

## A JOURNEY THROUGH THE HEALTH CARE SAFETY NET

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### INTRODUCTION

I began teaching health law in Spring 2002. The year before, I received a wonderful gift that has helped shape my teaching ever since—a book titled *Mama Might Be Better Off Dead: The Failure of Health Care in Urban America*.<sup>1</sup> Written by investigative journalist Laurie Kaye Abraham and published in 1993, the book received critical acclaim. It was hailed as a “provocative examination of our health care delivery for the poor,” a “book of unexpected power,” and “a convincing case for a massive overhaul of the nation’s health system . . . [with] the narrative force of a novel.”<sup>2</sup> It is definitely all of those things. But in this essay, I want to focus on one of its other attributes: its value as a tool for teaching students about the health care safety net. Even today—twenty-five years after the events in the book took place, and a few years into the significant expansion of public and private health insurance ushered in by the Patient Protection and Affordable Care Act (“ACA”)—Abraham’s book remains an invaluable teaching partner.

In *Mama Might Be Better Off Dead*, Abraham follows several members of a family living in an economically disadvantaged neighborhood of Chicago from May 1989 to April 1990, chronicling their experiences with the health care system. She takes readers on a journey that touches almost every part of the health care safety net, and in which Medicaid, the public health insurance program for the poor, plays a prominent role. Abraham’s investigation reveals the challenges the poor have historically faced in accessing health care—from the coverage gaps resulting from a health care safety net designed with gaping holes, to the street-level implementation decisions that effectively discouraged or impeded patients from accessing services to which they were entitled, to the

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1. LAURIE KAYE ABRAHAM, *MAMA MIGHT BE BETTER OFF DEAD: THE FAILURE OF HEALTH CARE IN URBAN AMERICA* (1994) (paperback ed.).

2. *Id.* (reviews on back cover).

“sociomas,” or social determinants of health that shape health access and outcomes.

Abraham presents a compelling and holistic view of the benefits and limits of the public-private health care patchwork that existed over twenty-five years ago, giving students a clear picture of the access, quality, and cost concerns that have driven health reforms since that time. Abraham also invites readers to think critically about the design and implementation of our health care system. She offers powerful critiques of the system during that time—critiques that remain relevant today. Although Abraham does not spend much time outlining proposals for reforms, she offers a list of prescriptions at the end foretelling the types of reforms that have been enacted over the years, including those taking shape under the ACA.

Perhaps most importantly, Abraham takes her readers on a journey through the health care safety net that is deeply personal, nuanced, and engulfing—a journey that facilitates a robust, informed, and thoughtful discussion among students as they share, question, and defend their own opinions about the system and how to fix it. The book is rich with details that allow students to connect with the people and experiences described within, and students become invested in the family’s health and well-being. For some students, reading about this family’s experiences unsettles assumptions they may have about the poor or the health care system. Other students find the book validating, encouraging them to open up about their own experiences and the struggles their family and friends have faced. In either case, students’ personal investment in this story makes them engaged and active readers who want to devour the complex and technical rules governing public insurance programs—rules that in any other context could seem dry and mundane.

One may wonder about my decision to continue using the Abraham book all these years later, in the face of so much change in health policy and with so many more timely resources available. I confess that a few years ago I reconsidered whether to continue using the Abraham book as an introduction to the health care safety net. After all, so much had changed since the book’s publication: throughout the 1990s and early 2000s, many states took incremental steps to expand Medicaid eligibility; Medicare was expanded to cover prescriptions; and most recently, the ACA ushered in significant public and private insurance reforms expanding eligibility and coverage. Why ask students to spend so much time reading about a family’s journey through a 1980s Medicaid program, only to then make them learn how much has changed? Might this simply cause more confusion or use precious time that could be devoted to a more detailed exploration of other timely or cutting-edge topics? In the end, however, I decided I could not give it up.

Twenty-five years of reforms have certainly improved access to care, and to teach students the current system, I rely on many wonderful sources. I have used the Furrow Health Law casebook<sup>3</sup> since my first class, and I am constantly compiling and updating supplemental materials, including health policy reports and studies, news articles, and cases or legislation showcasing the timely access issues facing our state and local governments.<sup>4</sup> But the Abraham book is one of the most effective tools I have found for giving students a deep and broad understanding of how the system has changed and then empowering them to evaluate the import of that change. I ask students to consider how the family members profiled by Abraham may have fared differently under the current system—how much sooner they may have been eligible for coverage or whether they would have been able to access care more easily and consistently. Very quickly, students realize that although there have been improvements, many of the access barriers identified by Abraham persist. They see that, even with the unprecedented federal steps taken to expand and regulate insurance in the ACA, states continue to play a critical role in shaping access, as do the socio-economic factors we see impacting the Banes family.

Indeed, the deeply personal experiences, investigative insights, and policy critiques in the Abraham book are still relevant today. Even when the ACA was enacted, I made clear to my class that far from resolving longstanding policy debates about whether and how to expand coverage, the ACA was simply the latest phase in an ongoing debate about federal health policy. The ACA certainly represented a significant turning point in which the federal government was adopting a far more active role in regulating health insurance and access. But the ACA also continues the practice of relying heavily on states and a public-private patchwork to define the health care safety net. In fact, the ACA has not resolved debates on Medicaid program design issues, such as how much flexibility states should be allowed in their Medicaid expansion waivers, what level of federal oversight of state rate-setting is adequate (especially where access concerns are raised), and the extent to which Medicaid funding should and can be used to address social determinants of health.

Medicaid is an enduring topic in the federal health reform debate and a persistent target of proposals to reduce federal funding, roll back entitlements,

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3. BARRY R. FURROW, THOMAS L. GREANEY, SANDRA H. JOHNSON, TIMOTHY S. JOST & ROBERT L. SCHWARTZ, *HEALTH LAW: CASES, MATERIALS AND PROBLEMS* (7th ed. 2013 & Supp. 2016).

