

Conclusion

How to Strengthen Health Care Civil Rights

Health care civil rights are a product of overlapping structures: the sprawling American healthcare system and our diminished civil rights regime. We can understand why health care civil rights seem hopeful but consistently disappoint by examining how rights refract through the institutions and practices that constitute them.¹ What people do in these structures surely matters, but I have argued that individual-level experiences, opinions, and arguments should be understood not only in terms of those people's deeply held, often conflicting commitments to ideas about gender, equality, medicine, or religion, but also in terms of the incentives that these structures provide. Health does not work well as a framework to motivate sympathy or promote social justice. It merely shifts debates about gender identity and civil rights into one of the most challenging policy settings of the last fifty years: healthcare. It inflects debates about justice and gender identity with concerns about patient satisfaction, for example. It moves conflict into the private control of health insurers, who still hold the power of medical necessity determinations. Health is no answer for those who believe that gender-affirming care is gender ideology gone off on a sinful path.

The most important forces for understanding what health care civil rights have become are the patient safety movement, the rise of managerial, industrialized healthcare, computerization and the rationalization of bureaucratic work in healthcare, the business and (non)regulation of health insurance, and the far-right religious Republican mobilization against health care rights for reproductive and gender-affirming care. These are forces that have arisen and changed, but there is also a recession and a weakening in the patchwork of civil rights. A conservative Supreme Court has removed remedies and weakened enforcement powers even

more, and Democratic majorities that could shore up civil rights statutes have been gerrymandered away or withered to tiny margins. The conservative legal movement has destabilized the ability of government to regulate and enforce laws generally across all sectors. There are many other important factors, of course. Social movement mobilization, litigation, election outcomes, and the COVID-19 pandemic all help shape what health care civil rights are today. The politics of the contemporary United States are critical because our slide into ever-more undemocratic rule because of the electoral college, equal Senate representation of wildly differently populated states, and Supreme Court appointments with life tenure has meant that conservative Republicans and religious traditionalists hold disproportionate power.² These forces all shape what gender identity can be and determine possibilities for transgender lives.

I argue that we should not remain within what political scientists call the “Overton window” of policy plausibility (that is, policies with a real chance of being enacted under current conditions) as we consider what different options might accomplish. In this conclusion, I reflect on what it would take to achieve a significantly different world for health care civil rights. My aim is to convince readers that precisely because our healthcare and civil rights systems are failing in so many ways, there many options for improvement. The options begin at the microlevel of the patient interaction in the healthcare setting but quickly move to the broader structures of health insurance and the national- and state-level political and legal orders. Most possible solutions require change at all levels, so my recommendations cannot stay cabined in our three-level approach for long. The suggestions I make here have been studied, some much more than others, and I offer them as a cascade of options, some much more realistic than others.

FRANK ACKNOWLEDGEMENT OF CONFLICTS OVER PATIENT CIVIL RIGHTS

I argued in chapter 2 that frameworks of patient centeredness and patient experience can refract civil rights into complaint management. The structural placement of these patient experience offices within a relatively powerless, feminized, bean-counting part of the organization means that they cannot really confront rights violations. Only doctors discipline other doctors, and so the most powerful people in healthcare are exempt from consequences when a patient has a bad experience. The separation of clinical wrongs that could lead to lawsuits from the nonclinical has meant that anything racist, sexist, or harassing (“rude treatment by staff”) that is interpersonal goes into the less important bucket. Harms beyond the patient’s experience are potentially vast but unrecognizable. Patients have no experience while under sedation, for example, and they have no experience of the clinician’s decisions, notes, curiosity level, or willingness to think capaciously or sympathetically

about their problems, for example. What providers say and do (and forget to do or never consider doing) about patients out of their earshot could add up to a lot of unfairness. Scholars have rightly focused on unconscious bias as a major driver of lower-quality care for patients from subordinated groups or who do not share an affinity with the provider.³ Health care civil rights refracted through patient experience frameworks lose most of their visibility, redressability, and potential impact. Strategies to make the patient feel better when they complain (fake apologies, listening) do not get at the source of discrimination. It is not surprising that we found that complaint management software often did not have a drop-down menu item to classify a problem as a civil rights violation or discrimination issue. Survey-driven financial incentives have routed these problems into a part of the organization that is not trained to see rights problems and lacks the tools or the power to address them. Even if we measure inequities better, we still need to put more power and money behind accountable change.

