

Health Care Civil Rights

Set Up to Fail

Peggy, an older white woman trained as a nurse, has worked at the same rural Michigan hospital for twenty-nine years. Her primary role is patient and family advocate, handling patient complaints. If health care civil rights violations emerge from discriminatory experiences with care providers, and if patients complain about them, health care staff like Peggy are the first people to hear about these experiences. What they do to frame, manage, and respond to the complaint shapes what health care civil rights are and could be. I wanted to understand how these frontline grievance handlers sorted problems and how they saw discrimination as a problem (and, indeed, if they did). The conversation turned from general questions about Peggy's job day-to-day to her responses to civil rights mandates at her hospital. When the interviewer asked Peggy about using patient scores to pinpoint possible dissatisfaction in protected civil rights categories such as sex, she pivoted immediately back to the need for high scores on patient satisfaction surveys to avoid financial penalties:

[On this general patient satisfaction survey, have you ever calculated, like, men rate patient care more highly than women, or things like that?] You know, we can. We have the ability to do that. Right now we go by our top box score, which is the, you know, always the nines or the tens. Anything less than those do not qualify and Medicare takes back money from us at the end of the year. Every hospital, that's what they do. So they drive organizations to provide the most best customer service and care, because if you don't, then they're going to be taking back, you know, money.

Peggy is referring to provisions in the Affordable Care Act (ACA) that increased pressure on healthcare organizations to pay attention to patient satisfaction by tying patient satisfaction survey outcomes to Medicare reimbursements under

its Hospital Value-Based Purchasing Program.¹ Hospitals do indeed face losing money if patients give low ratings in these satisfaction surveys. The survey in Peggy's hospital is the Hospital Consumer Assessment of Healthcare Providers and Systems. The Centers for Medicare & Medicaid Services publishes the results on a website called "Hospital Compare."² Physicians are also evaluated using a similar survey for their outpatient work, and scores impact performance evaluations and pay.

In her first response, Peggy denies the relevance of any civil rights categories because every patient who responds to the satisfaction survey matters to the organization in the same way—as a respondent whose unhappiness can result in financial loss. Peggy put up antidiscrimination notices and updated them when Section 1557 was enacted because she needed to do that for the hospital's accreditation under the Joint Commission.³ She explains that the hospital is located in an overwhelmingly white rural area, and they do not do any specialized "gender-change surgeries or anything like that," so she does not really see discrimination complaints. But moments later, she described using their scoring history to pinpoint problems using age. They found among pregnant patients in the obstetrics ward, the "really, really young patients, [who were] not educated and, you know, no prenatal testing, no insurance, no prenatal support, and we looked at that and found that we really needed to spend more time educating and talking and encouraging the younger patients."

Peggy carefully follows "the nines and tens" in the satisfaction surveys, and sometimes a dip in the numbers could point to problems caring for a particular subgroup. In the case of the very young pregnant patients, the surveys helped her hospital see that these patients were particularly vulnerable and needed more support. In other words, the organizational requirements and legal structures that comprise Peggy's everyday working reality are primarily determined by healthcare regulations and practices that are not primarily about civil rights or discrimination. She saw a problem in a group of patients with certain characteristics using the survey data but not as a problem of structural vulnerability for these young people giving birth without resources. Civil rights issues and discrimination problems are certainly present in the hospital regulatory regime, but they are surrounded by and interpreted through more compelling problems, practices, and procedures in the operation of Peggy's hospital. Possible civil rights problems are refracted through these policy pressures for measuring quality of care, for example, which is related to discrimination but not always the same thing.

How did we get here? As recently as the 1960s, hospitals were considered private entities beyond reach of federal antidiscrimination law.⁴ Southern hospitals segregated patients by race even as facilities popped up across the rural landscape in one of the largest postwar structural investments in American healthcare history. Federal dollars built those hospitals, but the federal government permitted racial segregation to continue. Peggy's hospital was constructed during those

boom years. The Civil Rights Act of 1964 and the new Medicare and Medicaid programs enacted in 1965 put a stop to hospital segregation as courts and the Johnson administration agreed that accepting federal funds meant healthcare facilities could not discriminate. Medicare billing remains the major tie between healthcare and civil rights, but legal enforcement has significantly lagged.

New incentives arose instead. Interest in measuring patient satisfaction dates to the 1980s, and the Affordable Care Act in 2010 was a major effort to incentivize high-value, safer, more patient-centered care. The patient safety movement increased professionalization and bureaucratization in health systems around patient issues with the rise of the patient experience or “PX” professional in the last decade. Hospitals have lawyers on staff, of course. But problems filter through this other bureaucratic compliance side of the healthcare system, in which patients trying to articulate a rights violation are lumped in with all possible problems and complaints and treated as part of a cascading mishmash. All these shifts—in the application of civil rights law, in the understanding of the patient experience, and in the ways financial incentives shape these interactions—have their own roots and histories, combining unevenly over time according to a reactive, volatile American health politics that has never been able to support a unified account of what health care civil rights are and why they matter.

HEALTH CARE CIVIL RIGHTS IN THE AMERICAN RIGHTS TRADITION

This book analyzes civil rights in health care in the contemporary United States. But civil rights are usually understood to be about voting, education, and employment, not health care. Scholars of civil rights have mostly studied them in the workplace, theorizing how rights can assist social movement mobilization but also reinscribe inequalities and ratify ineffective organizational practices that fail to produce much social change.⁵ What do civil rights look like when refracted through the lens of American healthcare, a massive and complex web of public and private relationships, laws, regulations, institutions, professions, norms, and financial arrangements that comprises one-fifth of the US economy? What rights are there in US healthcare, anyway? What would a nondiscriminatory health benefit plan look like? We are famously a country that lacks an explicit right to health. And yet our US healthcare and welfare systems offer a range of entitlements, protections, rules, and supports for health insurance, so much so that Christina Ho argues that we already have some rights to health that we fail to see as true rights.⁶ So then what is a civil right in health? It turns out that seeing rights through health is different in important ways than seeing them through other contexts like employment.

By rights in general, I mean an obligation either to provide something beneficial or to refrain from doing something harmful on the part of the state, which

is owed from the government to an individual. A typical top-down exploration of legal rights would begin with the rights in the US Constitution. This approach gives us little understanding about health care rights, however, because there is simply very little in the Constitution, particularly as it is interpreted in the federal courts right now, that supports health care rights. Our Constitution is notable for being one of the shortest, oldest, and most limited constitutions of any that currently governs a large democratic society. Over sixty-seven percent of countries have a right to health of some kind specified in their national constitution, but we do not.⁷ Our Constitution contains mostly *negative* rights, that is, the right not to have the government take some harmful action (like quartering soldiers in civilian homes or infringing the right to keep and bear arms), which envision an empowered individual who primarily needs forbearance from the state to enjoy his private property unencumbered.

Health rights are really only meaningful as *positive* rights: a right to be provided with something good, not simply the right to have the government refrain from doing something bad. From clean air and water to untainted food to emergency surgery, sustaining health requires the regulation and provision of resources through laws and government as well as collective and individual action. Finding a right to health in our Constitution would mean interpreting other broadly written clauses to include it or amending the Constitution to add it (a very burdensome process that is practically unusable). The Fourteenth Amendment's due process protections, both procedural and substantive, offer some protections from having entitlements from the state withdrawn or for the exercise of personal freedoms, such as freedom from sterilization and the ability to use contraception without it being criminalized by the state. Similarly, the Fourteenth Amendment's equal protection clause could be construed to prevent any state action that treats certain groups worse than others without adequate justification (such as denying health care to transgender people that is extended to cisgender people), and indeed attorneys have vigorously made these arguments in court filings.⁸

It is conceivable that in some alternate universe in which many political events had unfolded quite differently in the United States, we could now enjoy interpretations of our constitutional rights that guaranteed the kind of provisioning—positive rights to health—that we would need to promote the thriving of our citizens much more widely and equally than we have now. One could argue that to enjoy rights of self-governance, due process, and equal protection of the laws secured in the post-Civil War United States, we need conditions for freedom such as universally available high-quality education, basic income, and health care for all. But this vision is unimaginable under current interpretive conditions for the US Constitution to compel (and not politically realistic to hope for from Congress, either). Our Constitution has serious structural flaws that have permitted and strengthened minority rule, particularly in the presidency (because of the electoral college that permits a candidate who has lost the popular vote to win), the US Senate

(because each state gets two senators despite wild population variation), and the Supreme Court and the lower federal courts (because justices and judges are nominated by the president and confirmed by the Senate, thereby doubling down on minority power).