4. For up-to-date policy information about Medicaid and the health care safety net, I recommend consulting the following organizations: KAISER FAMILY FOUNDATION, <http://kff.org/> and THE COMMONWEALTH FUND, <http://www.commonwealthfund.org>. Both organizations provide timely and reader-friendly issue briefs that can give students additional context for evaluating and critiquing health reform.

and shift greater responsibility to the states. The 2016 elections, which delivered control of the presidency and Congress to Republicans, have breathed new life into longstanding desires to transform Medicaid. Just three years into the most significant expansions of insurance we have seen since enactment of Medicare and Medicaid in 1965, we are facing a strong possibility of retrenchment. Current proposals seek to repeal the Medicaid expansion,<sup>5</sup> cap federal funding,<sup>6</sup> and dramatically reduce or eliminate federal oversight of state program design.<sup>7</sup> The Abraham book gives students the history and context necessary to reflect on how far we have come, the choices before us today, and what those choices would mean for the future of the health care safety net.

The remainder of this essay gives more detailed examples of the lessons and critiques Abraham offers and how these can be valuable teaching tools for health law today. I do not have space in this essay to explore in depth all the valuable teaching gems I have mined from the Abraham book,<sup>8</sup> so I focus on those related to the design and implementation of the Medicaid program. Part I provides useful context by briefly profiling the central figures featured in the Abraham book. Part II highlights salient lessons on the benefits and limits of the Medicaid program as originally designed (“Old Medicaid”). Part III explains how Abraham’s critiques of that system remain relevant today, even under the ACA’s creation of a Medicaid expansion program (“New Medicaid”), intended to address many of the shortfalls of the traditional program.

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5. Robin Rudowitz, Samantha Artiga & Katherine Young, *What Coverage and Financing Is at Risk Under a Repeal of the ACA Medicaid Expansion?*, KAISER COMMISSION ON MEDICAID AND THE UNINSURED (Dec. 2016), <http://kff.org/medicaid/issue-brief/what-coverage-and-financing-at-risk-under-repeal-of-aca-medicaid-expansion/> [https://perma.cc/UF6F-KXCT].

6. Sara Rosenbaum, Sara Schmucker, Sara Rothenberg & Rachel Gunsalus, *What Would Block Grants or Limits on Per Capita Spending Mean for Medicaid?*, THE COMMONWEALTH FUND (Nov. 2016), [http://www.commonwealthfund.org/~media/files/publications/issue-brief/2016/nov/1913\\_rosenbaum\\_medicaid\\_block\\_grants.pdf](http://www.commonwealthfund.org/~media/files/publications/issue-brief/2016/nov/1913_rosenbaum_medicaid_block_grants.pdf) [https://perma.cc/9WGE-TKKH].

7. See, e.g., A BETTER WAY: OUR VISION FOR A CONFIDENT AMERICA: HEALTH CARE, BETTER.GOP 23–28 (June 22, 2016), [https://abetterway.speaker.gov/\\_assets/pdf/ABetterWay-HealthCare-PolicyPaper.pdf](https://abetterway.speaker.gov/_assets/pdf/ABetterWay-HealthCare-PolicyPaper.pdf) [https://perma.cc/BFK7-6UJR] (discussing proposals to change the financing structure of Medicaid using either a block grant or per capita allotment).

8. There are many other worthy issues addressed in the book. For those exploring health care policy in greater detail, Abraham addresses financing for long-term care, the neglected cost of relying on family caregivers, and the unintended impact of certain reimbursement structures on timeliness of care. For those teaching bioethics, Abraham touches on end-of-life counseling, how providers’ religious beliefs shape care, racial discrimination and prison experimentation in human subject research, and organ transplantation and resource allocation decisions. Health quality concerns also appear throughout the book, as Abraham offers reflections on the limits of state regulation, how forms of health care financing can impact quality of care, and iatrogenic harms that can result from poor care coordination. See ABRAHAM, *supra* note 1.

Finally, I should note that this essay was written before the 2016 election made ACA repeal a realistic possibility. Indeed, much of Part III is devoted to explaining why the Abraham book continues to be a valuable teaching tool *despite* ACA reforms designed to address many of the gaps identified by Abraham. In the editing process, I updated this essay to briefly note how recent developments could impact the health care safety net, and more to the point, the role of Abraham's book in teaching the health care safety net; but this did not require significant change. Recent developments do not detract from the book's value for teaching health law today; indeed they enhance it. As described in Parts I and II below, Abraham creates a vivid picture of the role of the health care safety net, how it helps those who depend on it, and the consequences for those the net does not catch. This picture becomes even more compelling if, instead of simply providing historical context for understanding the expansion of the safety net under the ACA, the book becomes a cautionary tale—a reminder of what lies ahead if we choose retrenchment. In addition, Part III shows how these lessons can help empower students to evaluate and critique any health policy in terms of its impact on the health care safety net, whether analyzing the ACA to determine if it has effectively addressed prior access barriers, identifying the potential impact of existing and newly emerging proposals to repeal and replace the ACA, or even inspiring students to develop and defend their own ideas for reform. The bottomline is that although the future of the health care safety net is uncertain, the lessons and critiques that Abraham offers are timeless.

#### I. MAMA MIGHT BE BETTER OFF DEAD

At the center of the story is the Banes family, which includes Jackie (manager of the household and caregiver), Jackie's husband Robert, and their three children. Another key figure is Jackie's grandmother, Mrs. Cora Jackson, who Jackie referred to as "Mama" because Mrs. Jackson raised her. At the time Abraham entered their lives, Mrs. Jackson was living in the Banes' home and was being cared for by Jackie. Finally, Jackie's father, Tommy Markham, did not live with the family but appears in the book periodically.