One first step, then, would be to change the healthcare organizational structure so that possible rights violations are seen for what they are and taken seriously by people powerful enough to make changes. Civil rights should not be routed to the patient experience department. The patient experience department should not be the first or only filter for patient problems because it diffuses discrimination before it can be fully understood. There must be a way for the organization to see discrimination in its full range of appearances and to name it as a problem. The recipient rights framework for people in mental health treatment, with all its rights language, monitoring committees, specific lists of protections, and transparent reporting structures, offers one model. Perhaps the problem of discrimination should not be handled by anyone who works for the hospital or clinic at all because the drive to bury problems to protect the organization (from lawsuits or bad survey scores) will be very strong. But if a civil rights coordinator were an attorney and reported to someone high enough in the hospital who valued antidiscrimination and health equity enough to confront problems rather than refract them—including taking the risk of attracting the Department of Health and Human Services (HHS) Office for Civil Rights interventions or lawsuits—then perhaps that inclination could be overcome. Let's first consider what it might look like to reform within the hospital or clinic structure.

I found that the one Section 1557 coordinator who had been a civil rights attorney and investigator and who was placed outside the experience department was able to challenge physicians and to see rights problems as the adversarial challenge that they are. (He did not seem to have a lot of success because overall the organization had not changed around him to make his approach effective, but it was notable all the same.) Acknowledging the pressures of rights denialism and being comfortable with adversarialism between the patient and the organization is critical. Hospitals should hire someone who starts with the assumption that patients

have civil rights and that staff at all levels may violate them and thus create a direct conflict that requires uncomfortable, reparative action. Most people currently in grievance handling roles have backgrounds in nursing, which is likely not sufficiently rights-focused and does not make them legally knowledgeable, comfortable managing and even amplifying adversarialism, or empowered to discipline physicians. Hiring a different kind of professional could start to turn the patient experience framework entirely on its head: name harassment and discrimination rather than downgrade them to rudeness or miscommunication, start by believing that rights violations or discrimination happened rather than start by disbelieving, dig into the possibility of harm and learn about it rather than soothe it over, and make civil rights violations as important as clinical harms to patient safety. Give the person in that role the power to recommend discipline for physicians as well as other staff. Success in this role would be defined by the ability to surface conflict and resolve it though changes that benefit disempowered patients.

One specific change organizations should make is to alter their reporting structures to dismantle the division between the clinical and the interpersonal. If these divisions are baked into software reporting programs, then the biggest hospitals need to lead the way in demanding a new product or creating their own version. It is absurd to separate clinical problems from discrimination when so much of what trans people describe as discrimination occurs during clinical time, i.e., during care with providers. Section 1557 regulations have explicitly raised the possibility of clinical care as a site of discrimination, such as if a doctor refused to provide surgical or medical services to someone on the basis of their gender identity (transgender status). Discrimination must be able to be captured at all levels of the patient's engagement with the healthcare providers and staff, including contexts where there is no "patient experience" at all: in clinical decision-making, in records the patient does not see, in care provision under anesthesia or when the patient cannot experience what is happening, and in moments of exclusion or denial of care when discrimination means the person cannot become a patient at all. The professional handling the possible cases must have access to tools and status in the hierarchy needed to probe all these contexts.

Current Section 1557 regulations take this integration even further, requiring that any use of patient care decision support tools, such as clinical algorithms, be nondiscriminatory. Algorithms are rules for a computer to put together bits of information and give the user something back out, like a clinical-decision support recommendation based on the patient's symptoms and traits and run through a database of similar cases. Algorithmic discrimination is a critical issue in health care civil rights because information about traits like race, income, and gender are built into algorithms, and then one might say the outputs are laundered as neutral when the algorithms reproduce the same inequalities that they are built from. The algorithm and the decisions it prompts are completely beyond the

patient experience. No system that relies on patient complaints or patient-initiated lawsuits will confront algorithmic discrimination because these algorithms operate within clinical care guidelines, behind electronic medical records logins, and underneath screening criteria that patients know nothing about.⁴

Concerned experts have pointed out that adding discrimination in patient care decision support tools to Section 1557 is well-intentioned and necessary but that it is difficult to task working providers with knowing whether the tools that they use such as algorithms are biased.⁵ The Food and Drug Administration regulates medical devices, and software is part of that scope. When HHS passes the civil rights regulations but the Food and Drug Administration holds the power to regulate algorithms and the software that uses them, it is clear that governance matters and that a much broader approach is required here. The burden should be on software creators to prove that their products are nondiscriminatory before sale to healthcare systems. We need open, consultative processes to understand how technologies can become racist and sexist and how to manage their powers in our lives. Democrats have introduced the Algorithmic Accountability Act, which would demand oversight and accountability for algorithmic bias in many areas including housing, credit, and education, as well as health.⁶ The complex case of algorithmic discrimination shows yet again how health care civil rights reveal large structural gaps in how we conceptualize, measure, and confront this thing we call health care discrimination. Tackling discriminatory decision tools is tackling disparate impact discrimination in its fastest-growing form. Fighting discrimination on these terms, provided there are enough resources, could be really helpful.

