

## Realizing Health Care Civil Rights

Jason had been newly hired to be the Section 1557 coordinator for a large hospital. He was an attorney, and his previous position was working as a state-level civil rights investigator. In one case Jason described to me, he confronted a doctor in clinical affairs about staff canceling appointments for deaf and blind patients if proper interpreters were not available at the scheduled time, which he thought was discriminatory denial of care. The doctor deflected the issue, which seemed to Jason to be “more of a response of a doctor protecting other doctors than it was actually of a concern for the patients and for being compliant, which is interesting to me.” Compared to the other grievance handlers we interviewed, Jason was unique in his willingness to label patient problems as discrimination, to confront doctors, and to express frustration that doctors protected each other in what he saw as a clear example of denial of care based on disability. Because he was previously an attorney, his professional tool kit included adversarial confrontation without regard to hierarchy. He confronted a doctor even though doctors are beyond the disciplinary reach of nonmedical professionals like the civil rights grievance handlers in patient experience. Critically, he did not receive the patient experience professional socialization described in chapter 2. Jason eschewed the techniques of disbelief, reinterpretation, and soothing that we saw were so important in that professionalized patient experience framework.

My argument has been that there are many ways for discrimination laws to fail patients and that generally they do. Refracting civil rights through health and healthcare happens through absorption, deflection, and defeat. All these outcomes fail patients because they diminish or demobilize what we hoped civil rights could do for health inequality. But my theoretical framework allows for on the ground variations as well as legal and political mobilization to transform what rights are

in practice, so of course it is possible for rights to be refracted in ways that amplify them or at least scatter and change them in ways that still advance the goals of trans health care civil rights. At each level of analysis in this book, people still found ways to realize rights. If conservative opponents succeed in dismantling trans health care civil rights in the formal law, they could still live on in these everyday voluntary practices.

In this chapter, I revisit all the frameworks and sites of the previous chapters, showing how rights are sometimes realized at each of our three levels. Different approaches to management and conflict over patient rights in healthcare settings allow alternate accounts to emerge. Intermediaries and trans self-advocacy in health insurance coverage disputes sometimes succeed in navigating insurance complexity to secure coverage for gender-affirming care. And despite the very conservative turn against trans health care rights at the Supreme Court and across nearly half our state legislatures, advocates for health care civil rights based on gender identity have won in litigation across the country.

#### SCATTERED EXCEPTIONS IN HEALTH CARE CIVIL RIGHTS ON THE GROUND

When civil rights are refracted through healthcare, that means that they move through the professional structures, training and attitudes, and material and digital tools that people use to do rights work in those settings. I argued in chapter 2 that the patient experience framework and tools explain much of the absorption and then demobilization of rights that I saw in hospitals. Rights broke through occasionally and inconsistently. Indeed, the lack of consistency in when and how health care civil rights were able to be realized shows that there is not a coherent alternative framework. The exceptions prove the point, that is.

Most grievance handlers drew on that patient experience framework, but a few—like Jason, the lawyer and former civil rights investigator—more clearly articulated discrimination as a problem and handled situations differently. Jason looked within his organization for discriminatory people and practices and did not sit within a patient experience department. Rooting out discrimination was even easier in other healthcare business models. Although my final sample was admittedly lopsided towards hospitals, where access to interview subjects was easier, I was able to see how a freestanding surgical center is a different organizational model that matters. Over half of surgeries in the United States every year are performed in these outpatient settings, which are often physician owned and quite profitable. They are covered by Section 1557, but they lack the bureaucratic problem management structures that hospitals have, such as patient experience departments and labor unions. They are more like standard businesses, with heightened profit motives, competition for customers, and the ability to fire at will.

Larry, the CEO of an ambulatory surgical center in New York City, simply fired staff whose actions upset or offended patients. In one instance, a patient waited alone in a cold preoperative waiting room in a gown for two and half hours because the surgeon was late. When the surgery ended, a porter escorted the patient in an elevator with garbage bags. “We literally took the patient out with the trash,” he said. Larry uses the common formulation of failed communication (“[T]here was a total lack of communication”), but in contrast to the nonconsequences we frequently heard about from other interviewees, he fired the porter (but not the surgeon). Larry also fired a doctor in another example for what he understood to be explicit sex discrimination (asking a cisgender man with long hair to take a pregnancy test).

There is no fellow doctor as chief medical officer to shield doctors from consequences in Larry’s business model. Ambulatory surgical centers are in competition for patients, and Larry believed their complaints. “There’s some validity in every single complaint,” he said. “You have to realize that to some level.” He was also highly aware that most patients complain because they do not want the same thing to happen to someone else and that a real apology can be effective. “Though we do live in a litigious society, you’ve just got to be very honest about exactly what occurred. I truly am sorry this happened to you. I’ve actually made [sure] that this won’t happen to you again.” Here, Larry distinguishes his approach from the “blameless apology” by expressing a belief in the importance of sincere apology, acknowledgement, and accountability. There is a version of the patient satisfaction survey for outpatient surgery centers, though the existence and pressure of the surveys are not organizationally instantiated through a cadre of professionals as in hospitals. Larry led a boiled-down, customer-focused small-business model that does not have those layers of organizational culture to absorb, diffuse, and ignore complaints. This model is dependent on the whims of the leader and thus only weakly capable of rights enforcement overall.

Others I spoke with drew on identity and understandings of discrimination to see rights differently. Some hospital grievance handlers openly wrangled with the implications of conflating customer service issues with rights violations, though this was rare. Dan, a nurse and patient safety officer in rural Michigan, identified himself as gay and felt that his sexual orientation gave him a different perspective on patient conflicts. Dan mused that his hospital could do more to distinguish discrimination complaints from other kinds of complaints, noting, “I think there’s a delineation between addressing the customer service aspect for the complaint versus “This is a really bad violation where we violated a human being’s rights.” He clearly saw that failures of recognition (say, deadnaming a trans person seeking care) would violate their health care civil rights but also that such a case would seem like staff rudeness as a customer service issue instead. Dan’s reflectiveness shows how heightened awareness about discrimination could break through the patient experience framework. Dan and Jason did not work in the same hospital,

but combining Jason's explicit civil rights investigatory perspective with Dan's more nuanced sense of what discrimination looks like would be a helpful correction to the patient experience framework.

Finally, some providers wrestled with the fact that there was simply a gap in healthcare for a vulnerable person who called it discrimination. They did not rationalize the harm away but saw that it was bigger than what Section 1557 can fix. Like Dan's thoughts, this reflection was not fully formed but nonetheless shows how care providers confronted the challenges of rights with little provisioning to support them, what Michael McCann calls the "unbearable lightness of rights."<sup>1</sup> Jan, director of a Federally Qualified Health Center (FQHC) serving low-income people, explained their denial of a root canal for a dental patient who was angry about it and claimed discrimination. "He needed a root canal," she explained, "which is unfortunately a thousand-dollar procedure, and we don't offer that level of care." The director saw that her facility could "barely scratch the surface of what the community needs" because of the structural inadequacy of FQHC resources for the poor. "I think he was just angry," Jan said. "It really didn't get resolved and he's probably still mad." There is no minimum dental care that must be provided to low-income adults under Medicaid, and most states provide only emergency dental care under their programs. Unlike many hospital grievance handlers who worked hard to soothe patient annoyances, Jan acknowledges that ongoing anger is a reasonable response to poverty and pain. Her formulation of "just angry" minimizes what could be a structural critique into individual feeling. Treating dental care as something outside regular health care and insurance is a political choice we've made that causes suffering as oral health needs go unmet. "It didn't get resolved" because there was simply nowhere for a poor person to get a root canal.

