

## How Insurance Companies Broker Health Care Civil Rights

Phoenix, a non-binary Michigan resident, described to us how difficult it was to obtain gender-affirming procedures covered by their insurance: “It was I’d say two years before I can finally get [my insurance company] to agree [to pay for surgery]. But it was just continuous letter writing after letter writing after letter writing. I have been suicidal, I have been depressive, and then they finally said, okay, we’ll go with it.” Why, if Phoenix’s surgery was supposed to be covered by insurance, was it so hard to get?

Michigan’s laws are formally supportive: state law prohibits exclusions of transgender care in private insurance plans, and state Medicaid policy explicitly affirms coverage. Health care civil rights apply to health insurance coverage and, at least under Democratic administrations, do not allow categorical exclusions for gender-affirming care. A categorical exclusion is a clause in a health plan that broadly excludes whole categories of care, often in vague and outdated language (such as no coverage for “sex changes”). Nonetheless, insurers are still allowed to use management techniques such as prior authorization and the medical necessity standard for coverage, and civil rights laws do not specify exactly what must be covered.<sup>1</sup> Gender-affirming care cannot be broadly denied as experimental or cosmetic, that is, but individuals are not guaranteed to receive specific procedures as a civil right. Denials must be for a legitimate, nondiscriminatory reason, but lots of techniques for denials are permitted. As Miranda Yaver has documented, insurance denials are a significant and inequitable barrier to health care for many people without the resources to slog through an appeal.<sup>2</sup> So although Section 1557 of the Affordable Care Act (ACA), a patchwork of state law insurance protections, and *Bostock* provide formal legal protections for trans people using health

insurance, insurance companies retain power to slow or deny coverage with tools that they are experts at using.

This chapter examines how health care civil rights to nondiscrimination in insurance coverage are refracted through insurance companies. One gets health care in the United States from one's insurance company as much as from a doctor. As I explained in chapter 1, health insurance is a complex mix of public and private support and subsidy that is regulated in a fragmented and shifting way. What I call the medical necessity framework is the primary way that health care civil rights are refracted through health insurance companies' business practices. Tara Gonsalves points out that medical necessity determinations are also "a deployment of medical authority and a classification grounded in normative understandings of embodied gender."<sup>3</sup> One may have a health insurance policy and a right to inclusive coverage for gender-affirming care, but the right still goes through the bureaucracy and business model of the American health insurance company most of the time. Health insurance companies shape gender-identity nondiscrimination rights quite literally, that is, by deciding what surgical interventions are necessary to change faces and bodies. Legal categories meant to protect on the basis of traits such as gender and race always also shape what is acceptable within those categories and then offer protections back to those who fit sympathetically.<sup>4</sup>

My focus here is on the common form of health insurance that working age Americans have, which is a plan sponsored by their employer. Most trans people have some type of health insurance, but they still report trouble using it to get the care they need, and trans people of color report even more barriers to care.<sup>5</sup> Eighty-six percent of respondents to the 2015 Transgender Health Survey had health insurance, with fifty-three percent of respondents reporting coverage under an employer-sponsored health plan.<sup>6</sup> When trans health care civil rights are successful in health insurance, that usually means that there is a law in place that mandates coverage for gender-affirming care or at least prohibits a categorical exclusion.

Health insurance expansion has been the most significant win for trans health care civil rights by far. One review found that ninety-seven percent of plans in a sample of 1,057 ACA silver marketplace options from 161 insurers in thirty-eight states had removed transgender exclusions in 2020, compelled by the Obama administration's Section 1557 nondiscrimination regulations, which banned categorical exclusions.<sup>7</sup> Categorical exclusions had been quite commonplace in health plans prior to the ACA. Access to gender-affirming care in a primary care setting as well as other health priorities like expanded HIV testing and PrEP access improved dramatically after 2014, all attributed to Section 1557.<sup>8</sup> Having some kind of coverage is one thing, but successfully using it turns out to be quite another. A health plan that does not mention gender-affirming care but does not have an

exclusion is hard to interpret. Fully-spelled-out affirmative coverage is the best-case scenario, but it can still be hard to use for all one's needs.