Even the best effort within the organization will require establishing trust with community partners and offering patients who have experienced discrimination direct supports from outside the hospital. The Section 1557 coordinator or office should work directly with community members and advocacy groups in paid, meaningful roles with access to decision-making power so that the perspectives of the patients most likely to experience discrimination are held up and put at the center. This arrangement would need to go beyond the patient advisory boards that may already be in place elsewhere. The Section 1557 office could become a hub for medical-legal partnerships to support the complex array of injustices that vulnerable patients confront, from evictions to criminal justice involvement, centered around real accountability to the community it serves in the form of restorative justice responses, review of problems (with redactions and privacy protections), and funding through an invigorated vision of community benefit obligations for nonprofits. These collaborations would likely be volatile arrangements, bringing together people with different loyalties and interests and vulnerabilities. The strife and vulnerability are already there, though. Leaning into this situation is what democratic engagement with health inequality and systemic discrimination might look like. It would at least be a good way to start. Starting with good faith

engagement and then revisioning based on experience is simply a baseline requirement for powerful healthcare entities interested in fighting health inequalities.

ALTERNATE FRAMEWORKS FOR RIGHTS AND REMEDIES

The challenge here is that if this person or office amplifies civil rights problems and helps patients make claims, they are not representing the interests of the hospital in a narrow legal sense. They could raise the litigative risk to the organization or attract bad publicity. If the hospital is for profit or has been bought out by a private equity firm, there will be no duty of community benefit and little interest in burdensome work with difficult patients. How should we understand the pressure of potential lawsuits or HHS investigations in organizational change? The larger issue here is about the role of different parts of the American governance system—the courts and attorneys, the federal agencies and civil servants, and legislative bodies and executives—in creating incentives to drive policy outcomes.⁷ Much of this book has been about scrutinizing our hopes for health care civil rights within actually existing incentives, policies, practices, laws, and politics and learning that they fail to hold up well. If increasing private lawsuits from patients is a good answer to civil rights violations, then we would need to use other policy levers to increase the supply of lawyers looking for clients who have suffered health discrimination and make those claims pay enough to be worth pursuing. Whether raising or reducing the risk of being sued increases safety and civil rights compliance are empirical questions, and policies should follow the evidence. The sides on these debates are already arrayed against each other from the medical malpractice and tort reform debates.

If we think of civil rights problems as similar to patient safety and medical errors and place them in that framework, other options emerge. We could adapt some of the patient safety reporting protections for civil rights reporting to drive change from within. The Patient Safety and Quality Improvement Act of 2005 set up a structure for hospitals to report errors that impact patient safety so they could be aggregated and studied without those disclosures being used against the hospital in a lawsuit. Hospitals produce quality-related event reports as part of the protected category of patient safety work product, which are essentially self-studies of mistakes. Patients who suffer harms from these mistakes understandably want to obtain copies of these documents in lawsuits against providers and hospitals. The policy choice is presented as either allowing organizations to air and study their mistakes or allowing patients to gain access to critical information to place blame for their injuries.⁸

Adopting a patient safety framework for civil rights violations would mean following that same dichotomy with the more powerful institutional actor, the hospitals, arguing that they should be free to surface civil rights problems and

then protect that information from being used against them in lawsuits. Without much stronger regulation (say, robust recordkeeping and scrutiny plus Office for Civil Rights [OCR] review of these records with significant fines available), it would be hard to tell if hospitals were simply burying or not even trying to find out if they violated Section 1557. It is too early to say how Joint Commission accreditation requirements for health equity will work on the ground or what impacts they will have. We've seen that patients may not experience rights violations as rights violations or may not know how to report them as such, and so such a system would also have far to go to capture and measure what the harms of discrimination are exactly. These are all significant challenges for the healthcare workforce now, where there is little expertise or cultural embrace around rights and discrimination. The patient safety framework would only work for health care civil rights with a throughgoing shift in federal regulations and organizational culture.

The patient safety framework analogizes a civil rights violation to a patient safety error such as giving the wrong medication, and suggests that similar detection, repair, and prevention processes could work on both from within a medical setting. Another option is to analogize civil rights violations to the medical malpractice threat posed by attorneys from outside the hospital walls, who are paid with a percentage of the money damages they win. Unfortunately, comparing the incentives that could attach to civil rights violations to those of medical malpractice lawsuits falters in one big way. The Supreme Court held in the 2022 case of *Cummings v. Premier Rehab Keller* that financial compensation for the emotional harms of discrimination in health care are not allowed under Section 1557 and Section 504 of the Rehabilitation Act.⁹ The plaintiff, Jane Cummings, is deaf and legally blind and requested an American Sign Language interpreter to communicate with her physical therapist. The center denied her request and she had to seek care elsewhere.