#### BEYOND COMPLIANCE: HOSPITAL-WIDE MOBILIZATION FOR GENDER-IDENTITY PROTECTIONS

Some hospitals approached 1557 compliance very broadly, almost always focused on trans patient rights rather than other gender-related issues, such as sexual harassment, which no one named as a civil rights obligation under 1557. I borrow the term *beyond compliance* to describe an organization that does more than is legally required.<sup>2</sup> Beyond compliance happens when the organization and its leaders begin to think through exactly what it would look like on the ground to avoid misgendering trans patients, to treat them with respect in every interaction, and to provide the best care. The Section 1557 committees I observed had a handful of core members and about a dozen participating members from throughout the hospital system and met approximately monthly. They pulled in allies from all around the organization, such as within the medical records management system, where one hospital created their own add-in to the medical records system to record a

patient's sex at birth, gender identity, preferred name, and sexual orientation. In a few instances, leaders analyzed patient experience surveys to see if patient experience varied systematically by demographic traits including gender identity.

The defining feature of a beyond-compliant organization was the presence of entrepreneurial professionals beyond the grievance process, often doctors and nearly always cisgender women, who took up the cause of improving trans care and promoted wide-ranging reforms. They formed committees, sometimes meeting on their own time and sometimes supported by staff assigned for the purpose. The same people who already worked on diversity committees, in the staff LGBT group, or on related areas such as HIV care would join the committee along with medical providers interested in transgender health (therapists, social workers, gynecologists, pediatricians, endocrinologists, and surgeons). They found and used trans health resources and best practices from sources such as the Fenway Institute and the World Professional Association for Transgender Health. Evaluations of hospitals by the Human Rights Campaign through their Healthcare Equality Index provided a way for internal advocates to convince higher-ups that attention to LGBT rights would have a reputation-enhancing effect. Once the organization asked what it would really mean to treat trans people seeking care respectfully and equally, it became clear that the task of change implicated professional culture, information systems, staff training, building layout and signage, and beyond, all in interconnected and messy ways. Each suggested change—let's modify our electronic medical records (EMR) system, let's add to the chart sticker or the inpatient wristband, let's have a new mandatory training—competed with other priorities, demanded staff attention and resources, and had to climb the agenda in multiple departments.

Take the example of using the correct name for a patient. There are physical and digital points of naming: the entry in the electronic medical record, the sticker that goes on paper charts, forms, and specimen containers, the wristband for those admitted to the hospital (often the only thing on the person's body besides a gown and which is checked by every employee from the food deliverer to each nurse on every shift), the white board in an inpatient room, and the electronic board projected in the operating room. A name is attached to a body, and what body parts someone has are critical to know and track, so advocates also developed organ inventories in EMRs to know when to do a prostate exam, for example. Each item a name is attached to belongs somewhere in the institutional landscape and hierarchy and often has very limited real estate on it (for a physical thing like a wristband) or has demands on its use from many constituencies in a health system. The billing department will insist on legal names for payment even if another name a patient uses has been added in all these other places, for example.

While some committee-led reforms had to grind through significant barriers like this example of billing system incompatibility, we observed other moments when the energy of one person had a significant impact. For example, a pediatrician

at one beyond-compliant hospital who works with gender-nonconforming youth in poverty secured free hormones for her patients throughout her city. She simply asked the pharmacist in their health system if such provision could be part of their community benefit program. Describing the pharmacist's response, the doctor said, "And she's like, all about it [snaps fingers], you know. She is totally supportive and didn't blink an eye in terms of like using the community benefit dollars for that." Free delivery to the LGBT community health center is included. This doctor emphasized that her hospital system's broad support for LGBT issues was deeply rooted in the culture because a prominent leader was a lesbian and had made it a priority.

### CONSTRUCTING RECOGNITION IN ELECTRONIC MEDICAL RECORDS AND ORGAN INVENTORIES

The original Department of Health and Human Services regulation that enacted a trans-inclusive Section 1557 required "treating individuals in a manner consistent with their gender identity" in health care.<sup>3</sup> This requirement is the foundation of trans health care civil rights in its strongest iteration. But what does that mean? I have argued that health care civil rights must involve both proper recognition and sufficient provisioning. Recognition turned out to be a major challenge in health care settings. To treat someone in a manner consistent with their gender identity in a health care setting, one must first know what that patient's gender identity is. One must have a way of seeing and tracking when transgender patients experience discrimination. As I argued in chapter 2, when that organizational task becomes more about tamping down problems and "moving those scores," the seeing and knowing cannot become part of rights enforcement. Knowing people's gender identity is the route to successful rights implementation prior to managing problems, though. Done well, it means that baseline conditions for rights protections exist in the organization. Enacting civil rights in healthcare means adapting systems to gather knowledge that can comprise proper recognition: managing complaints, determining gender in common interactions with frontline staff (such as signing in at the registration desk), and delivering clinical care focused on the body and its organs (such as determining who needs a cervical cancer screening). These technology systems powerfully shape health equity for trans people.<sup>4</sup>

The idea that health care records should include a patient's gender identity and sexual orientation gained prominence in a 2011 Institute of Medicine report on LGBT health. It recommended that SOGI (sexual orientation and gender identity, pronounced so-gee) data collection be part of "meaningful use" of electronic medical records.<sup>5</sup> Federal regulations subsequently required that demographics in EMR include SOGI by 2018.<sup>6</sup> The earliest implementers were federally funded health centers, required to report SOGI data in 2016 by the Health Resources and Services Administration.<sup>7</sup> I found that the concreteness of being required to

find out patients' gender identities and sexual orientations could anchor rights practices as both early adopters and more robustly compliant healthcare providers wrestled with how their information systems documented this information and what needed to change, how to go about asking patients, whom to ask and when, and how to prepare their staff to gather this information. Talking about one's sexual orientation and gender identity was supposed to become a normal part of medical registration for everyone. For the cisgender people working in patient registration and records and for the cisgender patients who encountered it for the first time, it was a learning experience. The SOGI requirement pushed tensions into view. Jean Marie, who runs a small rural FQHC that was required to implement SOGI documentation as a condition of their funding from the Health Resources and Services Administration, explains how that data collection requirement touched off an education process throughout her organization:

Once you start [documenting SOGI], then it opens up the door to other things, the discrimination, the healthcare aspects of it, that kind of thing. Our front office supervisor has been to some conferences and seminars on how to collect that data. Our providers have been involved in some education as far as treatment and you know, transgender and that kind of thing, stuff that was put on by the LGBT community.