Abraham's investigation follows each family member through the then public-private health care patchwork that served the poor. Abraham gives readers an intimate look into the family members' lives—their medical needs, the ways in which they were able to access care from different kinds of providers, and the barriers to care they sometimes faced.

Mrs. Jackson suffered from high blood pressure and non-insulin dependent diabetes, both of which could be managed with the right resources and support. Yet, we see how Mrs. Jackson's illnesses got worse, leading to frequent trips to the emergency room and multiple surgeries to amputate one foot, and then the other. Throughout this time, Mrs. Jackson required access to specialists, medication, nutrition counseling, home nursing, rehabilitation care, support

items or service (such as adult diapers, mobility support, and transportation), and treatment for depression. The woman who had once held several jobs and was an active member of her church, had become physically disabled, confined to her home, and withdrawn physically and emotionally by the time we meet her.

Robert suffered from a condition called focal glomerulosclerosis, which can lead to kidney failure. It progressed to the point that Robert required dialysis three times a week, while waiting for a transplant. Like Mrs. Jackson, Robert sometimes suffered complications that required visits to the emergency room. He used cocaine periodically, but there was no mention of him having access to a substance abuse program. Even assuming such a program was available to him, he would not have risked admitting to using drugs, as this would have jeopardized his chance of getting a kidney. Unlike Mrs. Jackson, Robert's condition was not totally and permanently disabling; he was still able to work, though the grueling dialysis schedule took a toll on Robert physically and mentally.

We do not learn as much about Tommy, in part because he is guarded and does not open up easily. Tommy was diagnosed with hypertension and provided medication to manage it, but he stopped taking the medication, which eventually led to a stroke. Abraham gleaned a few possibilities for why Tommy may have stopped treatment. One side effect of the drug was impotence, which not only impedes an important life activity, but also can take an emotional toll. Indeed, it is common for people to either stop taking medication or to try to self-regulate in order to avoid disruptive and unpleasant side effects. This was likely exacerbated by the lack of symptoms linked directly to hypertension itself. The absence of symptoms causes many people to neglect their hypertension, earning it the label "the silent killer." Finally, Tommy may have been generally suspicious of doctors in light of a troubling history of racism and state-sanctioned medical experimentation on Black people, including Tommy's own participation in an ethically questionable research experiment while in prison. This may have caused Tommy to mistrust his doctor, at worst, or, at best, to discount his doctor's explanation for why Tommy needed to take a drug that disrupted his normal functioning in order to treat a problem for which Tommy experienced no symptoms.

The children, apparently healthy, had important health needs as well, such as regular checkups and vaccinations. In fact, a measles outbreak during the time that Abraham was writing the book makes readers acutely aware of the importance of preventive care. Jackie, too, should have been getting preventive care, such as cancer screenings. But with so many responsibilities—as parent, manager of the household finances, chief health advocate and health benefits manager for Mrs. Jackson and her husband, and sole family caregiver for Mrs. Jackson—one can understand how easily Jackie could let preventive care for the healthy members of her family slip through the cracks.

Abraham's focus on the Banes family takes readers on a journey through the health care safety net. Abraham does not really address private insurance, except for a note explaining why some of the Banes family members were shut out of the private insurance system: the kinds of jobs that they worked did not provide them with health insurance; they could not have afforded to pay full price for a private insurance plan; and insurance company practices designed to exclude sicker patients meant that someone with the kinds of illnesses that Robert and Mrs. Jackson had would not have been able to get private insurance on the individual market. The book focuses on the patchwork of federal, state, and local programs, and the network of private providers that make up the health care safety net.

In order to facilitate students' engagement with the multiple layers of this system, including the complicated and technical rules of coverage, I assign each student a particular family member to profile for the class. Students must first identify the person's illnesses or injuries, the forms of care that person needed, and the types of providers from whom the person sought care. Next, students must explain how that family member paid for any tests or care received, for example, whether care was free or subsidized. If the person was covered by insurance, students must describe the kind of insurance, when and how the person qualified for coverage, and which services it covered. If a family member had been uninsured at any time, students must explain why. Finally, students are asked to identify any factors (insurance related or not) that may have impacted the person's ability or willingness to access care, the quality of care received, or their health outcomes. Through this exercise, students learn important lessons about the promise and limits of the health care system that have helped drive reform since that time.

## II. LAYING THE GROUNDWORK FOR UNDERSTANDING REFORM

Abraham documents the vital role that the health care safety net serves for the indigent and people with disabilities, especially the ways it helps those who are severely ill and those in need of life-saving care. But her investigation also uncovers huge holes in this net, illustrating how both the design and implementation of Medicaid and other safety net programs were falling short and, in some cases, undermining stated goals for improving care for the poor. Admittedly, the problems Abraham identifies are well-known and well-documented by now. But Abraham's book brings a richness and depth to our understanding of the importance and role of the health care safety net.

### *Lesson 1: A Safety Net for the "Deserving" Poor*

Abraham's survey of the health care safety net is particularly valuable as a teaching tool for a few reasons. First, it does a beautiful job introducing the readers to almost every piece of a fragmented health care safety net that

depends on a patchwork of federal, state, and local funding. Students accompany the Banes family into public hospitals, nonprofit hospitals, and community clinics, and on visits with a diverse range of specialists and primary care physicians. Students follow Abraham as she learns about the major public insurance programs, Medicaid and Medicare, supplemental state and local programs on which various members of the Banes family depend to help pay for care. Finally, students learn about the critical services provided by many allied health professionals, medical suppliers, and support services, particularly in the case of someone like Mrs. Jackson, who has become less mobile, more dependent on others, and at constant risk for complications that could exacerbate her condition and send her back to the hospital.