This middle range of rights in health insurance is quite different from the patient experience level at the hospital. Insurers responded rapidly and concretely to explicit legal requirements to remove exclusions. When states make gender-affirming care for minors or adults illegal, however, no provider will bill for it in that state. The medical organization level is interpersonal and governed by preexisting norms of managing problems that are difficult to change, but it could also be a site for norms of recognition and respectful provision of care to take hold that may carry on despite the churning law at the national level. Insurance billing requires diagnosis and thus remains tied to medicalization, which is not an encouraging basis for trans rights claiming.<sup>9</sup> Even so, broader access to health care and insurance generally under the ACA and Medicaid expansions—civil rights enforcement aside—has been critically important for lower-income people and those without access to generous employer coverage. Trans and non-binary people need all the same health care that everyone else needs, after all. The point is that insurance cuts different ways. Successes are bigger and “stickier,” meaning more permanent, when they come, which is why I argue in the conclusion that nationally available health coverage that includes gender-affirming care should be a top priority.

#### THE CHALLENGES OF RESEARCH ON HEALTH INSURANCE

We know relatively little about health insurance coverage in the private market because corporations are not required to share details of their employee benefits publicly. There is no law that says that all health insurance products sold in the United States must meet certain standards of transparency, content, or accessibility (though the ACA's requirements for the Summary of Benefits and Coverage for group plans is a notable exception). Benefit plan documents do not have to be uniformly accessible, say, in an open, searchable database that researchers and consumers could use to understand what health insurance looks like across all market segments and types of coverage. State insurance regulators require firms to file their fully insured health plans, but only the plans that they regulate and then often in obscure databases in offices across all fifty states. Many firms and carriers post their health plan documents on their websites voluntarily, but others place them behind a login for beneficiaries only.

There is an opaque federal government form that health plan sponsors with more than one hundred beneficiaries must submit to the Department of Labor, on which they describe in general terms what benefits they offer that are regulated by the Employee Retirement Income Security Act of 1974, but nearly half

of businesses neglect to file it at all and many file it late.<sup>10</sup> The form, called Form 5500, does not explicitly ask if a plan is self-insured, so the Department of Labor had to commission an algorithm to analyze the form to make a best guess about whether a company's plans are fully insured, self-insured, or mixed-insured. The Department of Labor estimates that there are about 2.5 million self-insured plans covering 133 million people in the United States governed under the Employee Retirement Income Security Act, but only 81,800 covering eighty-three million participants filed a form at all, and less than half of those indicated offering a health insurance plan.<sup>11</sup> Sixty-five percent of covered American workers have a self-insured health plan.<sup>12</sup> The ACA requires an annual report to Congress on self-insured health plans, and the secretary noted the "limited scope" of data, "complexities involved in interpreting it," and "substantial uncertainty" in its estimates.<sup>13</sup>

Research into health insurance coverage has focused on insurance market segments where documents are available, such as those on the Affordable Care Act marketplaces, Medicare, and Medicaid. Surveys of other private insurance offerings often do not analyze the actual insurance plan (the consumer-facing document), relying on phone calls to insurers and web searches to gather insurance company information.<sup>14</sup> Advocacy organizations such as the Human Rights Campaign (HRC) have been very important in filling the gap of knowledge for LGBT people with their Healthcare Equality and Workplace Equality ratings,<sup>15</sup> but these are self-reported surveys without outside scrutiny of documents. Health services researchers can study patterns of health insurance use through claims databases, but those only reveal instances when the insurer pays a claim and for what, not the actual terms of the health benefit plan or rejected claims.<sup>16</sup>