In other words, creating a legal obligation to “treat individuals in a manner consistent with their gender identity” in health care settings as a matter of civil rights started a cascade of information technology shifts and office-level practices that were visible, concrete, and radiated throughout a healthcare organization.

Working with technologies to achieve proper transgender patient recognition was both a result and a driver of mobilization. Frontline staff had to be trained to gather someone's name and to handle it smoothly if legal name, name being used, and gender presentation did not seem to match. Some of the named Section 1557 coordinators we spoke with understood this moment as critical and possibly embarrassing for all. They explained that transgender issues were new and strange to the frontline staff. Many settings that had achieved midrange compliance had not done much reception staff training. Others simply asserted that they were sure everyone would be treated with respect, although without any training, this confidence seems misplaced given the clear patterns of disrespect trans patients describe.

As hospitals began grappling with implementing Section 1557, they confronted myriad ways that a patient's sex classification could be recorded and be misaligned with their gender identity. A patient could be greeted with the wrong name checking in for an appointment. Insurance billing could fail to match recorded sex to sex-specific procedure codes (if, say, a transgender man had changed his legal sex to male but then sought a hysterectomy). Many different people would need to know the correct information to treat the patient the right way, from the nurse checking a bracelet to make sure the right medication is delivered to the right

patient to the food delivery to the automated voice sending the patient an appointment reminder call. Actualizing transgender patient rights took the form of organizational advocacy to change the objects that materialize gender identity. In a complex organization, that meant making SOGI designations important to a lot of different stakeholders. Dr. Byrd, a medical resident who joined her large hospital's 1557 implementation committee, related how hard it was to change the name on the precious real estate of the lab-specimen stickers:

We have these stickers that print out that get pasted on specimens, on people's labs. Some medical assistants used to call people from the waiting room, and until about a month ago, those only had legal name on them. And it was a whole long bureaucracy. It's a tiny space on a sticker and various groups want to claim that space to put certain markers on there that help their particular group. But [the 1557 committee] advocated and finally got "preferred name" on those stickers.

Dr. Byrd described going around to different groups in the hospital, bringing problems about gender misrecognition to their attention. "Security is a really good example where I was like, I don't know who I'm going to run into in security," she recalled.

And we identified some major problems, like currently if a visitor checks in, they have to provide a government-issued ID and that ID gets scanned. And then whatever name is on that ID populated onto a badge that that person has to wear. And there's no way for the security personnel to change the name that appears on the badge. So if a trans person, for example, has an ID that does not match the name that they use, and maybe their appearance, they could potentially be outed by this badge that they're supposed to wear. When I pointed [this] out to security, they identified it as a huge problem that needed to be fixed immediately and called the software company and are in the process of making a change so that last name only will appear, because we had this conversation.

Getting transgender recognition right in electronic medical records (EMR) was the biggest problem for organizations. Some hospitals had the resources to create their own gender-identity forms in EMR as the early requirements were enacted, but many relied on the corporate providers to update their software. Dave is a trans man who works on SOGI implementation at a major national EMR company. He has been the go-to person for clients to call when either "the organization just had their first out trans patient" and "something goes wrong" or when "there is a trans employee or some employee that, you know, kind of is an ally of the trans community and they are pushing their organization to do something." He described how people in hospitals pushed for SOGI recognition in their EMR:

It's an analyst who works with the software or, you know, not someone very high up on the food chain kind of pushing [better SOGI documentation], telling their organization, "You know, this is patient safety. We're not treating these patients correctly and we need to do so." Or they might be nurses. Some of the organizations, they

have like an LGBT employee group, and that group will get together and discuss, “Hey, our software isn’t really that great for LGBT patients,” and they’ll approach their executives and say, “We’ve been talking about this. We know we can do more. Can we get started on that process?”

Before 2018, he explained, all their institutional customers had access to a smart form that would collect SOGI information and an organ inventory. But in the 2018 product release, SOGI and the organ inventory became opt-out, that is, baked into the default program that every client gets. “We did that deliberately,” Dave says, “because this is a patient safety issue.”

Susan is part of the gender-identity working group at her large hospital, working in the IT department on adaptations to their electronic medical records system for SOGI. Before the new build that Dave worked to develop was available, she helped design her hospital’s own form. She explained how she developed the gender-identity options in their system:

[So on the gender-identity form, is that a write-in or is it a drop-down?] I could show you. It is a drop-down. See, we got the list of gender identities. If you’re not one of these gender identities, you choose “other,” then you need to document what did the patient say their gender identity is. And same thing with pronouns. We’ve got some people, their pronouns are zi, like Z-I. Gosh, I don’t know what that is. We don’t have that on ours because it’s not very common. Non-binary was one that we added after a while, because we did have more than a handful of patients that indicated that’s what they were. Like every six months, I’ll run the report and see is there’s something that’s showing up in “other” that shows up frequently, then maybe we should add it as to one of our choices.

Tellingly, Susan’s IT work on the gender-identity-recognition interpretation of Section 1557 does not interact with the patient-driven complaint side or the satisfaction surveys. “[When you guys do HCAHPS surveys or if they’re in your event reporting system, like if there are complaints and grievance filed, do those interface with the medical records?] I don’t really know what HCAHPS is. [The patient experience surveys.] They’re not in here at all. This is just really medical information. Those have their own separate databases.”

Accurate SOGI recognition is part of determining gender that everyone who uses EMR to interact with and name a patient would need. Clinicians wanted more, though, because for them proper care involves both the story of proper interpersonal gender-identity recognition and also caring for the body parts one has regardless of their role in lived gender identity. I opened this book with Sam’s tragic situation, in which he was properly recognized as a man but was also pregnant and experiencing an emergency complication that went undetected until it was too late. Conservative opponents of recognizing trans people as they are claimed that the problem was that Sam received gender-identity recognition as a man but was really a woman, thereby blaming him and trans existence itself for causing confusion. But the doctors I spoke with all saw gender-identity recognition

and proper care of the body, no matter what parts it has or doesn't have, as perfectly compatible.

The trans-affirming doctors and other clinicians who were active in their hospital's 1557 committees explained how EMR and organ inventories bolster trans rights and provide the best care. Lisa, a doctor at a beyond-compliant urban hospital, explains: "At the end of the day who you are or your gender identity is not always going to line up with your anatomy. What I really care about is what is the anatomy that you have. If you're a guy but you still have a cervix, we need to do a Pap smear." The solution is the organ inventory within the EMR that lists what organs a person has or does not have. Many people have an organ removed at some point in their lives—their uterus, gall bladder, or appendix—and that fact is medically relevant. An organ inventory lets a clinician know about a person's body at the same time as they recognize their gender identity. Religious opponents of trans health recognition do not want to use correct names or pronouns or be compelled to collect this health information, which would endanger trans people's health and make experiences like Sam's more likely to happen again.