In this way, Abraham provides a window into the truly vital role that the health care safety net plays in people's lives. Abraham points to Medicaid's generous scope of coverage that makes it the chief source of financing for the kind of long-term support needed by Mrs. Jackson. For example, we learn that Medicaid, not Medicare, covered her medication, adult diapers, and special transportation. Abraham also educates readers about the policy decision to extend Medicare to people with end stage renal disease, describing how federal, state, and local funding ensures that people like Robert can get regular dialysis, preventing the otherwise inevitable, painful, and early death caused by kidney failure. Readers also learn about the central role that hospitals play in the lives of the poor—from the violence, trauma, and poverty-related ills that land people in the emergency room, to the prevalence of chronic illness that makes the hospital the primary care provider for people who have complex and on-going health needs.

Once it becomes clear that public insurance is critical for helping the poor access needed care, Abraham reflects upon the policy decisions about who would be covered by Medicaid, and who would be excluded. She recounts the now familiar background of Medicaid as a program originally linked to welfare and narrowly designed to help those viewed as "deserving." It only covered certain groups, such as the disabled, pregnant women, and children, and income limits were often set so low that it only covered the very poorest of those falling into the special categories.

There have been countless critiques of the problems with narrow Medicaid eligibility categories, detailing the impact on those left uninsured. But I find Abraham's exploration particularly compelling in light of the Banes family story. She journeys through the family's past so that we can understand exactly why they were previously uninsured, what changed to qualify them for coverage, and what impact a lack of insurance may have had. Through the lives of the Banes family, students learn that Mrs. Jackson could not qualify for public insurance coverage until she was diagnosed with a disabling condition or Robert until he was diagnosed with end stage renal disease. This background helps students appreciate how, under the old system, many people



were one illness away from being deemed “deserving” and how this lack of insurance could contribute to the progression of a disease that ultimately ended in the disabling condition that, ironically, qualified the person for insurance. Although Medicaid improved access for those seen as most needy, it fell short when it came to improving or attending to the health of the poor generally.

### *Lesson 2: The Impact of System Design*

Through Mrs. Jackson’s experience, students also experience the unpredictability of the system for determining eligibility and the impact system design can have on care. At the most basic level, there was confusion about which programs covered which services. It is easy to see how patients could be confused by all the rules governing different health care programs, but sometimes it was health professionals who gave patients wrong information, such as when a nurse told Jackie that Medicaid would not cover adult diapers. Abraham also uncovered examples of how preventive health programs for children were underutilized by the community that needed them, in part because of a failure of government or health organizations to educate the community about their availability and the failure to provide the resources to ensure the necessary staffing to deliver care.

Administration of Medicaid’s income requirement created another kind of unpredictability. Because Mrs. Jackson received social security checks, her income was too high for her to automatically qualify for Medicaid. She had the opportunity to show that she met eligibility each month as part of the Medicaid spend down program for the “medically needy,” but this required Jackie to go to the welfare office each month so she could prove that she had spent a certain amount of money on Mrs. Jackson’s medical needs.

Abraham’s investigation shows how this unpredictability impacted the family’s health care decisions. Uncertainty about whether they would have Medicaid coverage meant uncertainty about whether they would have enough money to buy Mrs. Jackson’s blood pressure medication, so Jackie rationed it. It also meant uncertainty about whether they would have enough money for the special transportation that was needed to take Mrs. Jackson to her appointments with various specialists, so Jackie also rationed the trips to the doctor. In most cases, Jackie believed that rationing worked. But in one case, a missed doctor visit probably contributed to Mrs. Jackson ending up in the emergency room with an almost fatal result, because she missed a visit in which her regular doctor might have detected the risk of toxicity resulting from the medication he prescribed. Delayed diagnosis or missed treatment is not only personally harmful to patients; it is costly to society, as preventable or manageable illnesses progress and lead to more frequent and costly care, and, in some cases, disability.

Finally, Abraham demonstrates how Medicaid’s origins as a welfare-based program created other barriers to care. This “welfare” approach to Medicaid

fueled concerns about fraud and people taking advantage of the system, causing the gatekeepers of Medicaid eligibility to treat potential beneficiaries with suspicion. The hurdles patients had to overcome to prove eligibility could easily discourage people from getting the coverage to which they were entitled. Indeed, readers can feel Jackie's frustration and anxiety in her visits to the benefits office. Besides the fact that it was physically challenging for Jackie to get there, once there, Jackie worried that the workers would discover something that would cause Mrs. Jackson to lose her Medicaid coverage.

While numerous surveys and articles identify the problems of government bureaucracy and how it discourages access to care, Jackie's experiences concretize this problem. Readers follow Jackie in her daily duties as caretaker, accountant, and advocate, while also helping to manage her husband's illness and take care of their three children with few resources. This allows students to grasp just how formidable the barriers to care can be for those with the least resources. In fact, Abraham mentions that the systemic problems with Medicaid administration in Illinois were so bad that a lawsuit was filed which ultimately led to reform.

### *Lesson 3: Access Linked to Willing Providers*

Another problem revealed in the Abraham book is the challenge that Medicaid beneficiaries face in finding providers to treat them. This problem can manifest in two ways. One way is that providers may decide not to participate in the Medicaid program at all or may try to limit the number of Medicaid patients they see. Another way is through provider flight: the relocation of physicians, hospitals, nursing homes or other facilities typically from underserved urban areas, often predominantly Black or Latino, to more affluent, predominantly white communities. On balance, it seems that Mrs. Jackson, Robert, and Tommy were relatively fortunate at the point we meet them. They seemed to have access to good quality hospitals and specialists treating their illnesses. Nonetheless, Abraham's investigation revealed that access to quality Medicaid providers was a problem.