Instead, conservative, Republican-appointed judges dominate our federal courts and hold a conservative supermajority at the Supreme Court, where interpretive ambiguities in our constitutional text become policy outcomes in particular cases. Republican policy preferences often oppose civil rights to help minoritized groups or positive rights to health. After the 2022 *Dobbs v. Jackson Women's Health Organization* decision that abortion rights are no longer included in constitutional protections, all previously protected rights that relate to health, privacy, reproduction, and sex and gender discrimination protections are on much shakier ground.⁹ Republicans do not support policy proposals widely understood to promote health and health care access, such as greater health and welfare support spending, environmental protections, universal health care, better education, and health care civil rights. The growth area for constitutional rights in the present is in greater individual access to firearms of all kinds and in religious protections from duties not to discriminate based on conservative interpretations of evangelical Christianity and Catholicism. Both Republican-supported constitutional rights expansions are antihealth in profound ways, as firearms are now the top cause of death for children in the United States, and religious rights ground denials of health care from abortion to HIV medications to gender-affirming health care.

Civil rights is an ambiguous term that we use to refer to a collection of rights that can mean different things.¹⁰ It can mean legal protections from racial discrimination established during the civil rights movement of the 1960s (and indeed when we say someone is a “civil rights icon,” that usually means a prominent leader for Black civil rights to equal voting, public accommodations, and education during that period). This period featured major legislation as well as constitutional rulings to promote racial equality, and in that sense *civil rights* refers both to statutes such as the Civil Rights Act of 1964 as well as to constitutional law. People sometimes use the term *civil rights* to mean all rights related to equality, including constitutional rights or human rights, and critically, employment rights that apply to private companies. In this book, I use the term *civil rights* to mean the statutes that protect rights based on a named trait or set of traits in the contemporary US legal system. As we will see, civil rights in health care must apply to many private actors as well as the government, since employers, private insurance companies, and governments work together to provide health care in the United States. I distinguish civil rights from constitutional rights, which are the rights either spelled out in or interpreted by judges as grounded within the US Constitution or state constitutions. Sometimes these are nearly the same thing; sometimes they are not. This book is focused on the transformations of the Affordable Care Act and

its interventions into civil rights, which start in the statutory and administrative realms. Arguments about the meanings of discrimination and equality for trans and non-binary people rage across all these legal and governmental levels and within private companies and organized religious groups, and to understand how they unfold it is helpful to keep these basic distinctions in mind.

Often the impulse behind civil rights legislation is to require treating a person from a historically minoritized or stigmatized group the same as a member of a favored group: hire them, rent an apartment to them, and so on, as if the stigma attached to their identity did not exist or does not matter. But the laws are written to apply to anyone on the basis of the trait, so laws against racial discrimination protect white people and laws against sex discrimination protect men, for example. Usually civil rights claims are individual-level disputes over specific discriminatory decisions or practices rather than over the fact, for example, that entire school districts may be neglected and underfunded, that there is little affordable housing available, or that there are no jobs nearby that are compatible with raising a small child. These kinds of problems or harms are harder to tie to a bad actor doing discrimination on the basis of a protected trait to a specific person or group. The term *civil rights* can just as easily be applied to conservative causes such as anti-affirmative action (as discrimination against white people) and has indeed been successfully deployed for many different ends.

The health-based rights that I focus on in this book are the civil rights or anti-discrimination laws that apply to patients, protecting them from discrimination on the basis of race, sex, age, disability, and national origin or language (and depending on the jurisdiction, a few other traits). Health care civil rights laws, such as the nondiscrimination clause of the Affordable Care Act, Section 1557, Title VI, prohibiting racial discrimination in entities such as hospitals receiving federal funds, and state-level insurance nondiscrimination laws, often function in this list-driven way.¹¹ I use the term *patients* (and *people seeking care*) but I also mean health care consumers and holders of health insurance policies, since these laws touch many encounters in the healthcare system beyond the provider-patient interaction. Health care civil rights can be a right to be treated equally, respectfully, and in accord with one's gender identity, including having providers use the correct pronouns. It can mean being able to communicate with your health care provider no matter what language you speak, for example. It can be a right to be provided with publicly funded health care or specific health insurance coverage or terms of coverage. Health care civil rights are both rights of proper recognition and of sufficient provision. More specifically, one can be affirmatively provided with something such as health insurance coverage for pregnancy or gender-affirming care. Or one can be entitled to restraint or nondisclosure in a healthcare setting, such as the Biden administration's regulation that tells healthcare providers that they cannot provide private health information about reproductive health to

law enforcement if, for example, officers are investigating whether someone left a state where abortion is illegal to obtain a legal abortion at their facility.¹²

FEDERAL SPENDING AND HEALTH CARE RIGHTS

A person could have a health right in many ways. In the United States, we have them in fairly thin and fraught ways. What that means is that health rights do exist, but they are often contingent on being able to actualize them with additional resources and power, and access to those resources and power is not guaranteed and is regularly denied. Health rights mean a wide range of things in practice, and they appear across a lot of different laws, attach to different contexts, uses, and statuses, conflict with each other, and are not grounded in any overarching political commitment based on a shared understanding of why health rights are good and necessary. One could have an entitlement right to be provided with something like a health benefit. In practice, being provided with a health benefit may simply mean having the right to buy health insurance that covers a certain scope of care, to be charged the same rate as others, or not to have one's coverage cut off. It may mean actual provision of items one needs to live and thrive, such as home health visits for someone living with a significant disability or kidney dialysis treatment for someone with kidney failure. There are rights to procedures, such as being given notice and an opportunity to object before one's benefits are terminated. The provision one has a right to could be merely information, such as being mailed a copy of the employer health benefit plan.

Most of what counts as health care rights and healthcare regulation comes from statutory law passed by Congress or in the states and administered within the agencies of the federal and state governments. Outcomes that support health and equality have been driven by major federal spending programs that did not have civil rights as a core aim and were instead universal social welfare and health benefit programs, such as Medicare (universal after age sixty-five, that is). The basic social and health welfare structure of the United States is shaped by structures of federalism and policy commitments over time to age-based relative generosity for older people, legacies of racism, and a commitment to employer-based health insurance. We have a federal government with considerable power to spend money and regulate commerce under the Constitution, which means that there is strong national government power to shape healthcare systems and care delivery. But powers for health and welfare devolved in many important ways to the governments of the states, where policy variation is permitted, and have long been shared with private groups like businesses, unions, and religious organizations.

In healthcare, rights are typically legislative enactments because the federal government has used its power of the purse, or Constitutional spending power, to make requirements of any entity that accepts federal funding. Acceptance of

federal funding in healthcare means billing to Medicare, for example (as well as other forms of federal support for health clinics, the Indian Health Service, and technology grants). So even health care or services typically provided by private individuals acting as providers, private companies such as insurers, medical groups owned by a group of physicians, or nonprofit or for-profit hospitals and clinics can come under the tent of government's power to create obligations to do something or refrain from doing something. Federal health care rights are thus potentially very far-reaching.