Grievance records and satisfaction surveys did not track trans experiences well at all, while EMR entries recognize both the current gender identity and the organs that may not match it. These records are a helpful technology that is consistent with the organization's needs rather than transformative or challenging.<sup>8</sup> They offer the hope of resolving several possible conflicts. The first is the interpersonal awkwardness between frontline staff and someone whose gender presentation is unexpected, say when the registration desk calls out the wrong name. But the second is quite different: it is when a provider whose job involves probing someone's body parts must properly acknowledge the body as it is while also recognizing the person's gender identity. No one who thought this was important thought it was hard. The frontline staff person needs to determine gender socially and affirm the patient's "preferred name," as the EMR then described it, while the care provider needs to do that, too, but also to integrate the person's gender identity with whatever organs they have.

These systems are used and controlled by medical professionals and designed by private companies, not by the trans people seeking care whose bodies and identities are represented within them. Dave, a trans man, played an important role in shaping the dominant EMR software to better recognize trans people as the first set of Section 1557 regulations rolled out. Current EMR structures build in possibilities for gender change and recognize that it has happened, but they are still far from being what Oliver Haimson calls trans technologies.<sup>9</sup> They would need to be much more open to control by those they describe and capable of representing more realness and diversity of trans experiences with the medical world, for example. These are, of course, not what companies build EMR to do. Records are mostly for billing insurance companies. All the same, they are technological systems that permeate every health care interaction, and civil rights law requires that

they recognize trans people properly and respectfully. A government specifying that some data about its population must be collected is one of the hallmarks of modernity and a foundational practice of governance. It's easy to tell if an EMR system is collecting SOGI data or not. Outcomes are clearer than knowing, for example, if care has become more respectful.

The organ inventory is an example of how taking a person apart and seeing them as dissembled or out of alignment with their lived gender is not necessarily an undignified view of personhood (though it often is).<sup>10</sup> By contrast, grievance handlers often spoke of treating “the whole person,” which they meant to be dignifying but also hewed closely to denying that minority identity might explain poor treatment. Which is better as a basis for rights, a technology controlled by medical professionals that encodes bits of information about trans identity and change over time accurately or a set of organizational practices that gushes about patient centeredness and respect for everyone in generalized terms? I pose the question to illustrate the options, but there is no need to choose. These practices coexist in the refraction of health care civil rights at the patient level and thus mutually constitute what rights can be.

#### RECIPIENT RIGHTS IN BEHAVIORAL HEALTH

One particularly detailed, vivid, and highly rights-oriented account was able to stand out. It came from what grievance handlers called “recipient rights” in “behavioral health.” The complaint bucket generally is a jumble, but the rights of people getting mental health care have broken through as unique and specifically legally protected rather than watered down into complaints and miscommunication. Dave, a middle-aged white man who is the 1557 coordinator at his small critical access hospital, knows the law well: “Recipient rights is specific to patients receiving mental health services . . . mandated by the Michigan Mental Health Code, which is a law here in Michigan.” June, a white woman in her sixties handling HR and compliance in an FQHC, explains how being trained in mental health recipient rights frames her general approach: “Once you get the understanding of why we have recipient rights and what purpose they serve, it’s fairly easy to transfer that base of knowledge to working with patients in other areas too.”

Jordan worked as a McDonald’s manager for fifteen years before becoming a mental health technician. He was then promoted to patient advocate and recipient rights supervisor in a large hospital system. Jordan first describes his main job as “dealing with patient complaints,” then adds that he handles “recipient rights complaints from our mental health unit.” Jordan launches into a long description of the steps he takes for anyone in community mental health services or a psychiatric unit. When we asked why the language of rights get used for mental health patients but not for other patients, Jordan struggled to account for it. “They still have patient rights, general patient rights,” he replied. “It’s just that the Mental

Health Code, or all patients do. Just that the Mental Health Code happens to have . . . that's what they called it [laughs, trails off]." Rights for people receiving mental health care have an unusually robust elaboration in Michigan that breaks through the mishmash of bureaucratically managed rights encrusted in policies and captures grievance handlers' attention.

How did mental health services come to be called "behavioral health" and become so much more clearly tied to rights? (Every patient is a "recipient," right? How are they so well specified as rights holders when other patients are not?) What institutional structures shape rights recognition here, and what does it mean for healthcare civil rights more generally? The idea of behavioral health dates to the 1970s as health psychology was gaining a foothold in the discipline and psychologists pushed for understandings of health and illness to take individual responsibility for health behaviors seriously.<sup>11</sup> It was a moralistic push by psychologists for professional ownership with physicians.

But by the mid-1990s, mental health facilities were renaming themselves "behavioral health" facilities, behavioral health managed care plans were highly profitable, and the term had migrated from its more obvious meaning (behaviors, presumably personal choices, that affect health) to functioning as a more palatable overarching term for mental health services that included a wider range of outpatient services for substance use disorders, smoking cessation, and more. They are part of the institutional structures that insure employee retention and performance in our employer-based health insurance system, including wellness programs, employee assistance programs, adoption assistance, marital counseling, eldercare advice, and managing the aftermath of workplace violence. Psychology never secured professional dominance over individual responsibility for health behaviors likely because the idea was central to other health paradigms that arose around the same time, particularly wellness and preventative health. But while the term *behavioral health* was a successful new buzzword because it was broad, flexible, and more appealing than "psychiatric" or "mental health," the conception of rights in behavioral health would remain tied to the most medically interventionist treatments for severe mental health issues, such as electroconvulsive therapy and involuntary commitment (even though the illnesses being treated are understood as genetic or brain-based diseases, not behaviors).

There is good reason why Dave, June, Karen, and Jordan, all working in Michigan, focused their energy on recipient rights and channeled their understandings of health care rights through this prism. In 1995, the Michigan legislature substantially rewrote its Mental Health Code and created an extensive rights regime for people undergoing psychiatric treatment. Chapter 7, "Rights of Recipients of Mental Health Services," lays out explicit rights ("a safe, sanitary, and humane treatment environment;" "least restrictive setting;" "right to be treated with dignity and respect;" rights of family members; consent procedures for surgery, electroconvulsive therapy, and administration of psychotropic drugs; minors' rights to treatment

without parental consent; and protection from abuse and neglect). Mental health services providers (meaning community mental health facilities, licensed hospitals, and anyone contracting with the state) must have written policies that cover twenty-three specified rights from the statute, governing everything from the use of one-way glass for observation to resident labor, property, and funds.

The recipient rights booklet that each patient must receive is twenty pages long, including plain-language descriptions of all specified rights, “questions you may want to ask about your medication” with an extended list, a list of seven advocacy organizations that can help with rights claiming, and a civil rights section. The booklet goes on to list eight additional laws that may offer protections to a person with a mental disability, complete with instructions for making a rights claim. Page nineteen features a quote attributed to Nelson Mandela: “To deny people their rights is to challenge their very humanity.” There is a state Office of Recipient Rights with review and investigatory powers including annual site visits and “appropriate remedial action,” mandated trainings (three full days of in-person training), and the duty to make referrals to advocacy organizations to support claims-making. The Office of Recipient Rights website declares, “Rights is everybody’s business!” and includes the hotline reporting number, maps to find the rights office nearest you, the rights complaint form for easy download, copies of the patient booklet, links to training resources, and many other documents. The Office of Recipient Rights sponsors continuing education, hosts an annual conference, and bestows annual awards for Innovation in Rights Protection, Advocacy on Behalf of Mental Health Recipients, Consumer Empowerment, and the Cookie Gant Spirit Award, named for a mental health disability activist.