It is shocking that corporate health insurance plans for employees—the way most working Americans get their health care and for which companies receive billions of dollars in tax breaks—are so poorly regulated that we cannot systematically, publicly analyze what they offer and how well they are financed. There are many sites of ignorance in US policy and government because of federalism, local control of important functions like education and criminal justice, and the way our administrative state evolved. We do not know how many toddlers shoot themselves with guns they find, how many unarmed people are shot by law enforcement officers, or what is in most health insurance plans. Our databases are scattered and unable to speak to each other—for instance, we do not have a national immunization database, but rather ones at the state level that are not interoperable with each other. Researchers have painstakingly built databases to understand seemingly critical questions like what percentage of US children experience caregiver involvement with the criminal justice system. (It is thirty-nine percent overall and over sixty percent for Black, Native, and low-income children.<sup>17</sup>) As I'll argue in the conclusion, 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 in addition to substantive reforms to make what is for sale equitable and open to all.

#### CORPORATE SELF-INSURED HEALTH PLANS IN THE CIVIL RIGHTS PATCHWORK

I have described our health care civil rights system as a patchwork layered on top of a patchwork. What I mean is that we have thinly described, minimally enforced, powerfully opposed rights on top of other long-standing structures and practices that are themselves broken across jurisdictions, underfunded, uncoordinated, and technologically behind. None of this is anyone's nefarious plan necessarily. Nonetheless, this patchwork combined with our ignorance about insurance in particular advantages some and disadvantages others, and it makes it impossible to properly understand important costs, harms, and risks in our society that we otherwise misattribute or simply never think about. Critically, it enables blaming individuals rather than structures for problems when we cannot see and understand what the structures—private health insurance, criminal justice, gun laws and liability protections for gun manufacturers—are doing and how much power they have.

My team worked to improve what we know about coverage for gender-affirming care by coding the language of 435 self-insured health insurance plans offered in 2019 by forty major American corporations.<sup>18</sup> I negotiated access to data from a private healthcare consulting firm, Leverage Global Consulting. Leverage has developed a proprietary database that contains insurance plan offerings and coverage from private and public insurance market segments. They have pulled documents from public filings and websites to assemble a picture of health plan coverage for nearly all covered lives in the United States. Health plan enrollees receive a document called a Summary Plan Description from their employer annually. This document is usually very long (more than one hundred pages) and explains what is covered and what is not covered, among many other legally required details. These are the documents my team used to understand coverage. We hand-coded the plans to find what recommended elements of coverage they offered for gender-affirming care and published the results and over 1,400 plan documents with open access.<sup>19</sup>

Some of these corporate health plans excluded health benefits for gender-affirming care entirely, often in outdated language ("sex reassignment") that was probably in the health plans for years. Ten companies out of this group of forty (twenty-five percent) offered at least one healthcare contract with a total exclusion on coverage for gender-affirming care. The companies vary based on their seeming commitment to their exclusion, with some showing the exclusion in one hundred percent of the health plans we found while others seem to exclude strategically, with only certain health plans—perhaps for some groups of employees or some

geographic areas—including an exclusion and others lacking it. Health plans also used generic language (“cosmetic, experimental, or investigational”) or gave specific gender-affirming exclusions. Most exclusions we found were related to facial gender-confirmation surgeries and hair removal, which are critically important to gender-affirming care.<sup>20</sup> Surgeons cannot operate before hair removal is complete, and for some people, particularly trans women, facial features that do not match one’s gender identity can lead to harassment and even attack.

Outside pressure to be an LGBT-friendly company has been important in creating voluntary corporate change, but we wondered if trans-specific interests in health care were adequately recognized in the most important ratings from the Human Rights Campaign (HRC). We compared our category rankings to the Human Rights Campaign’s rankings of the same companies on the 2019 Corporate Equality Index. Only half of the companies (eleven of twenty-one) that scored a top score of one hundred on HRC’s rankings had clear coverage for all the health plans in our analysis. Others with a perfect score had silent or ambiguous coverage for gender-affirming care in their plans that we examined. Despite earning an HRC score of one hundred, five companies still offered fifteen health plans with blanket exclusions for coverage for gender-affirming care (Macy’s, Marsh McLennan, McKesson Corporation, Stanley Black & Decker, and Symantec), and one company (Stanley Black & Decker) *only* offered health plans in our analysis with exclusions. Finally, three companies with HRC rankings of sixty-five or lower offered at least some health plans with clear coverage for gender-affirming care (Avnet, Costco, and Windstream). While the HRC Equality Index provides important information about LGBT inclusivity overall, this research underscores that a perfect score does not always equate to coverage for gender-affirming care. Scoring trans health care needs with other policies that support gay, lesbian, bisexual, and queer employees obscures the degree to which specific health care needs for trans and non-binary employees are well met.