Congress and the president showed significant political will at midcentury to solve the problem of poverty for older Americans through Social Security and Medicare, which are the most popular and transformative social policies in American history that provide cash income and health coverage to people who reach the age threshold. In effect, older Americans are entitled to a basic income and universal health care. Everyone else lives under a patchwork system of employer-based health insurance coverage, poverty-linked Medicaid health coverage, poverty-linked benefits such as food stamps, Temporary Aid to Needy Families, and the Child Health Insurance Program, or any other services a community, state, religious group, or private organization wishes to provide, disability benefits, health insurance policies bought from somewhere other than an employer such as on the state exchanges, or going without any health insurance. There is no right to an income source *per se*. These health and welfare programs, even the nonuniversal ones that are not age-based entitlements, reach deeply into the middle class and are used by millions of Americans. Medicaid pays for over forty percent of births in the United States today, for example.¹³ All these programs have qualification rules, applications procedures, and are typically administered at the state level with a mix of federal and state funding and with state-level political prerogatives to be more or less generous. In California, Medicaid covers nonparent or noncare-giver adults with incomes at or below 138 percent of the federal poverty line, while in Florida, nonelderly adults who are not parents or caregivers are not covered no matter how poor they are.¹⁴

The reach of the federal welfare state, limited as it may seem compared to other countries, is also the key to protecting civil rights because taking federal funding is the means to require compliance. But it was not always the case that health care civil rights could use this key of federal spending to enable civil rights. The federal government had to shift from explicitly supporting white supremacy and the southern racial segregation system in healthcare to opposing it with the spending lever. After World War II, President Harry Truman hoped to establish national health insurance along with significantly increasing spending on hospital construction and public health. The legislation that emerged did not include national health insurance, but the Hill-Burton Hospital Survey and Construction Act of 1946 led to the building of 7,750 hospitals and clinics with \$3.7 billion sent out to the states.¹⁵

As historian Karen Kruse Thomas explains, “The Hill-Burton Act was debated in Congress and passed into law at the height of the South’s paradoxical status as the nation’s neediest yet most politically powerful region.”¹⁶ Southern congressmen made sure that Hill-Burton’s nondiscrimination provisions preserved racial segregation in health care by allowing “separate but equal” facilities (termed “like quality” for “separate population groups”) and by specifying that hospitals were private facilities under state rather than federal regulation.¹⁷ Framing hospitals as private meant that their segregationist policies, widely practiced throughout the South, were not state action under the Fourteenth Amendment’s equal protection clause and deprived the Department of Health, Education, and Welfare (the precursor to today’s Department of Health and Human Services or HHS) of jurisdiction over their internal policies, such as racially segregating patients by room and ward, maintaining “white only” and “colored” waiting rooms, and denying privileges to Black physicians and nurses.¹⁸

Hill-Burton spending was need based and focused on rural capacity building. Southern states received ninety-three percent of the early Hill-Burton appropriations (by 1950) and benefited from a funding formula that funded the poorest states at a per capita rate 3.56 times higher than the formula for the wealthiest states.¹⁹ This pattern, in which southern states most hostile to federal policymaking draw disproportionately on federal healthcare support, was entrenched in the architecture and care structures of the American landscape through Hill-Burton spending. This pattern continues in policies such as our current federal Medicaid reimbursements to states in which wealthy (on a per capita basis) Connecticut gets just fifty percent of its expenditures back while poorer Mississippi gets back seventy-eight percent.²⁰

The Supreme Court’s declaration in the school desegregation case of *Brown v. Board of Education* in 1954 that separate but equal public schools were inherently unequal and unconstitutional made segregated hospitals insecure.²¹ Public schools are clearly state run and thus part of state action, which tethers them to constitutional guarantees. Private entities, such as the many private schools that sprung up across the South to avoid admitting Black students, were not and thus were allowed to discriminate. The same legal idea sustaining racial segregation in healthcare settings, that hospitals were private and therefore not subject to antidiscrimination requirements even though they were built with federal dollars, held on for nearly a decade longer until 1963. Dr. George Simkins Jr., a Black dentist in Greensboro, North Carolina, and a local NAACP leader, led a class action lawsuit in 1962 against the segregated hospitals that barred both Black practitioners and Black patients. Dr. Simkins and the plaintiffs argued that the racial segregation violated the US constitutional guarantees of equal protection under the Fifth (due process) and Fourteenth (equal protection) Amendments. These arguments underlie the notion that when the federal government or a state is sufficiently supportive of an entity that is otherwise private (such as providing funding), that is

enough to bring its operations under the doctrine of state action, meaning that the entity must protect constitutional rights too. The plaintiffs initially lost their case in federal district court on the grounds that the nonprofit hospitals were private, free of constitutional duties, and could discriminate.²²

The US Commission on Civil Rights issued a sharp report in October 1963, pointing out that federally subsidized racial segregation in health facilities was unconstitutional under the school desegregation decisions and should not continue. The *Simkins* doctors and patients appealed with Justice Department backing. The millions of federal dollars that had gone to building these Greensboro hospitals and the state of North Carolina's role in managing the projects was more than enough for the federal appeals court to find for the *Simkins* plaintiffs in November of 1963. The majority on the Fourth Circuit Court of Appeals noted that, "Racial discrimination by hospitals visits severe consequences upon Negro physicians and their patients."²³ The Supreme Court did not take up the case and the Fourth Circuit's holding stood in that jurisdiction, finally extending the constitutional protections against racial discrimination to hospitals as (at least partially) state actors. Soon after *Simkins* was decided, and propelled by its successful linking of federal funds and nondiscrimination in health, Title VI of the 1964 Civil Rights Act passed, which prohibits race discrimination by entities receiving federal funding in healthcare and other areas such as education.

The contemporary period in which civil rights laws apply to health and healthcare begins with Title VI the Civil Rights Act of 1964 and the legacy of pushing back against white supremacy in healthcare settings. It provided a pathway for federal enforcement of health care civil rights using the carrot and stick of federal dollars. The Civil Rights Act of 1964 is probably better known for its employment protections under Title VII on the basis of race, color, national origin, sex, or religion, but patients are not employees.²⁴ Title VI statutorily prohibits racial discrimination by recipients of federal funding, the same funding affirmed in *Simkins* as conferring constitutional duties not to discriminate in healthcare facilities.²⁵ The Hill-Burton funding was a large and attractive source of federal dollars, but hospital construction would not go on forever. Title VI turned out to be an effective tool for dismantling racial segregation in health care facilities, but it took another part of President Johnson's expansive agenda plus considerable organizing around the South to make it happen.

Hill-Burton would soon be eclipsed by the most far-reaching spending and civil rights promotion tool ever enacted: the Medicare program, passed in 1965. Medicare would become the most important federal lever for civil rights compliance, perhaps ever.²⁶ Medicare payments for care provided to the elderly brought nearly every hospital under the aegis of Title VI and its nondiscrimination requirements by its implementation date of July 1, 1966, though there was a considerable fight to make it happen. Medicare legislation came in 1965 after Title VI had passed in 1964, but exactly what that meant for segregationist hospitals that

anticipated receiving Medicare payments was not discussed in Congress. Senator Robert Byrd of West Virginia, a prominent segregationist, asked the Department of Health, Education, and Welfare for clarification about whether Title VI would apply to hospitals under Medicare as the bill was near to passage. Labor and civil rights leaders opposed to segregation also wanted to know. If the Department of Health, Education, and Welfare did not think Title IV would apply to Medicare, liberals in Congress would want an antidiscrimination clause in Medicare to get the same result. Johnson administration officials and their allies in labor and civil rights groups worried that adding an antidiscrimination clause to the Medicare bill would risk southern support and divide the Democratic coalition needed to pass it. The decision was to work closely in Congress “to avoid any amendments being offered and to keep the whole thing as low keyed as possible” while affirming administration support for Title VI’s reach into Medicare.²⁷ It is worth remembering how hard it is to pass a healthcare bill with an antidiscrimination clause in it. Section 1557 was also kept “as low keyed as possible” in the Affordable Care Act passage.

Once Medicare passed with hospital segregation still widespread across the South, there was no avoiding the fight. Hospitals had separate “white” and “colored” facilities for everything from waiting rooms to beds. The Johnson administration’s hopes for a successful launch of Medicare ran directly into the persistent practices of white supremacy in American southern hospitals. During the time between Johnson’s signing of the Medicare law on July 30, 1965, and the July 1, 1966, start date when hospitals needed to be certified to participate in Medicare, civil rights activists and administration officials worked hard to dismantle the racial segregation that was standard in hospitals across the South. Civil rights advocates filed hundreds of complaints to put the spotlight on illegal racist policies in facilities. The Public Health Service dispatched investigators across the region to see for themselves if desegregation had really been achieved. Three months before the deadline, only forty-nine percent of hospitals overall and only twenty-five percent of southern hospitals were in compliance.²⁸ Johnson was caught between his two major initiatives: wanting Medicare to launch successfully with near-universal coverage for the elderly and civil rights progress. The formula to achieve both was to push hard at the local level, keeping lists of every hospital and its compliance state day by day as the July 1 deadline approached, combined with strict enforcement by threatening to withhold funds.