The Michigan policy for patient rights in mental health care catches the attention of those it regulates with its specificity, its enforcement, and its bureaucratic investments in the tools that people would need to understand and use these rights. Michigan policymakers rightly saw that people in mental health care facilities were uniquely vulnerable to abuse in specific ways—having their belongings stolen, being administered electroconvulsive therapy without their consent—and that a high level of formal vigilance would be needed. I call this formal vigilance because I have not evaluated the on-the-ground workings of this system and therefore I cannot say under my theoretical framework whether rights refracted through this recipient rights framework are indeed more robust. But it was clear that the same grievance handlers who failed to see discrimination problems as health care civil rights overall saw recipient rights in behavioral health very differently.

In contrast, recall that Section 1557 passed in the Affordable Care Act (ACA) with no elaboration about what it would mean at all. When regulations finally came out six years later, they offered some specifics (room assignments by gender identity not sex at birth, for example, echoing the desegregation fight about putting patients of different races in the same inpatient rooms) but left critical areas like medical necessity determinations to insurance companies. Updated regulations

leave that deference to medical necessity determinations in place. Announcing in detail how Section 1557 protected trans people threatened powerful social and religious identities but could only mobilize a smaller group as its direct beneficiaries. So while recipient rights in behavioral health are highly specified, people in mental health care are not a target group for right-wing mobilization to deny their existence and remove their rights. If they were, these specifications and robust bureaucratic investment in promoting rights would be much more politically costly and would likely become partisan and contested. Nonetheless, recipient rights in behavioral health care is a useful alternative reality that shows us that rights consciousness is compatible with healthcare bureaucracy.

#### PATHWAYS TO MEDICAL NECESSITY

I argued that expansions in insurance coverage and access for gender-affirming care, which were driven by the Obama administration's 2016 regulations that prohibited categorical exclusions in qualified plans, are the most significant achievement of Section 1557. Nearly all plans offered for sale on the ACA marketplace exchanges removed their exclusions for gender-affirming care soon after. Total exclusions for gender-affirming care, particularly surgeries, were common into this century before the ACA. At the time of the 2016 regulations, those plans only covered about ten million Americans (a relatively small share since most people are either old enough to be on Medicare or are covered by an employer-sponsored plan), but the share of people relying on these quasi-public plans and their subsidies has doubled since then. I call them quasi-public to make it clear that they are a shrunken-down version of what national health insurance might look like: plans with highly specified government requirements for generosity that private insurers would not otherwise sell that are heavily subsidized with public funds so that they are accessible for those who do not have another way to obtain health coverage. Most trans people report having employer-sponsored health insurance and another large share are on Medicaid due to lower incomes, but these ACA plans have been a critical source of coverage too. The marketplace plans are also policy drivers, normalizing removing exclusions and providing templates for companies not covered by 1557's requirements to mimic them anyway.

Insurance is the mesolevel of health care civil rights, between the hospital- or clinic-level interactions that people have when they seek health care and the government and legal level of legislatures and courtrooms. People wrangle over their rights with their health insurance company on the way to securing the health care interactions that they need in the hospitals or clinics. In chapter 3, I detailed how refracting rights through insurance diminishes and even extinguishes them through the interpretive ambiguity and procedural hurdles of medical necessity. Under health care civil rights law, insurers retain the power to construct medical necessity because Section 1557's rules let them keep that power.

Medical necessity is also constituted through achieved understandings of what the proper standard of care for a condition ought to be and to include. Allies act as intermediaries on an exclusive professional plane, such as when a surgeon gets on the phone with the doctor at the health insurance company to argue for coverage for a patient. Some gender-affirming procedures, such as facial surgeries, remain in a contested zone where they shift between being framed as merely cosmetic or as medically necessary. The World Professional Association for Transgender Health, or WPATH, publishes guidelines for health insurance coverage that are comprehensive and generous. Most actual policies do not cover the full range of WPATH-recommended procedures. Trans people and their allies can sometimes achieve an understanding of medical necessity that results in coverage, though, and there are specific ways to get there.

In this section, I delve into the success stories for rights mobilization through insurance. Trans people deploy strategies to qualify for medically-necessary care and fight for their rights against health insurance companies, typically outside any formal legal process. There are possibilities for eventual lawsuits or administrative proceedings against an insurer for coverage, but I focus here on the internal disputing processes within this mesolevel. These internal processes range from the more informal, such as repeated phone calls, to the formal internal layers of appeals and review that look like doctors being lawyers inside insurance companies. Health care intermediaries such as doctors, therapists, and administrators act as advocates for trans people seeking care by coding recommended procedures, drafting referral letters, and appealing insurance denials with an eye toward triggering medical necessity.

Most people do not insist on their rights in any context, especially when it is threatening to do so. Most people do not contest an insurance coverage denial and make an appeal.<sup>12</sup> Trans employees are no different and also have good reason to fear discrimination when their health insurance depends on their job. Even people aware of their rights hesitated to ask questions of their employer about health insurance coverage for fear of retaliation. Jill, a clinical social worker in a gender-services clinic, explains what she sees when people consider asking about their insurance benefits for transition care:

Anxiety among the trans population is very high. So of course that trans person could want a copy of their insurance plan for any reason at all. But sometimes people think like, 'Oh, HR is going to know that I'm trans and then they're going to fire me.' This is the kind of stuff I hear from my people. Of course, people can go online and log in. But some people are daunted to do that.

A critical point here is that ambiguous or silent terms in one's health insurance plan can be particularly confusing. An explicit exclusion is hard to contest, but I have found that many plans do not describe coverage and exclusions clearly or at all.<sup>13</sup> There is no legal requirement to state coverage terms about gender-affirming

care clearly or in any standardized way. (The ACA's requirement that group health plans publish standardized benefit information in a statement of benefits and coverage goes a long way towards transparency but does not include enough specifics to determine details about gender-affirming care.) So naturally many trans people would have questions about their benefits when they read their plans but then confront the problem of safety in raising the issue.

Despite the reality that even asking questions about insurance benefits that they are entitled to can be disconcerting, my team found that trans people often worked hard to mobilize their health care rights and that these efforts sometimes worked to secure care. As described in chapter 3, Phoenix engaged in “continuous letter writing after letter writing after letter writing” for two years before his insurance company would cover his surgery. Our interviewees spent hours on the phone to haggle with their insurance companies. These hours were unpaid labor—on top of extra jobs, loans, and consequences of delays in care that trans people already bore. Their cisgender coworkers did not have to spend these hours to use their benefits, meaning that in real terms, trans employees received less compensation at the same jobs. Even in the context of large expansions of formal insurance rights, rights mobilization is a costly undertaking that is privatized to trans employees’ “spare” time.