When the Roberts Court conservative majority ruled against her, they blocked any meaningful remedy for a very common form of discrimination: being treated badly and having to find another provider. When discrimination takes the form of humiliation, contempt, harassment, insults, and disrespect, there may not have been an accompanying physical harm that resulted in financial loss or pain. If the person seeking care is turned away but finds care elsewhere, there may not be any physical harm from not accessing care. There is simply no longer an injury that the law recognizes. Compensation for emotional damages from discriminatory treatment is the main way that victims would be compensated (and that their attorneys would be paid). Without the risk of a jury siding with a humiliated patient and awarding a large emotional-damage award, there is not much risk left for hospitals. Arguably, hospitals and doctors only invest so much in patient safety detection and analysis because the threat of major lawsuits looms (more than they think, sometimes). Without that, would patient civil rights violations be taken seriously?

This lack of a remedy explains why a medical malpractice framework does not bode well, why health care civil rights violations did not seem to concern hospital general counsel offices in the settings I studied, and why housing them in the patient experience department with the low-level problems seems like a good solution. The main threat they pose is to patient satisfaction. Real money attaches to those scores. For problems recognized as civil rights issues, however, HHS Office for Civil Rights investigations are rare and likely to result in an agreement to do more training or change a policy at best, there is no real risk of a damage award for most would-be plaintiffs, and the threat to revoke federal health-care funding seems weak because it is not actually used. Health care civil rights are emblematic of a bigger story in which the rights revolution of the 1960s and 1970s has been beaten back in the courts through undermining the remedial powers attached to private lawsuits and through undermining the regulatory powers of the administrative agencies.¹⁰ This arc is clearly visible when comparing two points of health care civil rights: hospital desegregation and Section 1557 implementation. We saw President Johnson using robust federal legislative carrots and sticks between Title VI and the Medicare rollout in the summer of 1966 (with litigation pulling in the same direction) to force hospitals to formally desegregate in remarkably short order. Now, regulators do not realistically threaten to withhold significant federal funding, there are no more private Title VI lawsuits, and there are no emotional damages under Section 1557 or Section 504. The last two of these three limitations on health care civil rights were all imposed by conservative Supreme Court majorities in rulings that seem arcane or mundane and never attracted much public attention.¹¹ Undoing these could restore our ability to detect and stop unconscious bias and disparate impacts in healthcare, as Danya Bowen Matthew has argued.¹²

When the Supreme Court interprets statutes passed by Congress, there are political ways to overrule them (unlike in the constitutional context where they have the last word). I have been arguing that the ragtag collection of civil rights laws we have is weak on purpose, and that one way it is weak is that it had to be watered down or silent on potentially controversial details to pass. The ACA was passed so hurriedly that advocates and drafters never got the chance to revise Section 1557 in a conference committee, for example. Their weakness at the macrolevel of national policy shapes incentives and behaviors all the way down, so we see how these three levels of analysis I have created to structure the book interrelate and produce conditions for each other. It is worth imagining what a national political commitment to nondiscrimination might look like.

Congress could pass legislation specifying the full range of discrimination captured under the term sex discrimination, including gender-identity discrimination. We could have full-scale LGBTQ+ civil rights protection legislation across all sectors, from housing to healthcare to employment (and it would not depend on the Supreme Court). Congress could pass legislation specifying disparate impact

claims and emotional damages are available under Section 1557 and making sure attorneys' fees are generous.¹³ Congress could establish a national fund to pay claims, set up training programs and pay public interest attorneys to take the cases, fund OCR investigations at a much higher rate, and require reporting, transparency, and measurement of progress in reducing discrimination in healthcare, perhaps tied to payments like the patient satisfaction surveys. There are many levers to pull, in other words, from rebalancing incentives to direct legislation to robust enforcement to transparency and public pressure. All these are limp or nonexistent now, and any option is worth trying. Then we might be able to study the empirical questions such as whether risk of lawsuits compels better civil rights compliance, whether hospitals are capable of creating rights cultures on their own, what seeing rights better might look like, whether improved compliance improves health, and whether civil rights compliance reduces inequality. We do not know because we have decided not to create meaningful conditions for any of these changes.