In the final days leading up to desegregation compliance in hospitals, officials placed National Guard helicopters on standby in case historically all-white hospitals refused to care for critically ill Black patients. The plan was to fly them to military hospitals or Veterans Administration facilities.²⁹ The Office of the Surgeon General set up a twenty-four-hour phone line for physicians to call if a non-compliant hospital refused admission to one of their Black Medicare patients.³⁰ The helicopters were not used; the large-scale push for compliance with Medicare

payments hanging in the balance worked. For a few more decades, Title VI litigation against racist practices in health care continued with some success against practices such as disproportionately certifying only a few beds for Black Medicaid patients.³¹

Black and white people sharing the intimacy and vulnerability of a hospital room had been a huge sticking point in the desegregation effort. Decades later, some of the first claims under Section 1557 were from trans women placed in the wrong inpatient room with a man instead of with a woman. But the enforcement environment has entirely shifted. Title VI became, as Dayna Bowen Matthew points out, “one of the most underutilized tools in the fight to protect equal access to healthy, pollution-free environments and to health care for marginalized communities.”³² Title VI lost most of its power in 2001 when the Supreme Court limited its claims for individuals to intentional rather than disparate impact discrimination. HHS can bring impact-based agency enforcement, but its budget and staffing are rarely up to the task. To implement nondiscrimination in rooming by gender identity, for example, HHS does an investigation and instructs the hospital to room transwomen with other women, but only on a case-by-case basis, not at all during several years when one federal judge blocked HHS enforcement, and without much realistic threat of withholding federal funds. The Supreme Court held that the provision of the ACA that required states to expand Medicaid or face denial of federal Medicaid funds for their whole program was too coercive,³³ and officials are reluctant to withdraw federal health funds in ways that might hurt the patients they want to help. On top of all that, conservative religious groups claim that conscience and religious protections mean that religious hospitals and employers do not have to recognize trans people at all, in rooming or pronouns or provision of care, even with federal funding. Removing explicit racial segregation in hospitals was a comparatively straightforward policy to implement and monitor compared to the ongoing multidimensional health inequalities that law has been unable to solve. The rest of this book is focused on the present and the recent past, but this history can reveal the past policy choices that structure what is currently possible in health care civil rights as well as some paths not taken.

HEALTH CARE RIGHTS AS A PATCHWORK

The federal push to end hospital racial segregation through Title VI enforcement with the threat of withholding Medicare funds was a singular campaign. We have not seen such an effective and coordinated effort against such a clear target since then. Congress has intervened with federal legislation to stake out important protections in health care and insurance since Title VII and prior to the Affordable Care Act in 2010, though unevenly and in reaction to specific crises and constituencies rather than with a comprehensive approach to equity in health care. In other words, political conditions as well as mobilizations around specific diseases

through social movements have profoundly shaped health care civil rights since the first and only major push for health care civil rights by President Johnson in 1966 with Medicare implementation and racial desegregation. This haphazard growth creates a patchwork of health care rights that lack any unifying explanation or rationale but have instead been prompted by their own unique histories of activist mobilization and political responsiveness.

For example, in 1972 Congress added specific, singled-out coverage for chronic renal disease to the Social Security Amendments, extending Medicare to nearly everyone with chronic kidney failure. Many circumstances combined to produce this distinct benefit right for one very expensive and devastating disease, including dramatic testimony before a congressional committee from a sympathetic white father on kidney dialysis and political interest in testing out national health insurance through a few catastrophic test conditions.³⁴ Those circumstances shifted and no national coverage emerged, but national coverage for that one disease became part of the patchwork of health care rights. This unusual example nonetheless shows how patchwork rights get made from political calculations and mobilizations that fit within general hostility toward broad-based health reform in the United States.

The disability rights movement has significantly transformed the legal landscape of rights over the last half century. Disability-based health care civil rights reach into all the areas of law and policy discussed in this book, though full and equal participation in society for all disabled people is far from achieved. Section 504 of the Rehabilitation Act, passed in 1973, protects against discrimination on the basis of disability in federally funded programs or activities, which include hospitals, educational institutions, and government buildings and programs (but not private sector employment or public places that are privately owned, like theaters and hotels, later reached by the Americans with Disabilities Act of 1990).³⁵ The terse language in the statute needed regulations to spell out what these protections would mean, but they had been blocked and delayed.

In 1977, a coalition of disability rights activist groups occupied a San Francisco federal building to protest that regulations had not been finalized. The 504 sit-ins, which lasted twenty-five days, yielded regulations that same year. Section 1557 brings in disability through mention of Section 504, and 1557 regulations (the first of which took six years to be proposed and implemented by the Obama administration in 2016) expanded disability nondiscrimination in health care with specifications about unlawful disability discrimination in insurance benefit design, telehealth, communication, and clinical decision tools such as algorithms (such as those used to ration care under crisis conditions).³⁶ The Office for Civil Rights in HHS issued a bulletin in 2020, at the height of the COVID-19 pandemic, reminding hospitals that civil rights remained in effect during the crisis and that “persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative ‘worth’ based

on the presence or absence of disabilities or age.”³⁷ Some crisis standards of care policies were updated during the pandemic to incorporate disability rights perspectives (such as removing categorical exclusions from lifesaving care based on having certain disabilities) and updates continued to include more disability and racial justice-focused provisions than pre-COVID versions of policies.³⁸

Another set of significant influences on the patchwork of health care civil rights came from social movements around diseases such as HIV/AIDS and breast cancer. Activist mobilization for resources to fight AIDS in the 1980s and 1990s transformed institutions such as the FDA and secured major legislation to fund HIV/AIDS research and treatments.³⁹ HIV/AIDS is also considered a disability under antidiscrimination laws. Women’s health activism in the 1980s and 1990s also resulted in changes to federal laws about the conduct of clinical trials for health research so that women would no longer be excluded from studies. Requirements to include “women and minorities” are now part of all federally funded health research, but as Steven Epstein has pointed out, they have also cemented ideas about race, ethnicity, and sex as biologically distinct and meaningful that obscure the social and political factors that constitute vulnerabilities around these categories.⁴⁰ Breast cancer activists successfully secured not only greater federal funding for research but also mandates for insurance coverage for breast reconstruction after mastectomy with implants (previously not covered because it was deemed cosmetic). Trans health rights advocates point out that this federal legal requirement is gender-affirming care for cisgender women since it addresses the distress one would feel as a woman appearing in public and intimate life with no breasts.⁴¹ Civil rights protections based on pregnancy and the need to pump milk at work are also important examples of the ways that cisgender women’s health concerns have gained some formal traction in the law.⁴² Perhaps the most emblematic law of the sad patchwork that is our healthcare system, the Emergency Medical Treatment and Labor Act of 1986, guarantees a right to stabilizing treatment in a Medicare-participating emergency department regardless of ability to pay. It stops hospitals from screening out and dumping poor people who have nowhere else to go.

As I pointed out above, the overall context for this patchwork of rights is the fact that national health insurance coverage for everyone is a political impossibility in this country. Health care civil rights related to insurance coverage fracture because different health insurance market segments (the people and policies that are grouped together based on how people get their coverage and who pays for it) are regulated differently and sometimes lightly. Access to public health insurance, such as Medicaid, Medicare, the State Children’s Health Insurance Program, the Indian Health Service, or TRICARE for veterans, depends on meeting the eligibility criteria based on age, disability, income, tribal membership, or military service. Federally funded community health clinics are also a critical part of our healthcare system for many people with lower incomes. These structures are publicly funded care to which civil rights laws apply. The next-most public insurance

plans are the ACA-regulated health insurance plans, which are offered for the individual and small group markets by private insurers but with considerable government requirements and subsidy. These plans are mostly purchased by people who work in small firms (with fewer than fifty employees), which are not required to offer health insurance benefits, or by individuals who are self-employed. Section 1557 antidiscrimination protections apply to all these public and what I call semi-public plans because they directly receive federal funding and/or are run by the Department of Health and Human Services.

