H. Bor, and Andrew P. Wilper. 2016. Access to Care and Chronic Disease Outcomes Among Medicaid-Insured Persons versus the Uninsured. *American Journal of Public Health* 106(1): 63–69.
- Clarke, John. 2004. *Changing Welfare, Changing States: New Directions in Social Policy*. Thousand Oaks, CA: Sage.
- Clemans-Cope, Lisa, Matthew Buettgens, and Hannah Recht. 2014. Racial/ethnic differences in uninsurance under the ACA: Are differences in uninsurance rates projected to narrow? *Urban Institute*. www.urban.org.
- Closser, Svea, and Erin Finley. 2016. A New Reflexivity: Why Anthropology Matters in Contemporary Health Research and Practice, and How to Make It Matter More. *American Anthropologist* 118(2): 385–390.
- CMS (Centers for Medicare and Medicaid Services). 2012. Emergency Medical Treatment & Labor Act (EMTALA). www.cms.gov.
- . 2016. Exemptions from the requirement to have health insurance. www.healthcare.gov.
- Cohen, Robin A., and Michael E. Martinez. 2015. Health Insurance Coverage: Early Release of Estimates from the National Health Interview Survey January–March 2015. *Centers for Disease Control and Prevention/National Center for Health Statistics*. www.cdc.gov.
- Collins, Sara R., Petra W. Rasmussen, Sophie Beutel, and Michelle M. Doty. 2015. The problem of underinsurance and how rising deductibles will make it worse—findings from the Commonwealth Fund Biennial Health Insurance Survey. *Commonwealth Fund*. www.commonwealthfund.org.
- Dao, Amy, and Jessica Mulligan. 2016. Toward an Anthropology of Insurance and Health Reform: An Introduction to the Special Issue. *Medical Anthropology Quarterly*, 30(1): 5–17.
- Dumit, Joseph. 2012. *Drugs for Life*. Durham, NC: Duke University Press.
- Dwyer, Rachel E., and Lora A. Phillips Lassus. 2015. The Great Risk Shift and Precarity in the U.S. Housing Market. *ANNALS of the American Academy of Political and Social Science* 660(1): 199–216.
- Enthoven, Alain C., and Victor R. Fuchs. 2006. Employment-Based Health Insurance: Past, Present, and Future. *Health Affairs* 25(6): 1538–1547.
- Ericson, Richard V., Aaron Doyle, and Dean Barry. 2003. *Insurance as Governance*. Toronto: University of Toronto Press.
- Franke-Ruta, Garance. 2013. Why Is Maternity Care Such an Issue for Obamacare Opponents? *The Atlantic*, November 22.
- Garfield, Rachel, and Anthony Damico. 2016. Issue Brief: The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid. *Kaiser Family Foundation*. kff.org.

- Goode, Judith G., and Jeff Maskovsky. 2001. *The New Poverty Studies: The Ethnography of Power, Politics and Impoverished People in the United States*. New York: New York University Press.
- Goodell, Sarah. 2014. Health Policy Brief: Risk Corridors. *Health Affairs*. healthaffairs.org.
- Haeder, Simon F., and David L. Weimer. 2015. You Can't Make Me Do It, but I Could Be Persuaded: A Federalism Perspective on the Affordable Care Act. *Journal of Health Politics, Policy and Law* 40(2): 281–323.
- Haney López, Ian. 2014. *Dog Whistle Politics: How Coded Racial Appeals Have Reinvented Racism and Wrecked the Middle Class*. New York: Oxford University Press.
- Health Resources & Services Administration (HRSA). 2016. About the Ryan White HIV/AIDS Program. hab.hrsa.gov.
- Himmelstein, David U., Deborah Thorne, Elizabeth Warren, and Steffie Woolhandler. 2009. Medical Bankruptcy in the United States, 2007: Results of a National Study. *American Journal of Medicine* 122(8): 741–746.
- Horton, Sarah, and Louise Lamphere. 2006. A Call to an Anthropology of Health Policy. *Anthropology News* 47(1): 333–336.
- Horton, Sarah, Cesar Abadía, Jessica Mulligan, and Jennifer Jo Thompson. 2014. A Critical Medical Anthropological Approach to the U.S.'s Affordable Care Act. *Medical Anthropology Quarterly* 28(1): 1–22.
- Horton, Sarah, Joanne McCloskey, Caroline Todd, and Marta Henriksen. 2001. Transforming the Safety Net: Responses to Medicaid Managed Care in Rural and Urban New Mexico. *American Anthropologist* 103(3): 733–746.
- Insin, Engin F. 2009. Citizenship in Flux: The Figure of the Activist Citizen. *Subjectivity* 29: 367–388.
- Jain, Sachin H., Brian W. Powers, and Darshak Sanghavi. 2015. Big Plans, Poor Execution: The Importance of Governmental Managerial Innovation to Health Care Reform. *Journal of General Internal Medicine* 30(4): 395–397.
- Jones, David K., Katharine W. V. Bradley, and Jonathan Oberlander. 2014. Pascal's Wager: Health Insurance Exchanges, Obamacare, and the Republican Dilemma. *Journal of Health Politics, Policy and Law* 39(1): 97–137.
- Kaiser Commission on Medicaid and the Uninsured. 2012. *The Uninsured: A Primer, October 2012*. Kaiser Family Foundation, Menlo Park, CA.
- . 2016. *The Uninsured: A Primer, November 2016*. Kaiser Family Foundation, Menlo Park, CA.
- Kaiser Family Foundation (KFF). 2012. A Guide to the Supreme Court's Affordable Care Act Decision. kff.org.
- . 2016a. Disparities in Health and Health Care: Five Key Questions and Answers, kff.org.
- . 2016b. Health and Access to Care and Coverage for Lesbian, Gay, Bisexual, and Transgender (LGBT) Individuals in the U.S., kff.org.
- Katz, Michael B. 2008 (2001). *The Price of Citizenship: Redefining the American Welfare State*. Philadelphia: University of Pennsylvania Press.