We must rebalance the power relationship between religious control of health-care and patients' civil rights. Our laws and constitutional interpretations have gone too far in protecting religious discrimination, which has been allowed to push aside other important values like equality and access. We should pull back towards patients' rights to receive nondiscriminatory care that is judged appropriate by scientific and medical authorities rather than religious authorities. We have large sectors of our federally funded health and welfare system run by religious entities that deny care to LGBT people and cisgender women. This situation is no longer compatible (if it ever was) with democratic equality or any conception of health care rights. It has become an openly disrespectful and expanding two-tier system of inclusion and exclusion driven by a coalition of religious partisans and supported by our tax dollars. One option would be to narrow the conception of religious objection to the individual level; that is, a person, not an institution, holds religious views and is protected from having to do anything in their health-care work that would violate their religious convictions.¹⁴ At the hospital or system level, however, there could not be policies against anyone providing care or firing someone for providing care. Conscience protections would apply equally to providers whose conscience or religion compels them to *provide* care as well as those who claim the right to *withhold* it, and the institution must respect their choices either way. Right now, entire religious hospital systems that cover large geographic areas or care networks are permitted to ban their providers from offering care (abortion, contraception, fertility, and gender-affirming care) that their church objects to. If religious hospitals gain an exemption from having to use a trans person's correct pronouns, providers could be fired for using the pronouns that respect a trans patient's gender identity. (One question will be how many providers, many of whom do not share this virulent anti-trans politics, would put up with such an employer.) A shift to an individual provider-level exercise of conscience, by contrast, would be likely to allow variation.

The Catholic Church would not agree to such a compromise, however, and so pushing this option legislatively (assuming it could pass, a nonstarter with the current Congress) would end with the church pulling out of healthcare or securing a Supreme Court ruling that the legislation paring back institutional religious rights was unconstitutional. The current Supreme Court would undoubtedly side with the religious entity on this question, as they consistently uphold conservative religious interests over nondiscrimination. Yet, it is worth imagining the changes such a new approach would bring. Religious healthcare operators could theoretically pull out of their markets or refuse all federal funding and operate free of any civil rights regulations. Healthcare is significantly federally funded through Medicare and other payments, though, so anything beyond a few small care settings is financially impossible. Hospitals would be sold, broken up, or merged, consistent with any other legislation passed at the time to manage that process.

Perhaps in this alternate political universe, religious entities would agree to a provider-level conscience policy only. Health care consumers would need to know at the provider level what care they could expect to get. Every provider profile should include a statement of what care will not be provided if the provider plans to invoke it, and patients should be informed at every visit if there are objections in place. OCR should require periodic filings of percentages of objecting providers in aggregate so they can track the ability of the public to receive nondiscriminatory care. That data should be publicly available and broken down by geography and insurance details such as provider networks and carrier. Each healthcare entity should have to prove that they can provide care to everyone in their insurance networks and in the geographic area or that they have sufficient referrals in place to meet patients' needs. Insurers should not be able to construct provider networks without proving that there is sufficient nondiscriminatory care available in it.

Even now, we could have much greater transparency about religious interferences with health care than we have. Currently, Section 1557 requires entities to post a notice saying they do not discriminate on the basis of sex, while at the same time they can pursue an exception from the duty of nondiscrimination, and they can refuse to offer a wide range of common services from placing an IUD to monitoring gender-affirming hormones. It's well established that ordinary people do not know about these restrictions and the Section 1557 regulations arguably require misrepresentation ("We don't discriminate" to the public and "We would like to discriminate" to OCR, simultaneously). Civil rights regulations should at the very least require any religiously affiliated healthcare entity to post information about the care it withholds or has an exemption not to provide in the same place and manner that it posts its nondiscrimination assurances. But instead, the most recent 1557 regulations only weakly note that it is a "best practice" to reveal that the hospital is in fact exempt from the very

nondiscrimination rules that it posts. There is no duty to inform patients of this complete contradiction.

INSURANCE REFORM FOR CIVIL RIGHTS

I have argued that the mesolevel of insurance refracts health care civil rights into a complex and even bizarre world of private employer regulation, ruled over by a confusing federal statute from the 1970s that was not supposed to govern health care, supplemented by a variable state insurance antidiscrimination landscape with laws that often do not even apply because of that federal statute, and topped off by generous deference in federal civil rights law that permits health insurance companies to use medical necessity determinations to slow down or deny care even when it is supposedly required by civil rights provisions. More than half of seniors in Medicare have Medicare Advantage plans run by commercial insurers, exemplifying a blur between government-run health care and privately-run health care. To make this refraction even messier, state laws criminalizing the provision of trans care have turned rights into crimes, leaving insurance companies in the untenable position of extending coverage as required by federal antidiscrimination law that is a crime to provide. On top of that, private companies are also religious believers, claiming religious protections against covering basic health needs for their employees. Our situation here is a total mess. At least that means there are plenty of ways in to start fixing it.