Once we leave the world of the most clearly federally funded forms of health insurance and health care, things get more complicated. It becomes more difficult to define what is private and what is public and who is playing what role with what responsibility for discrimination. The workplace is a particularly high stakes site for health care rights because most nonelderly adults in the United States get their health benefits, in the form of health insurance, through their employment. Most of these benefit providers are private firms (or two private companies: the employer and the insurer). In other words, private companies are acting as health care providers (or at least as conduits that make accessing care possible by providing health insurance), but they are obviously not hospitals or clinics themselves. Is the private employer, like Target or General Electric, a recipient of federal funds for health-care under Section 1557? The answer has been consistently no, both because they do not receive federal funds and because their business is not principally health care. But this decision is a political choice that could be otherwise. As Colleen Grogan rightly points out, even supposedly private health insurance from employers receives considerable but hidden public subsidy in the form of tax breaks for employers (that is, businesses are exempt from taxation on any money they spend on employee health insurance).⁴³ Supporting employer-sponsored health insurance costs the federal government over three-hundred billion dollars per year in tax expenditures (forgone revenue) and is the single biggest item in this category.⁴⁴ Even so, there has not been an interpretation of Section 1557's tie to federal funding that brings in the tax benefits as a form of federal financial assistance that would apply to all private employers, which would acknowledge that employers are the primary way that nonelderly Americans receive health care and that we divert a lot of money to help them do it. Nonetheless, health benefits are part of employment discrimination law. Title VII of the Civil Rights Act of 1964 prohibits discrimination in employment on the basis of race, color, sex, national origin, and religion, and that explicitly includes health benefits as a "term or condition of employment" that cannot be discriminatory to the employee. But such discrimination protections would not apply to the employee's family as beneficiaries of the health plan because they are not the employee.

Even if the company, like Target or General Electric, is bound by employment law but not health care civil rights law, the health insurance carrier that they work with is in the business of health care. The carrier receives federal financial assistance

in the form of payments, subsidies, or some other benefit, probably because some part of the carrier's business involves selling plans on the ACA marketplace and accepting advance payments of the premium tax credit or cost-sharing reduction payments or offering Medicare Advantage plans or Medicaid managed care plans and accepting a set amount per beneficiary. Under the most recent Section 1557 regulations, offering these plans would bring an insurer's whole operation into Section 1557 coverage. That clearly includes all the health plans that the carrier designs and sells to employers as fully insured group coverage. The carrier uses the premium payments from the employer to cover the costs of claims and to turn a profit. But what about when the insurer acts as the administrator for a plan that has been designed within a private company that self-insures its workers' benefit plan?

Self-insuring is a way for private employer-sponsored health insurance to become even more private. By that, I mean it seems to be even more wholly within the firm and more out of reach of regulation (remember to forget about that big tax subsidy). Self-insuring means that a company takes the risk of paying its own employee health insurance claims out of its own reserves. Insurance is mostly regulated at the state level under the McCarran-Ferguson Act.⁴⁵ Many states have enacted antidiscrimination protections or mandate coverage for certain things in health insurance, like infertility, based on the states' powers to regulate the business of insurance generally. The major benefit for companies in self-insuring, however, is that they do not have to comply with state insurance laws and instead they are very lightly regulated at the federal level. This route has been popular, and more and more companies are self-insuring, even smaller firms. An insurance product called stop-loss insurance, through which the firm insures itself against having to pay more claims than anticipated, helps buffer the risk for smaller firms to self-insure. Twenty-four states plus the District of Columbia have banned gender-identity discrimination in insurance,⁴⁶ but if a corporations' plans are self-insured these laws do not apply. Self-insured firms in states that mandate in vitro fertilization coverage do not have to offer plans that include it, either.

How could an employer doing business in a state sidestep that state's insurance mandates and insurance antidiscrimination law? To understand this situation, we have to take a brief tour of an important law most people have never heard of: the Employee Retirement Income Security Act of 1974 or ERISA.⁴⁷ This law was passed to put up guardrails to protect workers' pensions and other benefits when private companies provide them. The concern was that retirement pension funds, back when they existed widely, were being mismanaged and abused. The law was not designed to address health care as an employee benefit. It contains a preemption clause that allows ERISA to supersede state insurance laws for employee benefit plans that are health insurance as well as pensions.⁴⁸ That means that ERISA federal law applies, and state laws do not. Employer-sponsored health benefit

plans are still federally regulated throughout the patchwork because legislation has sprinkled in some federal health care protections explicitly, and other federal laws are not preempted.⁴⁹ But ERISA is mostly a deregulatory vacuum, not a health regulatory regime. The federally enacted right discussed above to have breast implant reconstruction covered after cancer applies to these self-insured plans, for example, along with federal requirements that mental conditions be covered on par with physical conditions. Title VII employment discrimination protections are also not allowed to be preempted under ERISA, so those protections remain as well, at least for the employee. (Section 1557 is a federal law and thus not part of ERISA preemption of state laws either, but remember that private businesses that are not healthcare related are not covered by it.) Courts have held that exclusions for gender-affirming care in employee health plans are discriminatory under Title VII.⁵⁰

The catch is that employers who self-insure do not want to be a health insurance carrier in addition to being say, Target or General Electric. The company hires a health insurer to act as their administrator for the self-insured plan, called a third-party administrator or TPA. The TPA is typically a large commercial insurer, but they are providing this other service, not the plan itself. The TPA processes all the claims for the sponsoring business. Those carriers are the same entities discussed above (already in the health insurance claims processing business) that are not allowed to discriminate under Section 1557, likely because they sell Medicare Advantage plans or marketplace plans. That means that they cannot administer discriminatory plans even if employers wish to hire them to do exactly that. If Section 1557 works the way its 2024 regulations spell out, even employers who want to draw up their own discriminatory health benefit plan will not be able to find a TPA willing to administer it in violation of civil rights law, and that's how Section 1557 will succeed despite the rise of self-insured health plans.

If this sounds confusing, it is because it is. Complexity is good for creating billable hours for lawyers and profits for corporations but not for people seeking care. Health care civil rights laws are really a patchwork upon a patchwork upon a patchwork, with state laws, federal laws, and private employer and insurance decisions making up the reality of what discrimination protections and benefits exist in health insurance in any particular case. That is because our health care landscape generally is a mix of public and private health care in a federal system and because private employers play such a big role in the American provision of retirement and health care. Section 1557 of the ACA is the newest health care civil rights innovation in this patchwork context. As I detail below, Section 1557 is simultaneously broad but vague and thin. It gestures towards what it wants to protect rather than spelling out those protections forthrightly. It was passed without much notice when a flurry of other things seemed more important. It uses the worn paths of previous laws but also extends health care civil rights in some bold

ways. Its combination of ambiguity and boldness has meant that it has attracted controversy at the same time it has been watered down in practice.

HOW SECTION 1557 BECAME PART OF THE PATCHWORK

The patchwork of health care civil rights described above still permitted a lot of exclusions and discrimination in access to health insurance. People who did not work for an employer that offered health insurance could not afford or were shut out of the market for individual health plans. There was no market solution for them. President Obama made health care reform his top priority, and the ACA squeaked through in 2010. Its cryptically short antidiscrimination clause provides that, “[A]n individual shall not, on the ground prohibited under title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d et seq.), title IX of the Education Amendments of 1972 (20 U.S.C. 1681 et seq.), the Age Discrimination Act of 1975 (42 U.S.C. 6101 et seq.), or section 794 of title 29, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity, any part of which is receiving Federal financial assistance.” The text of the law simply lists other preexisting civil rights laws for its coverage (such as Title VI for race, the Age Act for age, and Section 504 of the Rehabilitation Act for disability), and its reference to Title IX ushered in sex. The other laws already reached healthcare settings, but the addition of sex discrimination in healthcare was new. There is no other language announcing or explaining what a right to nondiscrimination in health care is. There is no legislative history.

Why were health care civil rights so unelaborated in the ACA? As one health policy advocate explained to me, “Writing it that way through those cross references was a way politically for members of Congress who were drafting this version to signal to their colleagues that this shouldn’t be really this controversial because they were just extending principles that were already well established in federal law.” Recall that the innovation of Medicare and Medicaid came without their own statutory nondiscrimination clause and without playing up the implications of Title VI’s ban on race discrimination on purpose because of concerns that it would create opposition from white supremacist senators like Robert Byrd of West Virginia. When I asked all the administrative insiders and advocates about the process for getting the nondiscrimination clause into the bill, everyone said some version of the same thing: it was relatively unnoticed and noncontroversial in the chaos of getting the ACA as a whole passed. The extensive conservative and religious opposition to nondiscrimination that exists today did not yet exist. “To our knowledge, there wasn’t anybody out there lobbying against passage of 1557,” this advocate said.