First, the supply of providers willing to serve the community was tenuous. This was partly due to the design of the Medicaid reimbursement system. States have discretion to set Medicaid rates that are often much lower than Medicare and are constantly vulnerable to cuts whenever state legislators face budgetary pressure. But the problem of provider supply was linked to other socioeconomic factors as well, such as the racial and economic demographic shift that had occurred in the Banes' neighborhood. The book chronicles the on-going struggle among Mt. Sinai hospital executives and physicians about whether to stay in the community or leave. In fact, the hospital tried to leave but was unsuccessful. Many physicians did leave, however, following their more affluent patients to the suburbs. Some split their time between their new offices and Mt. Sinai, reserving limited time to see patients in Mt. Sinai's

outpatient center. This made consistent care for Mrs. Jackson challenging, as she only had a limited window for appointments, and could not always pay for the transportation to get there.

Low Medicaid reimbursement, dwindling provider supply, and the concentration of poverty, which generates more frequent and serious health needs in communities without adequate resources, leaves these communities vulnerable to poor quality care. In fact, Abraham's investigation into the family's primary care provider, the physician they had had for years but who did not have privileges at Mt. Sinai, suggests this was a problem for Mrs. Jackson. According to Abraham, the physician's practice looked like a Medicaid mill, in which a physician serves almost exclusively Medicaid patients and too many to be doing so effectively. As further evidence of the poor quality care this physician was providing, Abraham learned that he had failed a peer review by the state and was put on monitoring status—an incredibly rare action reserved only for the most troubling cases. In tracing Mrs. Jackson's health history, it seems that this doctor failed to recognize a serious infection developing in her foot and thus failed to provide her with a timely referral that may have prevented the subsequent amputation.

#### *Lesson 4: Social Determinants of Health*

Abraham moves fluidly between describing the family's health care needs, and grounding these needs in an even more challenging set of personal circumstances and social ills that further shape their health care access and outcomes. It becomes clear that coverage alone cannot guarantee access or good health outcomes. Many other factors contribute to individuals' ability to access care, as well as their willingness to seek care and follow treatment advice. And this is where the richness of the story really pays off. Take the issue of Medicaid provider supply. Abraham shows how the concentration of poverty that deprives a community of resources, as well as residential segregation along racial and economic lines, contributed to physician flight, draining the community of critical resources. As the neighborhood changed and resources dwindled, Mt. Sinai increasingly struggled economically as it became a key source of care for the poor—those on Medicaid and the uninsured.

Even beyond the issue of health care resources, however, we see how other social determinants of health can impact health directly and indirectly. Poverty makes it more difficult to purchase the nutritional foods that Mrs. Jackson and Robert need. Past experiences of race discrimination may have made Tommy suspicious of treatment recommendations, while making Robert more reticent and less likely to ask questions about his care. The concentration of poverty and crime can increase the risk of harm from physical violence, emotional trauma, or addiction. And for all the adult family members, a certain kind of fatalism, likely due to the frequency of loss they see from illness or violence,

may have impacted their outlook on the importance or effectiveness of medical care.

### III. ABRAHAM'S TIMELESS CRITIQUES

In the Epilogue, Abraham lays out a brief list of prescriptions for reform. She suggests that all Americans should be guaranteed a basic level of health care, calls for either replacing Medicaid with a universal health care system or fixing Medicaid to close its gaps and improve reimbursement, and highlights the importance of support for patients to help them navigate the system. In addition, Abraham insists we must also address the social ills that impact care. Some of these reforms are reflected in the ACA. Yet the lessons and critiques Abraham offered in 1993 continue to animate debates about health policy and the implementation of health reform. The Abraham book provides a helpful framework for identifying unresolved issues and critiquing existing reforms, as well as current proposals to repeal and replace the ACA. This Part identifies only a few of the major issues I explore with my students.

#### A. *Old Medicaid: Still with Us*

The ACA expands Medicaid to include all adults up to 133% of poverty level,<sup>9</sup> eliminating the arbitrary line drawing that excluded so many groups previously. It also reforms the private insurance system to make it more accessible for consumers, by adding guaranteed issue and rating protections, and public subsidies for those with incomes between 100% and 400% of the federal poverty level.<sup>10</sup> Together, these reforms mean that many who previously fell through the cracks in the safety net can now get coverage. Indeed, HHS estimates that twenty million people have gained health insurance because of the ACA.<sup>11</sup> While the ACA does not actually adopt a universal health care system, President Obama has touted its potential for bringing us closer to universal coverage, and key to this vision was the expectation that New Medicaid would be available in every state.

The Supreme Court dashed these expectations, however, in *National Federation of Independent Business v. Sebelius* (“*NFIB*”).<sup>12</sup> In *NFIB*, the Court held that the federal government could not require states’ participation in the

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9. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 2001, 124 Stat. 119, 271 (2010) (codified as amended at 42 U.S.C. § 1396a (2012)).

10. §§ 1402, 2702, 124 Stat. at 156, 220 (2010) (codified as amended at 42 U.S.C. §§ 300gg-1, 18071 (2012)).

11. U.S. DEP’T OF HEALTH & HUMAN SERVICES, *20 Million People Have Gained Health Insurance Coverage Because of the Affordable Care Act, New Estimates Show* (Mar. 3, 2016), <http://www.hhs.gov/about/news/2016/03/03/20-million-people-have-gained-health-insurance-coverage-because-affordable-care-act-new-estimates> [https://perma.cc/7KGY-PAYX].