If a federal health care civil right means everyone having a health insurance plan that upholds civil rights, what does that look like and how do we get it? We need to shift to a universally available healthcare system that requires robust civil rights recognition and insurance coverage provision generally, including for gender-affirming care. The most realistic is introducing an option to buy into an expanded Medicare or other public option (part of the original ACA legislation that did not survive Republican Party and Joe Lieberman's opposition) while leaving employer-sponsored health plans undisturbed. Troyen Brennan argues that incrementally expanding access to Medicare Advantage-type plans (by lowering the age to buy into them) is realistic and will eventually crowd out employer plans because the federal government's power to negotiate prices and control costs is so powerful.¹⁵ Commercial insurers would still sell plans, but subject to much more regulation that could include full-throated civil rights protections. The least realistic—that is, all path dependencies and formidable forces are arrayed against it as far as the eye can see—is a full-scale government single-payer health system in which employers and private insurers play no role or limited roles. States could run their own single-payer systems or the federal government could run it. A public option plan could simply cover gender-affirming care and anyone could buy it and receive a subsidy to afford it. A national care system could shift what we as employees pay in premiums and lower wages to taxes to fund benefits for everyone.

Expanding health care for everyone creates new questions about what the federal government would consider civil rights-based health care and perhaps just moves those debates elsewhere.¹⁶ We already see major disagreements in Congress over federal health care coverage questions around abortion access for members of our armed forces, for example. In an alternate world in which some version of a universal healthcare option could gain political support, however, we could also expect gender-affirming care alongside abortion access as provisions of equal citizenship and nondiscrimination on the basis of sex, gender, pregnancy, or a rein-vigorated integration of all three. We could also meaningfully address the other harms to health that providers now just enter as ICD 10 Z codes: lack of transportation, homelessness, and food insecurity. For the first time, we could offer health plan options to everyone that are subject to the same national-level requirements for nondiscrimination in both recognition and provision.

Medicare (“Medicare for all”) is the primary option for an expansion point because it is already universal for those over sixty-five. The Veterans Health Administration is the largest health system in the United States, but it is not governed by the specific requirements of the Biden administration’s Section 1557 regulations. The administrative rule applies to HHS-administered programs or activities, and Veterans Affairs, Defense, and Personnel Management are different government agencies. The basic clause of the law written into the ACA applies to Veterans Affairs, but implementing regulations to say what nondiscrimination would mean for service members have not been written yet. Public or government health plans are not yet the best examples of civil rights-based healthcare delivery, but why not work to make them so? We need a model health plan or set of plans that could be the basis for a nationally available public plan for anyone to buy into, that is, if we implemented something short of national single-payer system and more like the ACA public option or Medicare Advantage for all.

We could look beyond Medicare or the military health care system to the other complete federal health system as a point of innovation. The Indian Health Service (IHS) is a federal health system for “American Indians and Alaska Natives” that provides health care, including gender-affirming care, to people of all ages. There are IHS facilities in thirty-seven states serving 2.6 million people from the 573 federally recognized tribes.¹⁷ As sovereign nations, the tribes receive federal funding and operate their own hospitals and hundreds of health clinics; other parts of the system are jointly operated.¹⁸ Oklahoma state law makes provision of gender-affirming care to minors a felony, but a federal IHS clinic there has received national recognition for their provision of gender-affirming care.¹⁹ Many IHS clinics do not offer surgical services generally, though the Navajo Area Indian Health Service serves nearly a quarter million people with sites including a comprehensive hospital.²⁰

The case of Native and Indigenous health illustrates both the deep inequalities that leave these communities less healthy and more likely to experience violence

than non-Native peoples and also the possibilities of a community-led engagement and sovereign empowerment with federal health care.²¹ Medicare is focused on the elderly, and the military has distinct health goals for troop readiness. The Employee Retirement Income Security Act of 1974 (ERISA) makes state-level single-payer systems difficult to develop. Why not elevate and invest in the Indian Health Service, making it an enviable example of how our government can deliver comprehensive and equitable health care? Could non-Native health leaders envision “standing with” instead of “giving back,” in Kim Tallbear’s terms, and collaborate with Indigenous people on such a model?²² Failing to consider the IHS as the best first site for investment in health equity when we need a national model feels like repeating the settler-colonialist mistake of regarding Indigenous people as stuck in the past or as a tiny sample of the population that is too different to be centrally important.²³ A reparative and justice-informed approach in this already-existing federal health system could yield lessons for policymakers who care about other communities where racism has created poorer health. Instead of or in addition to bringing more people into the public-private partnerships of Medicare Advantage, why not also invest in a community-driven democratic process to develop model plans in IHS?