- Kingfisher, Catherine. 2002. *Western Welfare in Decline: Globalization and Women's Poverty*. Philadelphia: University of Pennsylvania Press.
- Levitt, Larry, Gary Claxton, Anthony Damico, and Cynthia Cox. 2016. Assessing ACA Marketplace Enrollment. *Kaiser Family Foundation*. kff.org.
- McMorrow, Stacey, Sharon K. Long, Genevieve M. Kenney, and Nathaniel Anderson. 2015. Uninsurance Disparities Have Narrowed for Black and Hispanic Adults under the Affordable Care Act. *Health Affairs* 34(10): 1774–1778.
- Mol, Anne Marie. 2008. *The Logic of Care: Health and the Problem of Patient Choice*. New York: Routledge.
- Morgan, Kimberly J., and Andrea Louise Campbell. 2011. Delegated Governance in the Affordable Care Act. *Journal of Health Politics, Policy and Law* 36(3): 387–391.
- National Center for Transgender Equality (NCTE). 2016. HHS issues regulations banning trans health care discrimination. www.transequality.org.
- National Health Law Program (NHeLP). 2014. NHeLP and the AIDS Institute file hiv/aids discrimination complaint against Florida health insurers. www.healthlaw.org.
- National Women's Law Center (NWLC). 2012. *Turning to Fairness: Insurance Discrimination against Women Today and the Affordable Care Act*. www.nwlc.org.
- Obama, Barack. 2016. United States Health Care Reform: Progress to Date and Next Steps. *Journal of American Medical Association* 316(5): 525–532.
- Okongwu, Anne Francis, and Joan P. Mencher. 2000. The Anthropology of Public Policy: Shifting Terrains. *Annual Review of Anthropology* 29: 107–124.
- Organization of Economic Cooperation and Development (OECD). 2014. OECD Health Statistics 2014. How does the United States compare? www.oecd.org.
- . 2015. Health at a Glance 2015: OECD Indicators. www.oecd.org.
- Paradise, Julia. 2015. "Medicaid Moving Forward." Kaiser Commission on Medicaid and the Uninsured. kff.org.
- Pear, Robert. 2015a. Health Insurance Companies Seek Big Rate Increases for 2016. *New York Times*, July 3.
- . 2015b. Many Say High Deductibles Make Their Health Law Insurance All but Useless. *New York Times*, November 14.
- Pigg, Stacy Leigh. 2013. On Sitting and Doing: Ethnography as Action in Global Health. *Social Science & Medicine* 99: 127–134.
- Robert Wood Johnson Foundation (RWJ). 2011. Issue Brief: How does the Affordable Care Act address racial and ethnic disparities in health care? www.rwjf.org.
- Sered, Susan S., and Rushika Fernandopulle. 2005. *Uninsured in America: Life and Death in the Land of Opportunity*. Berkeley: University of California Press.
- Shear, Michael D. 2014. Sebelius Resigns After Troubles Over Health Site. *New York Times*, April 10.
- Shore, Chris, and Susan Wright. 1997. Policy: A New Field of Anthropology. In *Anthropology of Policy: Critical Perspectives on Governance and Power*, ed. Chris Shore and Susan Wright, Pp. 3–39. Oxford: Routledge.

- Soss, Joe, Richard C. Fording, and Sanford F. Schram. 2011. *Disciplining the Poor: Neoliberal Paternalism and the Persistent Power of Race*. Chicago: University of Chicago Press.
- Taylor, Janelle S. 2014. The Demise of the Bumbler and the Crock: From Experience to Accountability in Medical Education and Ethnography. *American Anthropologist*, 116: 523–534.
- Willen, Sarah S. 2012. Migration, “Illegality,” and Health: Mapping Embodied Vulnerability and Debating Health-Related Deservingness. *Social Science & Medicine* 74(6): 805–811.