12. *Nat’l Fed’n of Indep. Bus. v. Sebelius*, 132 S. Ct. 2566 (2012).

expansion, as a condition of their participation in the Old Medicaid program.<sup>13</sup> This effectively gave states a choice about whether or not to expand Medicaid on these new terms, and so far nineteen states have resisted expansion.<sup>14</sup> Thus, in non-expansion states, Old Medicaid is quite literally still with us. In virtually all of these states, the residents must continue to meet the narrow categories that define Old Medicaid, including extremely low income levels for certain optional categories.<sup>15</sup> For this reason alone, it seems that Abraham's critique of such gaps—from the health harms and financial burdens suffered by individuals, to the economic effects on the providers and state and county social services systems—remains a powerful indictment of the political barriers to expanding Medicaid in all states. And as Republicans consider repealing the Medicaid expansion and further rolling back Medicaid funding and entitlements, the book serves as a cautionary tale about the potential health and economic costs of repeal.

But students are surprised to learn that Old Medicaid continues to shape our health reforms in other, more subtle ways as well. Some states that initially resisted the public and private reforms in the ACA have come to view the law as an opportunity to leverage federal dollars to expand public or private insurance on *their* terms. In the case of Medicaid, states have attempted to negotiate waivers with the federal government allowing them to structure Medicaid expansion differently. For example, some Republican-led states have sought waivers that would let them implement premiums, cost-sharing, work requirements, wellness program participation, and thinner benefits, on the assumption that such requirements increase personal responsibility and discourage the overutilization of health care services.<sup>16</sup> Some of these requests have been allowed, and some rejected. And legal scholars argue that many of the requirements states seek to impose reflect the kind of dangerous and discredited assumptions that animated the arbitrary line-drawing under

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13. The Court's reasoning turned on the significant differences it saw in the traditional program and the ACA's expansion: "The Medicaid expansion . . . accomplishes a shift in kind, not merely degree. . . . Under the [ACA], Medicaid . . . is no longer a program to care for the neediest among us, but rather an element of a comprehensive national plan to provide universal health insurance coverage." *Id.* at 2605–06 (opinion of Roberts, C.J., joined by Breyer & Kagan, JJ.).

14. Kaiser Family Foundation provides regular updates on the status of states' decisions on Medicaid expansion. *Status of State Action on the Medicaid Expansion Decision*, KAISER FAMILY FOUNDATION (Jan. 1, 2017), <http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D> [https://perma.cc/HQ8P-KUU2].

15. Julia Paradise, *Medicaid Moving Forward*, KAISER FAMILY FOUNDATION (Mar. 9, 2015), <http://kff.org/health-reform/issue-brief/medicaid-moving-forward/> [https://perma.cc/2YV9-TGN2].

16. See Sidney D. Watson, *Premiums and Section 1115 Waivers: What Cost Medicaid Expansion?*, 9 ST. LOUIS U. J. HEALTH L. & POL'Y 265, 266–68, 271, 280 (2016).

traditional Medicaid and often discouraged access to care.<sup>17</sup> Nonetheless, the current political climate has reinvigorated this debate, and states are taking this opportunity to fight for even greater flexibility in Medicaid design.<sup>18</sup> The knowledge students gain from the Banes's experience primes them to understand the implications of this debate and helps them evaluate current proposals to increase state flexibility.

### B. *Medicaid Financing & Safety Net Providers*

Medicaid financing, especially its impact on access and quality for Medicaid beneficiaries, continues to challenge health advocates and policy makers. To give students current context for this problem, I assign surveys and policy reports that describe complaints by providers about low Medicaid reimbursement, and concerns by health advocates of Medicaid provider shortages and provider flight. After having learned about the vital role that private providers play in the health care safety net from the Abraham book, many students express surprise that provider access problems persist and disappointment at how little the ACA has done to address this problem.

The ACA created a narrow stopgap, requiring primary care providers to be reimbursed at the same rate as Medicare providers for a limited time. But the ACA did not eliminate rate disparities for other health care providers; nor did it require greater transparency or accountability for states to demonstrate that access and quality protections were being met. In fact, another provision in the ACA may even exacerbate the strain on hospitals in underserved communities—one that requires the reduction of disproportionate share hospital funding to safety net hospitals over time. The authors of the law assumed such reductions could be made based on estimates of newly insured patients through Medicaid and private insurance expansion that would increase hospitals' revenue base. But, as already noted, there are many places where

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17. See, e.g., *id.* at 281–82; Laura D. Hermer, *On the Expansion of “Welfare” and “Health” Under Medicaid*, 9 ST. LOUIS U. J. HEALTH L. & POL'Y 235, 257–58, 263 (2016).

18. Letter from Terry McAuliffe, Chair, Nat'l Governors Ass'n to Honorable Kevin McCarthy et al., Majority Leader, United States House of Representatives (Jan. 24, 2017), <https://www.nga.org/cms/home/federal-relations/nga-letters/health—human-services-committee/col2-content/main-content-list/health-care-reform.html> [<https://perma.cc/572N-GR88>] (asking Congress to not shift costs to states and suggesting that any reform proposals should protect states from unforeseen financial risks due to spike in Medicaid enrollment or increased per beneficiary costs); NAMD'S LEGISLATIVE PRIORITIES FOR 2017, NATIONAL ASS'N OF MEDICAID DIRECTORS, [http://medicaiddirectors.org/wp-content/uploads/2016/12/NAMD-Legislative-Top-Is-sues-for-2017\\_FINAL.pdf](http://medicaiddirectors.org/wp-content/uploads/2016/12/NAMD-Legislative-Top-Is-sues-for-2017_FINAL.pdf) [<https://perma.cc/NN9T-N5MB>] (statement of priorities from bipartisan association suggesting reforms to increase state flexibility, improve federal-state collaboration, support innovation, and modernize Medicaid that do not involve capping Medicaid funding).

this expansion has yet to occur, and there are still some individuals who are eligible for Medicaid or private insurance subsidies, but who remain uninsured.