The major transformations of the ACA mandated insurance coverage in some nondiscriminatory ways in its regulated markets. It intervened in the smaller

section of the health insurance market to stabilize and prop up options for individuals and small businesses that otherwise could not operate at the edges. Everyone else kept their Medicare or employer-sponsored plans. Participation in ACA marketplace coverage reached its highest levels ever in 2024, but that share is only a little over six percent of the US population. These changes did not require use of Section 1557 because they were part of the other structural provisions. The ACA changed the rules for insurance companies in the individual and small group markets, telling them that they could not refuse to extend a policy because of someone's preexisting condition, for example. This new "goodie" could be called a right or a benefit or protection from health discrimination, but instead it carries the boring bureaucratic name of "guaranteed issue." Before the ACA, a person with a preexisting condition or even someone over a specified weight with no other health conditions would simply not be able to buy health insurance on the private market at all.

The ACA-governed plans also had to provide maternity care and newborn care as an essential health benefit without charging women more. Before the ACA, some insurance plans would not cover pregnancy and birth or charged women more because they might incur these costs. (The Pregnancy Discrimination Act of 1978, an amendment to Title VII, had partially alleviated this problem but not entirely.) The National Women's Law Center ran a campaign in support of the ACA with the slogan "Being a woman is not a pre-existing condition" to highlight the problem of gender discrimination in health insurance. Breastfeeding support and supplies, including breast pumps that cost around \$500, were included in the ACA as maternity and newborn care. These new ACA structural provisions had a powerful equalizing force because discrimination based on pregnancy and other preexisting conditions had excluded people from accessing any coverage or resulted in them being charged more. Critically, this provisioning was achieved through changing the structural rules of the game for insurance companies and through national legislation, not through creating a civil right that individual patients would have to claim and fight for within an organizational culture.

Advocacy groups mobilized around these new rights as the ACA rolled out. Much like Section 504 disability rights, the rights in Section 1557 were so abbreviated that they would need regulations to spell out what they meant even though technically the Office for Civil Rights (OCR) began enforcement upon enactment. Advocates turned their attention to getting people signed up for care. Out2Enroll, an LGBT-health advocacy group, started in 2013 in anticipation of the ACA marketplaces opening up. LGBT people were more likely to need health insurance coverage, and Out2Enroll wanted to help enroll people with targeted messaging and training for LGBT health concerns. They worked with the more than five thousand enrollment assistants in every state working on the frontlines to sign people up for marketplace plans. The assistants who received Out2Enroll training got a rainbow icon next to their name in the search website for people looking for help signing

up for their ACA plan, so that the person buying insurance could select someone informed about the issues that LGBT people faced when trying to buy a health plan. For instance, it was common for a trans person who had changed their name at the state level to be listed in the marketplace with their previous name.

Another big problem for LGBT access to health insurance in 2013 and 2014 was confusion and barriers due to marriage inequality for same-sex couples. The *Obergefell v. Hodges* ruling to protect marriage rights for same-sex couples would not create a federal right to marriage until June 2015.⁵¹ A same-sex couple would complete the process on www.healthcare.gov, but then the insurance company handling the policy would reject it, saying they do not offer a family policy for two men or two women, even if they were legally married in their home state. “It wasn’t explicitly 1557,” one Out2Enroll advocate explained, “but what HHS ended up doing was putting out guidance saying if you offer family coverage to heterosexual couples you also have to offer family coverage to same-sex couples, and trans people need to be able to change their name on their marketplace profile.” This equality requirement for insurance pre-*Obergefell* was anchored not in 1557 but in the guaranteed issue part of the ACA for individual and small group plans, telling insurers that they must issue a policy regardless of health status, age, gender, or other predictive traits.

Advocates continued to see discrimination in the ACA rollout, however, and kept pushing the Obama administration to do more. They wanted strong implementing regulations. The health discrimination problems most prominently encountered by cisgender, heterosexual, and child-bearing women had been addressed in the structural rules about maternity care and essential health benefits including contraception, but there were forms of gender-based health discrimination that were not captured in the ACA structural provisions. Subsidized plans under the ACA with essential health benefits that no longer excluded gender dysphoria as a preexisting condition could have been immediately beneficial to trans people, but nearly all states had explicit exclusions for gender-affirming care (often called “sex changes” or other outdated terms) in their benchmark plans. Even free preventative services under the ACA—say, a mammogram—would be denied because the person’s gender marker did not match the service, and insurance would not pay.

Rights that apply to everyone may falter in practice and thereby showcase the unique vulnerabilities for some people, who then are understood to need trait-specific civil rights elaborations. HHS put up a website to help trans healthcare consumers navigate these problems, which Out2Enroll advocates would point to and say, “Guys, the federal government has a page on transgender health—the government sees you.” HHS issued an FAQ in 2015 explaining that sex-specific services needed to be covered without cost sharing regardless of gender identity and sex listed on documents as part of the ACA preventative services requirements. These developments came before the first formal regulations implementing

Section 1557 were published in 2016, showing how advocates used the general benefits and rights under the ACA to amplify trans health issues in particular. The 2016 final rule from the Obama administration implementing Section 1557 included a ban on explicit categorical exclusions for gender-affirming care in insurance and a requirement that care be given with parity, that is, if a cisgender person would be able to get a prostate screening or a mammogram, then a trans person who needs it must also be able to receive that care.

It initially seemed that Section 1557 could have major impacts throughout the healthcare system. Both the ACA generally and these specific rights promised expanded access to health insurance and health care, and advocates hoped that the well-documented patterns of discrimination, stigma, and abuse of transgender and gender-variant people in health care settings would become recognized and possibly eased along with health disparities based on other categories such as race.⁵² Business-side lawyers appeared to agree that there could be a lot more litigation pressure on insurers and healthcare providers for discrimination claims of many kinds. One healthcare attorney called Section 1557 “the future of health-care discrimination litigation” and the “legal side of health equity,” warning clients that the private right of action and access to disparate impact claims made Section 1557 “a powerful tool in the hands of a private plaintiff.”⁵³ Moreover, health care *is* different: it is more complicatedly regulated than other domains, highly specialized and segmented into many professional subgroups, significant in its impact as a sector of our economy, and also part of highly personal experience for many people.⁵⁴

Indeed, Section 1557 protections started off strong under the Obama presidency. The Office for Civil Rights (OCR) at the Department of Health and Human Services (HHS) began taking complaints to enforce it when the ACA passed in 2010. Implementing regulations for Section 1557 issued in 2016 required all covered health care entities with fifteen employees or more to appoint a grievance officer and establish a process to hear claims, to notify the public about these requirements and options, and to provide all health care services equitably to transgender people (among other things).^{55,56} There were therefore several new and potentially significant features of this new healthcare rights law (the provision itself combined with the implementing regulations): (1) it added sex to the list of protected categories in healthcare; (2) it required that at least part of someone’s job be focused on civil rights in nearly all healthcare settings in the United States; (3) it required a grievance process on site about civil rights claims; (4) it gave patients a private right of action to file a lawsuit without waiting to go through that internal grievance process; (5) it embraced gender-identity and sex stereotyping as part of sex discrimination, thereby explicitly elevating transgender health care concerns; (6) it made it illegal for a covered health plan to have a categorical exclusion for gender-affirming care; and (7) it expanded the scope of legal remedies to include disparate impact claims.⁵⁷ The basic principle was parity: if a form of care

would be available to a cisgender person, such as cervical cancer screening for cisgender women, that same service cannot be denied to someone because he is a transgender man (but may still have a cervix). Importantly, the 2016 rules did not include a religious exemption from the duty not to discriminate. A former Office for Civil Rights employee who worked on the Obama rule described the impact of the Section 1557 implementing regulations to me as transformative, especially the ban on categorical exclusions for gender-affirming care in ACA-regulated insurance plans.