I am not suggesting that non-Natives take advantage of the IHS to gain access to care that antiabortion and anti-trans state laws have blocked, which would be an extractivist approach that pits vulnerable people against each other rather than solving the underlying injustice. (Recall that the Johnson administration had National Guard helicopters ready to fly Black patients to military hospitals if white supremacist hospital administrators balked at caring for them at the launch of the Medicare program in the summer of 1966. There are other options, though again we would need to fix federal policies for health equality first.) Rather, I am pointing out that we already have a federal direct-care health system that we could invest in to prove that health policy can confront centuries of injustice and current health disparities in compelling ways. Even under current political and legal conditions, tribal sovereignty, federal investment, and the supremacy of federal laws over discriminatory state laws could combine to make gender-affirming care (and many other improvements) through the Indian Health Service a model for future federal health reforms. The IHS has already shown itself capable of innovation as a health system.²⁴ Centering and empowering gender-diverse and queer Indigenous people who work in and get health care from our IHS facilities to improve federal health policy is a feasible option now. It also builds expertise for a time when the national political climate is more open to health reform.

A truly national healthcare system is one big country-wide insurance risk pool, but once it takes on that scale we typically just call it national healthcare, not health insurance. We would not need all people currently employed in private insurance billing, processing, rate setting, screening, denying, advertising, contract writing, lawyering, and so on. We spend more than other nations on healthcare through

these administrative costs (eight percent versus one to three percent), but the main reason why Americans pay more for care is because our prices are much higher for everything, including provider salaries.²⁵ We would still need determinations of medical necessity, however, and means to decide what treatments are worth paying for and which are not. National healthcare would come with price setting and government salaries for providers, big reasons for its historic unpopularity with the American Medical Association. Other systems like this elsewhere still entertain debates about gender-affirming care and provide care in different ways, as a look at Great Britain and Western Europe shows.²⁶ Systemic change at this level, though far from easy, is the way to bring a right to health into the United States and to infuse the values behind our weakened civil rights laws back into healthcare. It is the primary way to advance both recognition *and* provision.

We have gotten far from the world of health insurance most of us live in, though. Pulling back to a more realistic world in which the basic parameters of our healthcare system remain in place, there are still major improvements that could improve health care civil rights in our insurance system. An amended Section 1557 could specify that civil rights obligations attach to any entity that provides health care through benefits, including self-insured employers and the plans they write for their employees, and that the tax assistance employers receive counts as federal financial assistance. Passing the Equality Act and specifying the full range of protections from sex discrimination under the ACA would give LGBTQ+ civil rights the firm foundation of explicit congressional approval. The Equality Act states that the Religious Freedom Restoration Act cannot be used as a reason to discriminate, thereby pulling back on conservative expansions of religious shields for discrimination. Religious employers like churches could enjoy special exemptions to discriminate in favor of their own believers, but who counts as a religious employer and which jobs are religious jobs could be more tightly specified to match the spirit of the individual-level conscience exception discussed above. These changes involve legislation as well as turn-arounds in the Supreme Court's interpretations, which have been broadening rather than narrowing religious employers' rights.

ERISA, the pension protection law from the 1970s that focused on insolvent and fraudulently mismanaged pension funds and was never supposed to govern millions of working-age adults' health care, needs reform.²⁷ Defined benefit pensions have gone the way of the molded Jell-O salad. Self-insured employer health plans are expanding. We could separate the question of what oversight workers' pension plans require from questions about their health benefits. As Elizabeth McCuskey explains, several ERISA reform options are possible.²⁸ Right now ERISA creates a deregulatory vacuum by sweeping aside state law but only putting a patchwork of protections for health insurance in its place. ERISA preemption waivers (which take away its power to ignore state laws) would permit state laws to have force again. Options from strongest to weakest include repealing the preemption provision in ERISA entirely, closing the loophole for self-funded plans to escape state

regulation, allowing HHS to grant waivers if it decides to, or deciding on a list of state laws to exempt from preemption.²⁹ We could cease allowing stop-loss policies to prop up self-insurance for smaller firms. Understandably, companies did not want the laws of fifty different states to create a maze of rules for them in insurance and benefits when ERISA's federal preemption was created. But the ACA ushered in more federal uniformity in its requirement for large employers to provide health insurance that meets minimum value and affordability standards. There have been many attempts to reform ERISA, but powerful business interest groups currently benefit from these deregulatory, antiquated, and poorly anticipated circumstances and have held off reform so far.

I argued that we simply do not know enough about health insurance plans, what is in them, and how private health insurance companies administer them. ERISA has even thwarted development of an all-payer claims database. We need a fully transparent public data source for all health insurance plans sold in the United States with uniform requirements for clarity, standardization, readability, and accessibility. This obligation to publicly report what is in health plans would be entirely new for private, employer-sponsored plans that cover most working adults and their beneficiaries in the United States. I've already discussed substantive reforms to make what is for sale equitable and open to all, by which I mean offering nondiscriminatory coverage and pricing for gender-affirming care specifically and developing a civil rights-informed healthcare system generally. Transparency on its own does not drive the normative concerns I've raised, and presumably firms could use the information to standardize offerings or even to price fix. But there is also reason to think that unflattering attention to discriminatory or meager plans would influence employees and consumers in ways that could prompt firms to offer better benefits voluntarily. Significant expansions in benefits for same-sex couples in the workplace happened in these ways before marriage equality became law.³⁰