In class, I use this as a jumping off point for exploring other legal tools for addressing the Medicaid provider problem, assigning cases that illustrate how patients and providers have tried to use litigation to protect Medicaid access to providers.<sup>19</sup> We consider the Medicaid Act's access and quality promises, including the requirement that rates are sufficient to meet these promises, as well as the numerous lawsuits brought against states alleging that state Medicaid rate-setting violates this federal law. We also review how civil rights laws were used sometimes successfully in the late 70s and 80s to prevent hospital flight and discrimination against Medicaid beneficiaries. In both cases, however, students learn how the Supreme Court has dramatically narrowed the ability of patients and providers to bring these kinds of suits in federal court, essentially leaving the enforcement of access and quality protections to federal regulators. Finally, I introduce students to the regulations promulgated by CMS under the Obama administration, announcing its renewed focus on Medicaid access and providing new guidance to states to promote a more robust rate-setting process. With this background, I ask students to critique a system that relies solely on federal regulators to enforce federal access and quality guarantees against the states. President Trump's recent executive order titled *Minimizing the Economic Burden of the Patient Protection and Affordable Care Act Pending Repeal*,<sup>20</sup> provides a compelling and timely example of the consequence of relying solely on federal regulators to enforce federal law.

Of course, this pointed critique about provider reimbursement and the enforcement of access protections relating to rate setting occurs within the context of the current Medicaid financing structure: federal funding for Medicaid is not capped; funding increases as enrollment and need increases; and federal entitlements and other access protections constrain state program design decisions. The problem of low provider reimbursement is minor, however, compared to the massive cuts in Medicaid financing threatening the stability of the health care safety net if President Trump's calls for block granting Medicaid come to fruition.<sup>21</sup>

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19. See, e.g., Brietta R. Clark, *Medicaid Access, Rate Setting and Payment Suits: How the Obama Administration Is Undermining Its Own Health Reform Goals*, 55 HOW. L.J. 771 (2012); Brietta R. Clark, *Hospital Flight from Minority Communities: How Our Existing Civil Rights Framework Fosters Racial Inequality in Healthcare*, 9 DEPAUL J. HEALTH CARE L. 1023 (2005).

20. Exec. Order No. 13,765, 82 Fed. Reg. 8,351 (Jan. 20, 2017), <https://www.whitehouse.gov/the-press-office/2017/01/20/executive-order-minimizing-economic-burden-patient-protection-and> [<https://perma.cc/9AKB-6HZ5>] (indicating a lack of political will to enforce the ACA and expressing the intent to afford states flexibility, through waivers or exceptions, to the maximum extent permitted by law).

21. Rosenbaum, *supra* note 6.

C. *Navigating the System: New Challenges & Tools*

One of the particularly promising aspects of the ACA, which does not get enough attention, is the comprehensiveness of its reforms with respect to system design. Policymakers not only plugged existing holes in the safety net, they also gave considerable thought to how patients would navigate this new system. The goal of the ACA was to increase the numbers of insured, and policymakers were committed to designing a system that would encourage enrollment—whether in Medicaid or private insurance. Policymakers considered a number of tools to create a streamlined, simple, and transparent process for getting coverage through the new health exchanges. The Institute of Medicine (“IOM”) has also made valuable contributions in this regard. Drawing upon studies about the health literacy of patients in the public and private insurance systems, the IOM issued a series of reports and policy recommendations for states and the federal government to ensure that the new health exchanges would be health literate—that is, easier for people to navigate, understand, and use in order to access the information and services they need to take care of their health.<sup>22</sup> The ACA incorporated a number of these recommendations, as evident in its goal of creating a centralized website that is accessible and easily understandable to the public, its approach to the labeling and design of benefit plans to make them easily comparable, and its recognition of the importance of customer assistance (through navigators, for instance).<sup>23</sup>

Even with these laudable intentions, however, navigational challenges persist. Early crises with the functionality of exchange websites received a lot of media attention. But there have been other cases of people being improperly disenrolled from their plans or errors in provider lists that people use in choosing their plan or provider. Such mistakes create the kind of uncertainty or confusion that can disrupt and delay care. Moreover, while one may have expected the elimination of special categories in New Medicaid to alleviate the confusion and uncertainty that plagued Old Medicaid, this is not necessarily the case. Federal law allows states to define required Medicaid benefits for those eligible under the expansion (“Alternative Benefit Plans”) a bit differently than under traditional Medicaid.<sup>24</sup> Although most states have aligned benefits, a few states have Alternative Benefit Plans that may provide more generous coverage in some areas (such as in behavioral health or preventive care) but narrower coverage in others (for example, prescription

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22. See INST. OF MED., FACILITATING STATE HEALTH EXCHANGE COMMUNICATION THROUGH THE USE OF HEALTH LITERATE PRACTICES: WORKSHOP SUMMARY 2 (2012).

23. See Brietta R. Clark, *Getting People To Make the Right Choice Under the ACA: The Most Important “Sales Pitch” of Obama’s Presidency*, 17 J. HEALTH CARE L. & POL’Y 3, 44–54 (2014).

24. Paradise, *supra* note 15.



drugs and long-term services).<sup>25</sup> Finally, specific income eligibility requirements for Medicaid still exist and are applicable to public subsidies for private insurance.<sup>26</sup> This means that changes in income can lead to changes in eligibility status, creating potential uncertainty about coverage and disruption of care.<sup>27</sup>

Because our system continues to rely on a patchwork of public and private insurance programs with different eligibility criteria, it is impossible to completely eliminate risks of churning or mistakes that disrupt coverage. The good news is that the ACA reflects a decidedly different attitude about, and appreciation for, these problems, and states and the federal government have useful tools for minimizing this risk and making system navigation easier. The more sobering news is that these ACA reforms are currently at risk of being eliminated as part of an ACA repeal.