Some people navigated the additional cost burdens of coverage denials by getting additional jobs. At one point, Quinn, a Black trans woman, had three jobs simultaneously to pay for out-of-pocket expenses while negotiating with her insurance. Riley, who is white and non-binary, paid for their electrolysis services by working part time at their electrologist's clinic. Other people relied on credit cards to fill this financial gap. People sometimes simply switched insurance plans. After Joshua, a white trans man, learned that his Catholic insurance plan would never cover his mastectomy, he switched jobs. Another person relocated to a job out of state to obtain insurance that explicitly covered the services he sought. Other interviewees began saving hormones after encountering challenges with coverage. Quinn explains:

I've had two enrollment periods with the marketplace under the Trump administration. And each time there's been less and less that they've covered, and things are more and more expensive. And every time I can get it [the oral and injected estrogen] filled, I get both filled. And I've got a stockpile about a year's worth of oral estrogen on the chance that it won't be covered fully.

Saving medications is a common behavior for many people that is well studied in the medical literature and sympathetically understood as driven by fears of loss, exacerbated for Quinn by the Trump administration's anti-trans policies.<sup>14</sup>

Some trans people also recognized the importance of structural change and saw fighting with their insurance company as activism. For example, Joshua wished he “could have been a trailblazer” to create change with his insurance company. He

took pride when insurance company staff noted that he was “certainly not the first person with this company to fight for transgender services but was certainly the most persistent,” even though he eventually got a new job to get his care without any policy change at his previous employer. (It is unlikely that he would have been successful with a Catholic facility.) Others continued to push for structural change within their insurance company despite significant cost in labor and time. For example, Adrian spent eight months demanding his insurance company produce a written document to clarify coverage after his employer (with a self-funded plan) assured that him that it had negotiated coverage for these services, but the third-party administrator would not present the details. At the time of the interview, the document had not yet materialized; however, Adrian was committed to persisting. Jayla, a Black trans woman, advocated for structural change by working with nonprofits seeking expanded coverage both in policy language and in practice for trans people. Other trans people identified the importance of sharing information about their experiences in online communities and networks to help others avoid the time and labor they expended navigating insurance barriers. This information exchange created a type of interpersonal mobilization in response to the complex barriers they navigated.

Trans people seeking care could sometimes count on professional allies to work with them to mobilize for coverage from their insurance companies. It is after all in the interest of the provider that the insurance company pay. These health care intermediaries strategically reframe medical necessity to include the care they want to provide. Their reframing happens in three distinct ways: letters by mental health providers defining care as medically necessary, letters and phone calls from physicians appealing coverage denials by insurers, and careful, negotiated, and sometimes creative coding of procedures by physicians to trigger their own reimbursement.

Trans people are often required to obtain two letters from mental health providers indicating particular procedures are appropriate. The first concrete step to convincing an insurer about medical necessity comes through careful letter writing and framing concerning the importance of the care. Documentation of gender dysphoria, for example, is a key hurdle to establishing medical necessity. As discussed earlier, these are burdensome gatekeeping mechanisms that may require a trans or non-binary person to describe themselves as afflicted in ways they do not really feel just in order to jump through hoops. Their allies understand their gatekeeping role and often feel uncomfortable with it too. They focus on “keeping it moving,” that is, doing what needs to be done to check the insurer’s requirements off so the person can advance to the next level for their care. Health care professionals are particularly careful in how they frame their letters to insurance companies to support a finding that the requested coverage is medically necessary. Jill describes how she approaches letter writing:

I know what the insurance companies want to hear and need to hear, and I write what they want and need to hear. [So what do they need to hear?] That the patient

checks those boxes, if you will. And I give as little information as possible. Because I don't want them to sort of glom onto anything that I said to use it to deny care. And this is how I teach other people to write letters as well. Like, let's keep it short and simple, basic, just outline that they meet the criteria, and keep it moving.

Referral letters convey a particular kind of clinically recognizable qualification for treatment and are written to satisfy that requirement. Professional allies often provide training and guidance in an informal network to other social workers and therapists writing evaluations on how to properly draft letters.

Once a person has passed through these points of diagnosis and gotten their letters, their doctor needs to help them secure prior authorization for surgery to go forward, and then the office needs to bill the procedure in a way that will result in payment. Gender surgery specialists have staff who are well versed in the steps and act as intermediaries and interpreters of the insurer's requirements. One major center employed a "health insurance navigator" whose job was to help trans people manage their insurance issues once they became prospective patients at the clinic. Other staff, such as surgery schedulers and office managers, were performing much of the same work.

Angela is the surgery scheduler in the surgery department at a large hospital where gender-affirming procedures are commonly performed. She can "look at this policy and say, okay, I have one referral letter. I have well-documented dysphoria. The patient is over the age of eighteen. I can check these marks, and I can tell a patient if it's going to be covered or not." But then there is still unpredictable behavior from the insurance company's own doctors. "If [the claim] gets there, it depends on the doctor whose desk it's sitting on," she explained. "Like, 'Oh, maybe they meet that criteria, but maybe they don't. So I'm going to deny it for that reason,' you know." The office staff and the surgeons need to stay engaged all the way through the process, managing problems that they cannot entirely predict.

Doctors negotiate with insurance companies directly, writing appeal letters when insurers deny coverage for certain services. There is an internal appeal process after an insurance company denies pre-authorization for coverage. Doctors assume the role of a quasi lawyer, blending their medical knowledge with their knowledge of WPATH guidelines for gender-affirming care and the insurance policy in question to advocate for coverage up through the layers of authority at the insurance company. When doctors join in appealing insurance company pre-authorization denials, for example, they must present the case to a medical director at the insurance company. The medical director is an MD who does not practice medicine and, in their view, is not aware of the needs of trans people. As Dr. Pielson, a surgeon, put it: "You can be speaking with a physician who's a medical director of an insurance company with absolutely no medical knowledge related to the procedure. They're just interpreting it in regard to their contract." If the surgeon can mobilize their expertise convincingly enough in this peer-to-peer conversation, that can successfully turn around a denial.

Allied professionals were exasperated because they thought these work-arounds would not be necessary if insurers followed the WPATH guidelines in their insurance policies and did not add additional requirements and hurdles. Although doctors conceded that the WPATH guidelines are not perfect, they considered them to be the best set of comprehensive recommendations with a stamp of consensus-driven expertise. “WPATH is full of experts in the field with a lot of experience, whereas insurance companies are not,” Dr. Barker argued. In other words, they thought that insurance company practices undermined their expert judgment. In Stef Shuster’s study of twenty-three trans medicine providers, the doctors and other clinicians moved between invoking the firmness of WPATH guidelines and interpreting them more flexibly, trying to manage the lack of a body of evidence that would normally undergird their gatekeeping role while managing to secure the services their people wanted.<sup>15</sup> We found more affirmation of the WPATH guidelines in the insurance context, perhaps because invoking it to an outside entity (the insurance company) is straightforward. Physicians note that they often reference WPATH guidelines in appeal letters and peer-to-peer conversations with the insurance medical director. Intermediaries counter the contested meanings of medical necessity and the barriers by countermobilizing with careful coding of procedures, thoughtful but equally strategic letter writing, and at times taking on a role of a quasi lawyer. These tactics and strategic narratives appear to at least partially assist trans people in establishing that the requested procedures are medically necessary.