There were not many complaints filed at the Obama administration's Office for Civil Rights (OCR) about gender identity between 2010 and 2016 (my Freedom of Information Act request yielded eighteen, another study with a slightly later time frame yielded thirty-four, and OCR has estimated between fifteen and twenty per year).⁵⁸ The remedies OCR imposed were limited to nonpunitive solutions such as trainings. The Obama-era administrative responses aimed at critical drivers of transgender mistreatment in health care settings: misgendering, humiliation and stigmatization, and denial of care. OCR admonished hospitals for misgendering trans patients by rooming them with patients of the other gender, delaying their care, denying their same-sex relationship status, refusing them care that would have been granted to cisgender people, mocking a (presumably cisgender) man for coming to the ER after a domestic violence incident at the hands of his girlfriend, and for sending bills to a (presumably cisgender) woman's husband rather than to her, even though she had her own job and health insurance. These judgments were well publicized, and I found they had made their way into training slides and legal advice prepared for healthcare organizations.⁵⁹

The surprise election of Republican Donald Trump to the presidency in November 2016 slowed this clear expansion of health care civil rights for transgender people as he took control of the administrative agencies in charge of civil rights, health, education, and more. President Trump took significant steps against transgender rights and in favor of evangelical Christian and Catholic conservatives, rolling back Department of Education guidance protecting transgender students' access to bathrooms that match their gender identity and banning transgender soldiers from serving except under their sex assigned at birth. Trump's director of the HHS Office for Civil Rights, Roger Severino, created a new Conscience and Religious Freedom division in the office to protect the rights of religious conservatives to avoid participating in care or subsidizing care that they objected to. The conservative legal movement had mobilized against Section 1557's gender-identity protections before Trump's election, however, filing lawsuits to stop HHS from enforcing Section 1557's gender-identity protections.

Before getting into some of the legal details that set the stage for the rest of the story in this book, it is worth reprising why Section 1557 became so legally contentious. The biggest political reason is that it was the first time in federal civil rights law that trans people's health concerns and rights to be recognized with dignity

were significantly advanced by the federal government. More doctrinal legal reasons added ambiguity. First, the way it was written cobbled together other statutes and lacked a freestanding statutory text and fact-finding that would have given it independent grounds beyond those stilts of the other listed statutes to hold it up. That meant the relationship of those listed statutes (and each one's own legislative history, judicial interpretation, implementing rules, and remedies) to Section 1557 cases was up for debate in the courts. Could plaintiffs rely on any of the remedies listed in any of the referenced laws or only the ones linked to the particular trait that law had been cited for in Section 1557? Recall that "sex" came into Section 1557 linked to Title IX, so the question was whether all subsequent interpretations had to remain under Title IX doctrines only. Some federal courts have held that Title IX bans transgender discrimination as sex discrimination, but the Supreme Court has not decided that issue. Title IX otherwise permits a lot of sex-based differentiation (on sports teams, in single-sex dormitories, and so on) and draws on biological differences between the sexes to justify differential treatment. Title IX also has its own religious exemption. How much influence would these different civil rights statutes from other realms have on Section 1557 in healthcare?

Second, what legal rights did the clause on its own confer, distinct from the 2016 rules that elaborated them? Lawsuits continually target the implementing rules as an overreach of the administrative state, but the clause itself is still there. Republicans have failed to repeal the ACA despite claiming it is a top priority. Even if judges do not have to defer to the HHS interpretation of what the clause means, the clause remains for judicial interpretation on its own terms. A judge who regards Section 1557 as enacting its own distinct new health care civil right would interpret it as uniting all the prior civil rights traits under a clause that then had its own independent legal force and health-specific *raison d'être*. It should be read within the goals of the ACA, which were to broaden health care access and intervene in discriminatory market behaviors that hurt people. This approach is a maximizing view that would expand civil rights remedies in health care by bundling them together, essentially.

A judicial minimizing approach would take apart the bundle, limit the sex discrimination provision to only what is provided under the referenced Title IX, amplify the essentialist gender-binary-focused elements of Title IX, deny that Title IX interpretations should be influenced by other civil rights statutes such as Title VII (thereby limiting remedies and definitions, most importantly the *Bostock v. Clayton County* ruling that Title VII protects trans employees), refuse deference to HHS's interpretation in its regulations, and grant generous religious exemptions. There are long-standing statutory protections for conscience exemptions in medical care, but religious groups resisted the idea that if they provided a hysterectomy in medically indicated cases for cisgender women, they would have to provide it for a transman, for example. Will religious exemptions be allowed to swallow the duty not to discriminate entirely? Each of these questions mattered a lot as lawsuits

against Section 1557's transgender-inclusive interpretations unfolded. They continue to define the debate over gender-identity protections in the ACA today.

In the first major salvo, the Becket Fund for Religious Liberty, representing a group of conservative Christian physicians and dentists, several states, and a Catholic hospital association, sued the Obama HHS over the 2016 regulations in August 2016, arguing that the rule required them to perform abortions and gender-affirming care or face penalties for discrimination on the basis of gender identity and termination of pregnancy and that their religious freedom was violated, among other claims.⁶⁰ They filed their case in a federal district court in Fort Worth, Texas, with only one active judge, Judge Reed O'Connor. Judge O'Connor is a well-known and reliable conservative judge, consistently ruling against LGBT rights and the ACA itself, and by filing there the plaintiffs would be assured he would hear their case.⁶¹ Judge O'Connor issued a nationwide injunction against HHS on December 31, 2016, to stop them from administrative enforcement of the transgender and pregnancy-termination protections in the newly enacted Section 1557 implementing rules.⁶² When Trump assumed the presidency a few weeks later, his HHS would not appeal the ruling against its enforcement powers.

The clause in the statute itself remained since Republicans were not able to repeal the entire ACA under Trump. Section 1557 gives individual plaintiffs a right to sue on their own, so even when HHS was enjoined from enforcement, lawsuits could continue. Other federal judges declined to follow Judge O'Connor's injunction, noting that the statutory language has supported transgender inclusion all along by reference to sex discrimination.⁶³ Katharine Prescott sued Rady Children's Hospital in San Diego under Section 1557 after staff repeatedly used feminine pronouns for her teen transgender son, Kyler, when he was an inpatient for extreme psychological distress due to gender dysphoria. Kyler died by suicide a few weeks after his hospital stay. Even though the O'Connor injunction was in place, the federal judge ruled that his mother's Section 1557 claims on Kyler's behalf could go forward because the clause itself covered gender-identity discrimination. Ms. Prescott settled with the hospital in 2019.⁶⁴ This case is an example of the pro-health care civil rights "bundling" approach to Section 1557 that would not be limited by the injunction on the Obama or Biden implementing regulations. As a matter of formal law, any covered entity could still be subject to a lawsuit from a patient making this argument throughout the time that I was researching this book, though I found most people on the ground barely knew about any of these litigative details.

The Trump administration attempted to define sex in federal law as either male or female, unchangeable, and fixed at birth through new Section 1557 regulations issued in 2020 to replace the 2016 Obama regulations (and will surely do so again). The Trump regulations took out all the gender-identity protections from Section 1557 and ten other regulations, stripped other protections from LGBT people and those living with HIV, limited application of the clause, and offered broad religious exemptions.⁶⁵ The Trump regulations also removed the

duty to post antidiscrimination notices and to designate someone to be the 1557 coordinator. The Supreme Court was deciding a case that term, *Bostock v. Clayton County*, about whether Title VII's employment protections extend to gay, lesbian, bisexual, and transgender people under that statute's ban on sex discrimination.⁶⁶ Trump officials must have expected the conservative court to limit sex discrimination coverage in similar terms (such as to only biological males or females on the basis of sex at birth), which would have further supported the conservative roll-back of LGBT rights under sex discrimination law across the federal government that Trump's administration had begun.

Instead, the Supreme Court opinion in *Bostock*, written by Trump appointee Neil Gorsuch, held that discrimination against an LGBT person was necessarily sex discrimination in the *employment* context. LGBT health and advocacy groups immediately filed five different lawsuits challenging the 2020 Trump regulations as arbitrary and capricious (given well-documented problems of transgender health discrimination, especially under pandemic conditions) and untenable after the *Bostock* ruling that transgender discrimination is sex discrimination.⁶⁷ Favorable decisions in those cases affirmed that, indeed, the Trump 2020 rules were contrary to the law of *Bostock* and should not have been issued without considering the outcome of that case.⁶⁸ The 2020 Trump regulations for Section 1557 were then also placed under injunction and many of their provisions did not go into effect.⁶⁹ The Biden administration then turned policy around again, enacting new 1557 regulations that affirmed gender-identity protections in care settings and health insurance coverage. Just two days before those new regulations were set to go into effect in July 2024, a conservative district court judge placed them under preliminary injunction yet again.