NATIONAL STRUCTURAL CHANGES FOR DEMOCRACY AND HEALTH

Investing in a national model for eventual broad access, establishing federal standards for all health insurance plans, or regulating uses of algorithms are national-level reforms. We could enact wholesale civil rights reforms that document, defend, and remedy sex, gender, and gender-identity discrimination across sectors, both properly recognizing and provisioning for intersectional identities. Major structural reforms for access to care, including funding for those who cannot pay, have been more successful than discrete identity-based protections, but it would be nice not to have to choose. Readers may point out that all these reforms are impossible with our current Congress and Supreme Court (and sometimes the presidency). My response is to concede that, indeed, they are impossible now, but

the first step toward change is to articulate a positive vision of an alternative and start convincing others that it is desirable. If we want a better world for the people we count in datasets as health disparity populations, then we must defend why they deserve better and start explaining what it will take to get that for them (and for everybody else too).

I want a world in which people of all ages who experience their gender identity as different than others expect it to be can explore and express their identity without ridicule or injury. I want that because I do not assume that there is a correct distribution and appearance of gender identity in the world. I suspect we all would be better off if many of our current requirements simply went away or became much less important, but a diverse world of beauty pageant contestants, *WrestleMania*, people whose gender identity is not readily apparent, and pants and makeup everywhere is also benign. The world I want includes access to supportive resources that are appropriate to every individual's situation (a seven year old in a family is differently situated from a twenty-five year old in the workplace, for example) and that they can guide and control as much as possible. When this includes medical interventions, they should be provided according to a well-justified and evidence-based understanding that has been shaped by the people seeking care as well as by professionals with ethically produced and interdisciplinary research expertise. Decisions should be based on informed consent and respecting the autonomy of persons (including individual-level conscience rights for providers to participate or not). Everyone deserves care derived this way, and in an ideal system, efforts to contain costs and avoid overuse (problems I certainly acknowledge) would be comanaged with these aims.

Democratic self-governance requires earnestly trying to convince other people of things, even when it seems like one should not have to defend basic humanity and dignity. Yet clearly we do. Polls suggest that Americans have a range of opinions about trans rights and do not agree about the vision I shared above. I started there, but it should be clear from my approach to gender-identity protections that structural change, not simply persuasive arguments, is essential. We cannot persuade democratically only to continue to fail at enactment. Our institutions have deteriorated to the point that democratic persuasion has been effectively cut off at the pass in some of our heavily gerrymandered state legislatures, for example. The Supreme Court was never supposed to be democratic, but even it has become untethered from its democratic linkage via the Senate appointment process because the Senate is also undemocratically designed and run and has become even more so as US territory and population distributions have increased and skewed.

One way to approach reforming the Supreme Court is to reform its personnel, such as by so-called court packing with additional justices appointed by a Democratic president or by imposing term limits or a partisan balance, but another approach to reforms is to think about disempowering it as an institution

that blocks progressive legislation.³¹ Legislative goals from health care civil rights to restrictions on guns to campaign spending reforms are effectively blocked for decades by our current Supreme Court, and it is that broader frustration of democratic self-governance that is the problem. Congress has the power to determine the jurisdiction of the federal courts under Article III of the Constitution and to make exceptions and to regulate the Supreme Court's appellate jurisdiction. Disempowering reforms would use this power to take away entire policy areas from Supreme Court reach, giving whoever holds the majority in Congress and holds the presidency the last word instead. Legislatively enacted civil rights, alongside other progressive legislation for health care, environmental protections, and education, have long outpaced Supreme Court protection for rights.³² Until we reform the Supreme Court and reconsider its role in our democracy, we will not be able to achieve much of anything to advance health care civil rights in even the most narrow sense, let alone achieving a fully integrated approach to health and equality with large-scale investments and strong rights.

Sam checked into the emergency department without health insurance coverage. He had lost access to the regular medications he needed. He had not realized he was pregnant and had no prenatal care. He used the emergency department at a crisis point, as many people without insurance do, because there was nowhere else to go. The health care team did not recognize Sam's gender identity and his health needs fully and accurately as a pregnant man with an obstetrical emergency. Recognition went awry, but provisioning had failed long before that. We can fix provider awareness with training sessions (maybe). We can add organ inventories to medical records. But bringing about the alternate world in which situations like Sam's are nonexistent will take much more. Turning to health may not have any simple power to promote equality or to solve political problems. But studying health and rights through their implementing institutions lets us see their limitations and thus all the opportunities to do better.