Once the surgery has been approved, the surgeons remain concerned about how to bill the insurer and get paid adequately for their work. Insurers use detailed medical policies to tell doctors what they will cover. These documents are also not publicly available and are written in medical language. Doctors communicate what they are billing for through coding, which is the practice of breaking down and listing out everything that can be billed to the payer with a code (Current Procedural Terminology) from the International Classification of Diseases (ICD-10 to indicate current version 10). Doctors told us that insurers’ approval for gender-affirming procedures has improved since the ACA’s passage. They noted there are fewer appeals and battles with insurance companies over coverage, and the process of applying codes to describe gender-affirming procedures, especially surgeries, has become clearer and easier.

Although the situation has improved, doctors were also quick to point out that things are not perfect. There remains significant variation in coverage by insurers. This variation forces doctors to be mindful of how they code to achieve coverage. “If you look at trans surgery coding, it’s a total mess,” Dr. Fischer explained. “And different insurance companies have different rules.” Here is a delicate balance for doctors between framing medical evaluations in ways that trigger medical necessity when they believe such care is warranted but do not go so far as to mislead insurance companies. Dr. Fischer elaborated:

So it becomes one of those things where there’s a lot of gray zone. On one hand, you want to advocate for your patient and you want to try to help them to the maximal

extent to achieve coverage for the surgery that is appropriate for them. On the other hand, you can't lie or defraud insurance companies. And so, like I said, our team is pretty good. Our team may err on the sort of overly strict kind of, you know, totalitarian side of things. But it is an issue. The coding is very imprecise.

Coding is imprecise. A whole operation could plausibly involve a range of procedures that could be defined and thus coded in ways that are somewhat open to interpretation. Coding is also how to get paid. One surgeon explained that "the way we get paid as physicians is by a system called the relative value unit [RVU]. And that's how insurance companies reimburse for procedures." All involved are aware of the importance of coding procedures in terms of coverage and reimbursement for services. "There are codes that are, you know, male to female and female to male, genital. I think it's actually called genital sex reassignment," he continued. But procedures common for transgender and non-binary people are often devalued or given low monetary amounts for reimbursement. "Those codes are associated with a very low RVU value. Not even remotely close." His office negotiated both for meaningful coverage for their patients and fair compensation for themselves:

So we have to negotiate with insurance companies on how they're going to reimburse for these things. We went through a long negotiation with [insurers] about vaginoplasty, about which codes would be included and what RVU values would ultimately be reasonable. The coding, the whole coding thing and how to code ethically becomes a complicated thing.

Low RVU values are an obscure detail only visible to those within the medical system, but they are an example of problem navigation that complicates trans people's access to care because of the way insurance payments to surgeons work. Here, however, this team at a large hospital with a gender-services center was able to push insurers to achieve coverage and to pay at rates the surgeons thought were more fair. Elite professional interests coincided with civil rights aims.

#### DEMARCATING RELIGION, PUSHING BACK UNCERTAINTY, AND AFFIRMING EXPERTISE

I argued in chapter 4 that conservative opponents of trans health care civil rights have plenty of legal tools and political power behind them. When conditions favor them, they defeat the idea that there is a civil right to gender-affirming care and basic recognition, such as requiring health care providers to use correct pronouns. Judges who support religious conservatives in their rulings tend to see religious freedom as paramount, frame gender-affirming care as uncertain or even dangerous, and broaden the boundaries around appropriate expertise in trans health issues, allowing opponents' expert witnesses to mobilize uncertainty in scientific terms even when they were supported by religious legal organizations. They deny that trans people are a group that should get any heightened

scrutiny under the Constitution when laws burden them. They dispute the unity of federal antidiscrimination statutory conceptions of gender identity as part of sex discrimination, arguing that the Title IX educational context affirms gender essentialism and the sex binary through endorsements of things like single-sex dorms, and that this essentialism and binary perspective carries through Section 1557 and fits well in health care. Focusing on children rather than adults heightens emotions and fear. These are the primary pathways to national political and judicial squelching of trans health care civil rights and constitutional rights. I continue the discussion here with a focus on the pro-trans wins, using primary source documents and analysis at a level of generality that pulls out frameworks rather than getting bogged down in the dizzying pace of litigation that these issues have produced.

The conservative legal movement, especially its well-funded evangelical and Catholic groups like Alliance Defending Freedom and the Becket Fund for Religious Liberty, brings heavy hitters and major funding to the social and political movement against gender-identity nondiscrimination. But there are formidable groups on the left that have been successful in mobilizing information and winning lawsuits too. Trans and LGBTQ+ legal advocacy and political action groups have been well organized for several decades, including the Transgender Legal Defense & Education Fund (merged with the National Center for Transgender Equality), the Transgender Law Center, the National Center for Lesbian Rights, Lambda Legal, and the American Civil Liberties Union, among others. The National Women's Law Center has fought against gender discrimination in health for decades, including providing major support in getting Section 1557 included in the ACA and in translating what it means for cisgender and trans people. As state legislators introduced hundreds of anti-trans bills across the country in recent years, a complementary tracking and analysis part of the movement became more prominent. Groups like the Movement Advancement Project take a think tank approach to social change and have become a prominent resource for documenting the dramatic shift against trans rights that came quickly after the media-announced so-called "transgender tipping point" of acceptance around 2015.

A successful legal framework for defending trans civil and constitutional rights in health care relies on legitimizing trans identities and delegitimizing opponents, particularly in trials that pit expert witnesses against each other. The legitimization process involves affirming the reasonableness and scientific credibility of gender-affirming care as a treatment for something real. The delegitimation process involves connecting religious denials of trans people's existence with animus against them as a group and exposing that animus as the real motivation for faux scientific uncertainty. This is, after all, the most infuriating part to religious conservatives: that their religious beliefs are made out to be simple bigotry toward trans people, stirred up relatively recently for political advantage. They see themselves

as under attack because the legitimacy of these beliefs as the basis of medical and social policy is precisely the question, and sometimes they lose decisively.

A basic conception of health care civil rights for trans people must include access to gender-affirming medical care, not all of which is about transition. Cutting off and criminalizing gender-affirming transition care is a way to try to stop trans people from existing. At least twenty-two states have passed laws banning gender-affirming care (with some variations).<sup>16</sup> Some federal courts have upheld these bans and others have struck them down. As this book goes to press, a state law that makes providing gender-affirming care to trans youth illegal is before the Supreme Court on Fourteenth Amendment equal protection grounds in *United States v. Skrmetti*. Federal district court judges in both Arkansas and Florida have blocked state laws making gender-affirming care illegal.<sup>17</sup> The fate of gender-affirming care for trans minors (and likely adults too) turns on a combination of the power of professional medical societies and experts to defend it as reasonable and appropriate and on acceptance of the idea that trans people are an oppressed group who deserve to exist both as they are and in the shifting and moving state of gender that transness signifies.