It is a dizzying story, with health care civil rights that protect gender identity whipping back and forth between judges, presidents, and the Supreme Court. Some branches of the federal government wish to protect gender identity as a nondiscrimination category while others are much more hostile, and commitments shift depending on elections and judicial nominations. The statutory versus constitutional settings for trans rights matters, too, as does state versus national politics. Notably, there is no Supreme Court ruling about gender-identity protections under Section 1557 as this book goes to press. A Fourteenth Amendment equal-protection ruling about trans rights that fails to protect them from state action, such as bans on gender-affirming care for minors, would preserve those bans on care but would not reach Section 1557 itself. The conservative justices in the majority on our Supreme Court would likely prefer to halt transgender-inclusive interpretations of Section 1557, but with *Bostock* as such recent precedent it would be tricky to find a way to say so. One way would be to deny that Title IX's ban on sex discrimination is the same as Title VII's ban on sex discrimination and to distinguish them. That would mean a finding that health care discrimination and educational discrimination against transgender people is permitted but

employment discrimination against them is not. States could ban care that federal civil rights regulations say must be provided without discrimination against trans people. Conservative legal organizations like the Becket Fund and the Alliance Defending Freedom are busy serving up lawsuits and amicus briefs in preselected jurisdictions to supply all the legal reasoning the conservative Court majority will need to select the policy it prefers.

The easiest way to defeat Section 1557 trans health care civil rights has likely already happened in the Supreme Court's overturning the so-called *Chevron* deference in *Loper Bright Enterprises v. Raimondo*, however. That's because the ruling allows the judicial branch to brush aside the regulatory process that yielded the detailed Section 1557 rules (or any other regulation) and substitute another understanding of what an ambiguous or brief clause requires.⁷⁰ This route steers interpretation back to Title IX (because of its reference in the clause itself) and its acceptance of seemingly biological essentialist accounts of gender in defense of sex exclusion in education, as in fraternities, sororities, father-son or mother-daughter activities, and beauty pageant scholarships. Indeed, this reasoning underlies the most recent injunction against the HHS rules from Mississippi federal judge Louis Guirola Jr. that there is no deference to the agency's interpretation of Section 1557, and instead the best understanding is based on ideas about sex from 1972 when Title IX was passed.⁷¹ Title VII protections for gender identity under *Bostock* cannot simply move over into healthcare, he found. The spending clause requires that Congress direct its intentions more clearly, Judge Guirola held, so if Congress wants sex discrimination to include gender identity it must say so explicitly.

The Trump administration and the actions of Trump-appointed judges certainly thwarted some implementation and enforcement of Section 1557's protections, though it is not clear exactly how much. One of the biggest impacts of Section 1557 was the large-scale removal of categorical exclusions of gender-affirming care from ACA-governed health insurance plans.⁷² As I explained, the 2016 Obama regulations prohibited covered entities from having or implementing these categorical exclusions.⁷³ Almost half the states also banned categorical exclusions in their state insurance laws. Exclusions for gender-affirming care had been common prior to the ACA, but an analysis by Out2Enroll, the LGBT healthcare advocacy group formed at the launch of the ACA, found that ninety-five percent of insurers had removed transgender-specific exclusions from their 2017 silver ACA marketplace plans.⁷⁴ This significant social change persisted despite Judge O'Connor's quick injunction against HHS enforcement of the gender-identity protections in Section 1557. In 2018, the same analysis found that ninety percent of covered insurers continued to offer silver marketplace plans without trans care exclusions.⁷⁵ Moreover, courts continue to find that Title VII employment discrimination law protects trans employees from discriminatory health benefit plans that exclude their needs. Major insurers sell plans nationwide in many markets and would be reluctant to rewrite them every few months or to guess how the litigation over

gender-affirming care would finally conclude. Importantly, the individual right to sue under Section 1557, serving as another form of enforcement, remained and could still pose a legal risk to organizations. I found that generally, large corporate entities like insurers and hospital systems took steady actions towards transgender rights expansions and treated the Trump administration's rollback as temporary, though Out2Enroll found that discriminatory exclusions increased slightly in 2023 and 2024.⁷⁶

Almost no one at the patient-care level, including the more informed Section 1557 coordinators, even knew what Judge O'Connor's injunction was. Among the management-level people I spoke with who knew about it, there was total disregard for it and a determination to forge ahead with gender identity as a health care civil right, at least as they understood it. A senior diversity manager at a hospital system was explaining everything his system did in 2016 to respond to Section 1557, including systemwide trainings, getting a new electronic medical records system that would properly gather the correct name, a wristband with the correct name, and so on. I asked whether the injunction would have any effect on their plans. "So to your point about the injunction put there by the judge," he responded, "we're saying, okay, we get that, but we believe that the law of the land will ultimately say, yes, you have to include [transgender people] and you need to do whatever accommodations for that." Another interviewee in state-level leadership put it more bluntly: "We're going to just continue acting like 1557 isn't enjoined until somebody who's my boss tells me otherwise." Federal district court judges can issue preliminary injunctions against enforcing the gender-identity protections in Section 1557 regulations, which is certainly one way the law fails in the face of conservative legal mobilization against it. But then managers on the ground in organizations could simply ignore those injunctions.

I've argued that the American system of civil rights and rights generally includes negative rights that are unhelpful for health, a sphere in which specific provisions of care are needed for a right to amount to anything. The political misfortunes of our overall approach to health policy refract health rights, breaking them up into disparate, measly provisions for the poor and vulnerable through unpopular spending programs like Medicaid and blocking anything like a national healthcare system that would provide everyone with a reasonable baseline of care. Instead, we may end up with a genuinely weird situation in which trans employees have the right to nondiscriminatory employer-sponsored health plans as a job benefit, but trans people *as people seeking health care* are not afforded those protections under a nondiscrimination law in a health care law. The ACA, limited in some ways since it only reshaped the margins of our employer-based health system, nonetheless created structural changes that banned a lot of health discrimination that had been widespread and harmful. Recall that the Johnson administration could not risk a fight about nondiscrimination by race in the final stages of passing Medicare because segregationists might have withdrawn their support. The ACA squeaked

through Congress with an antidiscrimination provision, which no one noticed or defended, and which has since come under relentless attack once it became clear that it mattered a lot for trans people's health.

The structures of our federal judiciary also make it possible for conservative lawyers to direct cases dismantling health care civil rights to a single right-wing judge (so-called forum shopping). A powerful and effective conservative legal movement has mobilized to feed cases through the system (concocting injuries that never happened to recruited plaintiffs) and tee them up for the conservative Supreme Court majority. Health care civil rights can fail at this national level of refraction through neglect, lack of political support, injunction against their enforcement, and defanging of real enforcement powers. At the mesolevel of insurance law and regulation, we see that the organization of our health care system into mostly employer-sponsored health insurance further refracts rights through a tangle of state and federal regulation. Health care civil rights refracted through insurance in the United States are strongly influenced by employers' and insurers' own profits and market decisions, such as the option to self-insure and opt out of state antidiscrimination requirements. Some constituencies have won health rights through federal legislation, but overall, we live under a regulatory system designed in the 1970s for regulating retirement pensions that is no match for the modern healthcare economy. Health care civil rights can fail at this mesolevel because of neglectful politics and the autonomy of corporate benefit designs.

Finally, there is Peggy, watching the "nines and tens" on her patient satisfaction surveys. Organizational culture refracts rights at the patient-care level, and sometimes it safeguards them. Some leaders kept complying with Section 1557 in their own organizations even though they knew HHS enforcement power had been removed. Perhaps they will do so again now that civil rights regulation and enforcement have been undercut again, perhaps fatally. But health care civil rights can also fail at their microlevel by refraction through other hospital performance incentives or, even when they are still supported, by being left to enforcement on a voluntary basis. Notice that none of these forms of failure for health care civil rights are about the complexities of health disparities or the depth of the social problems that produce inequality in our country, which is the focus of much important research trying to explain why solving these problems is so hard. Instead, the forms of failure I explain here are driven by the structure of our institutions, mobilized conservative opposition, the political economy of healthcare, and the political decisions we have made over decades. The next chapters elaborate on all the ways that health care civil rights are refracted through these different levels of meaning and enforcement. They are mostly changed for the worse, though not always.