#### D. Reforms Addressing Social Determinants of Health

A persistent theme throughout Abraham's book is the extent to which social ills, like poverty, racism, segregation, and violence, shape health care for the poor in ways that the existing safety net could not address. Interestingly, Abraham ends with a reflection suggesting that social ills "are outside the scope of what a health care program can and should fix."<sup>28</sup> In asking students to consider this critique, I introduce students to the ways that some health care providers, advocates, and policy makers have re-imagined a system of health care financing or delivery that targets the effects of these social ills on health outcomes and access.

One reform addressing social determinants of health is the medical-legal partnership—a partnership between health care providers (such as physicians, hospitals, nurses, and care managers) and attorneys (especially public interest organizations or lawyers with expertise in poverty-related advocacy). These partnerships began with physicians reaching out to attorneys for their help in applying legal tools to fight the sources of serious medical problems that could not be cured by medicine alone. In fact, in one of the side trips Abraham takes to a neighborhood clinic to explore more fully the kinds of problems facing the community as a whole, students see a textbook case for a health care problem in need of a legal solution. A physician describes his frustration with a patient who kept coming to him for serious allergic reactions to the family cat. When

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25. *Id.*

26. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 2001, 124 Stat. 119, 271 (2010) (codified as amended at 42 U.S.C. § 1396a (2012)).

27. *Annual Household Income Changes? Report Them to the Marketplace ASAP*, HEALTHCARE.GOV: BLOG (Sept. 24, 2015), <https://www.healthcare.gov/blog/reporting-annual-household-income-changes/> [<https://perma.cc/42HS-ZBAS>].

28. ABRAHAM, *supra* note 1, at 259.

the physician finally asked the patient why she would not just give up the cat, the patient explained that the cat was the only thing protecting her children from the rats. In another case, a woman brought her two-year old child in with frost bite, caused by the landlord's failure to provide heat. Health care could provide temporary relief for the symptoms of these problems but could not eliminate the problems themselves.

Environmental health threats to which the poor are particularly vulnerable—infestation, lead, polluted water, and other dangerous conditions—are fixable with legal help. We have seen an increase in medical-legal partnerships to address these and other social and economic factors that impede access to care or jeopardize health outcomes. These include the improper denial of public benefits, discrimination resulting in unlawful evictions or job loss, domestic violence, and immigration-related issues. We have also seen emerging partnerships between government and health care providers to direct health resources toward other persistent social problems that have a significant impact on health care, such as creating more housing and transitional care for homeless populations and increasing access to affordable, healthy food.

We have even seen attempts by states to integrate these kinds of targeted interventions for social problems into Medicaid plans. It is not clear how much flexibility federal regulators will give states in this regard, but one scholar makes a powerful argument in favor of such an approach. Professor Jacobi describes states' experiments with their version of Accountable Care Organizations ("ACOs") but for Medicaid, as a tool for improving the health status of Medicaid recipients. He warns that "Medicaid ACOs must be mindful of the extent to which these recipients' health statuses are dependent not on medical intervention but on improving their access to the social goods and services that impede their ability to thrive."<sup>29</sup> He gives one example called a "totally accountable care organization" or "TACO," which includes social services to address housing barriers, substance use disorder, and community reentry for ex-offenders.<sup>30</sup>

In this Part, I have offered just a few examples of how Abraham's critiques remain relevant in today's system and in current debates about the ACA. Have the public and private expansions in the ACA increased coverage enough? What impact will these expansions have in light of on-going concerns about Medicaid financing? Is the administration realizing its goals of a simplified and easily navigable health care system? Can and should Medicaid plans address

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29. John V. Jacobi, *Medicaid, Managed Care, and the Mission for the Poor*, 9 ST. LOUIS U. J. HEALTH L. & POL'Y, 187, 199 (2016).

30. *See id.*; *see also* Hermer, *supra* note 17, at 235 (describing a vision of Medicaid which "seeks to include within Medicaid's auspices various means of ameliorating not merely medical problems, but also socioeconomic determinants of health").

the social ills that threaten health care access and outcomes? Will all these questions become moot as a result of current plans to repeal and replace the ACA? Or has the ACA so significantly reshaped the terms of the debate and reframed public expectations, that Republican promises to repeal the expansion and dramatically shrink Medicaid may be too costly politically and economically?<sup>31</sup> What vision of the health care safety net should be driving proposals to reform the ACA?

#### CONCLUSION

In describing Abraham's book, Alex Kotlowitz, the author of *There Are No Children Here*, said that "[s]uch an honest and candid account is essential if we are to seriously explore a restructuring of the health care system."<sup>32</sup> I believe that Abraham's account of the health care safety net remains a valuable tool to aid in this exploration. Indeed, a meaningful exploration and critique of today's health care system requires a deep and thorough understanding of the problems that modern health reforms were designed to address. And I cannot think of a better way to give my students that understanding than through the compelling, penetrating, comprehensive, and compassionate journey we take with the family profiled in Abraham's book.

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31. Congress's rush to clear a path for repeal without a replacement triggered fears that millions would lose insurance and that states and safety net providers would suffer devastating cuts. Increasingly vocal demands from the public for a replacement that preserves coverage highlights the potential costs if Republicans get this wrong. As of the final editing of this essay, it seems that promises to repeal the ACA are bumping up against political and economic realities that are making it difficult for Republicans to agree on a replacement plan. The most recent statements from the Trump administration suggest a longer timeline for reform than originally expected. Zachary Tracer, *Trump Says Obamacare Replacement Could Take Until Next Year*, BLOOMBERG POLITICS (Feb. 5, 2017 4:52 PM), <https://www.bloomberg.com/politics/articles/2017-02-05/trump-says-obamacare-replacement-could-take-until-next-year> [<https://perma.cc/X5UD-95P7>].

32. ABRAHAM, *supra* note 1 (review on back cover).