The judge in *Doe v. Ladapo*, the 2023 Florida case challenging the law banning hormone treatments for minors, noted that “the elephant in the room” is whether transgender identity is real and not made up. The state of Florida and those opposed to gender-affirming care are opposed “to transgender status itself.” “Gender identity is real,” Judge Hinkle, a Clinton appointee, responded.<sup>18</sup> He concluded that “dissuading a person from conforming to the person’s gender identity rather than to the person’s natal sex is not a legitimate state interest” and found that the prohibitions failed both the intermediate scrutiny *and* rational basis tests under equal protection analysis. Seeing trans people as a group that exists and is oppressed because they violate gender expectations likely leads to legal protection, and here we see it is possible for a judge to declare that forcing people into binary birth sex and the matching lifelong gender identity should not be a goal of the state at all.

It did not help the opponents’ cases that the only expert witness who had treated transgender patients and could muster a standard account of medical expertise in the area of gender-affirming care offered opinions that helped the other side. Dr. Stephen B. Levine, a psychiatrist and national go-to expert witness for those supporting anti-trans laws, does not invoke offensive language or religious terms. He presents himself as a reasonable scientific expert with carefully parsed hesitations who has a long professional history in transgender care, mostly dating to the 1990s (he is in his eighties). But the litigation is about criminal bans on providing care enacted in a hot anti-trans environment, no place for this dated middle ground Dr. Levine tries to occupy. Dr. Levine’s perspective cannot legitimate all-out criminal bans. In the Arkansas trial, Dr. Levine described being cut off from treatments

because of these laws as “shocking” and “devastating” for trans people.<sup>19</sup> Judge Hinkle’s Florida ruling noted that Dr. Levine affirmed that transgender identities are real, that he would not ban all treatments himself, and that treatments with safeguards are appropriate. Surely if anti-trans legal advocates could find a doctor who is as mainstream but supports banning treatments, they would have done so. Dr. Levine seems to be the only legitimate expert available, used in case after case, seemingly excusing himself for his own role in assisting “shocking” and “devastating” withdrawals of care.

Trans health care rights win in court when their opponents can be cast as religious zealots who want a world in which trans people do not exist, or at least are neither recognized nor provided for. That was the fate of the other expert witnesses, the new generation selected for this mobilization of anti-trans litigation. Judge James Moody, an Obama appointee, did not credit the expertise of the anti-trans witnesses beyond Dr. Levine in the Arkansas trial. Judge Moody noted that the other experts—Prof. Mark Regnerus, Dr. Paul Hruz, and Dr. Patrick Lappert—were recruited by Alliance Defending Freedom (ADF) at a meeting explicitly aimed at finding experts opposed to gender-affirming care. They are religious conservatives who do not treat gender dysphoria or have any expertise in it. “The ADF,” Judge Moody concluded, “is an organization committed to protecting God’s design for marriage and family,” that is, “not a scientific organization, but a Christian-based legal advocacy group.” The experts were chosen for their demonstrated commitments to conservative evangelical Christian and Catholic views of gender identity, in his view, not their expertise in gender-affirming care. The Florida district judge Hinkle cited Dr. Lappert’s radio interview comments that “gender-affirming care is a ‘lie,’ a ‘moral violation,’ a ‘huge evil,’ and ‘diabolical’” to discredit him.<sup>20</sup> The Arkansas district judge Moody pointed out Prof. Regnerus’s previously rejected status as a credible expert on the harms of same-sex marriage (“fringe,” “entirely unbelievable and not worthy of serious consideration”)<sup>21</sup> to push him beyond the boundary of credible expertise. He found these ADF experts were “testifying more from a religious doctrinal standpoint rather than that required of experts by *Daubert*.”<sup>22</sup>

The national legal push to defend the state bans on gender-affirming care is led by Alliance Defending Freedom with explicit religious grounding. Even though I have argued in chapter 4 that our constitutional order and federal laws give religion broad protections, even to discriminate in health care, this analysis shows that the religious framework does not hold up nearly so well in the case of assessing expert witnesses’ legitimacy. Religious reasons do not typically count as valid grounds for an expert opinion on a medical or scientific question. Once a legal fact finder assesses trans opponents as primarily religiously motivated it is easy to dismiss their scientific credibility.

But as Joanna Wuest and Briana Last have documented, there are more “agents of uncertainty” than the straightforwardly religious.<sup>23</sup> Organizations that oppose

gender-affirming care seem to recognize the benefits of distancing themselves from overtly religious linkages, instead holding conferences and forming think tanks designed to give the impression of a diverse transnational association of concerned parents, detransitioners, experts, and critical thinkers not afraid to ask hard questions about gender. Genspect, a group formed to counter what they see as the wrongly settled consensus in established groups like WPATH, named its conference “The Bigger Picture,” describing speakers as “leading lights from across the gender space.”<sup>24</sup> These organized groups contain a broader range of perspectives, from people talking about their own lived experience with gender transition and detransition to providers to those more easily characterized as right-wing hacks. They tend to carefully avoid religious frameworks.

As long as Alliance Defending Freedom leads litigation in the United States and relies on religious experts outside the scientific and medical mainstream, however, those efforts will continue to be easily linked to evangelical religious opposition. It may be easier for a more diverse group of opponents to gain traction across Europe and North America by shedding the religious framework in favor of a “question the consensus” approach. Mobilizing shifts in health policies in the UK and Europe to tighten access to gender-affirming care—not places associated with conservative religiosity—could prove useful for advocates in rehabilitating the US anti-trans perspective from religious zealotry to what they prefer to present as sensible caution. The Supreme Court majority may not even need such cover to rule against gender-affirming care. We shall see.

Judicial affirmations of trans health care rights pull trans adults and youth closer into already-protected categories and well-established notions.<sup>25</sup> That is, they affirm that sex discrimination means using sex or ideas about the stability of sex at birth as the governing frame for binary gender to give or withhold benefits. If anyone who is not trans could get access to a procedure or therapy and it is only withheld from trans people because they are trans, how can that not be discrimination? Sex discrimination is punishing gender nonconformity, in other words, and there is no good reason to do it. The winning opinions insist that our civil rights laws share overlapping and similar commitments to equality across the fields of the workplace, education, and healthcare. And they accept that animus toward trans people—a recognizable minority group subjected to subordination across multiple spheres of social and political life—is the same kind of discriminatory animus condemned by our constitutional commitment to basic equality.

All the moments at every level where health care civil rights become intelligible and powerful are nonetheless fragile. At the hospital level, they depend on professionals whose personal perspectives are different from the profile that is elevated by the organization and on changes in the healthcare professions generally (lawyers intervening in patient experience, gay Section 1557 officers who see discrimination because of their own experience). At the insurance level, wins

depend on nonexclusionary policies as well as the personal exhaustion of trans people seeking care and the perseverance of their professional allies to argue about medical necessity determinations. At the national level, the arguments in favor of gender-identity protections are strongly rooted in the law but face an uneven and generally hostile judicial branch that has been tilted rightward. And yet, these contingent moments are not random events. They are part of systemic refractions of rights, and in the conclusion, I reflect on ways to strengthen the bits and pieces that scatter about.