So far I have argued that it is hard to find out comprehensively what is in corporate self-insured health benefit plans and that even outside indicators are not reliable for understanding gender-affirming-care coverage in particular. It is worth reprising what civil rights law applied to these plans in 2019 as a way of reviewing the patchwork of rights. The Obama trans-inclusive Section 1557 regulations were in place, but they only applied to health care entities like insurance companies who took federal funding. Self-insured corporate plans would not have been covered (and still are not covered) under Section 1557’s nondiscrimination clause because the company itself is not a healthcare entity. Fully insured plans created by an insurer that also participates in the ACA marketplaces or otherwise takes federal funding would be covered under Section 1557, by contrast.

Because the plans are an employee benefit and because gender-identity discrimination is sex discrimination under the 2020 *Bostock* ruling, it is likely that trans employees would have a strong Title VII case against exclusions for

gender-affirming care in their plans. Since our data come from 2019 plans, the strength of a Title VII claim would have depended on the law by jurisdiction but would have still been a strong claim. Federal antidiscrimination laws like Title VII, Section 1557, and the ADA are not preempted by the Employee Retirement Income Security Act of 1974, the federal law that takes away states' powers to regulate employer-sponsored health benefits, and thus some civil rights protections still apply.<sup>21</sup> If the company takes a discriminatory benefit design from a third-party administrator (TPA) and lets the TPA administer it for them, however, that TPA is liable for violating Section 1557's ban on gender-identity discrimination. But if the discriminatory design originates with the plan sponsor—the self-insured company—then it is not covered by Section 1557 even now because that company is not a health care entity.<sup>22</sup>

Many corporations provide quite generous employee health benefits, though, including all recommended forms of gender-affirming care as well as other benefits that are not required, like *in vitro* fertilization (IVF). Why extend benefits if one has not been legally required to do so? Companies tend to move together towards similar organizational forms, so expanded coverage required by the ACA for some plans has moved the bar for everyone.<sup>23</sup> There is a strong consensus in the medical community that gender-affirming care is medically necessary.<sup>24</sup> Companies may have been responding to extralegal pressures such as the desire to recruit LGBT employees and to earn high ratings from HRC. They may calculate that gender-affirming services will cost relatively little but be worth the progressive image benefit. Their employees and people they want to hire may demand it. Indeed, the long history of success in expanding sexual orientation nondiscrimination in private company policies without a federal law shows that internal employee organizing for benefits can be successful.<sup>25</sup> Transgender advocacy organizations such as the National Center for Transgender Equality and the Transgender Legal Defense & Education Fund counsel clients to approach their employers directly to extend coverage since this strategy may be much easier than litigation or fighting the insurance company. For self-insured plans that the employer controls entirely, this strategy can be the most efficient.

When health care civil rights are refracted through health insurance plans generally, a lot of different things can happen that reflect different regimes of law and policy that apply to different kinds of insurance. We do not have a way of knowing about a lot of what happens because no one can see it except for the person receiving a denial letter, for example. Bans on coverage through programs like Medicaid, which exist in nine states for adults and three states for minors, are devastating for low-income trans people who do not have employer-sponsored insurance. In those cases, the failure of health care civil rights for trans people is starkly apparent. I wanted to understand how a health care civil right in the form of health insurance coverage for gender-affirming care might work in practice for those who have it. This approach helps us see the close relationship between

any health care civil rights regime and our huge, complicated, powerful health insurance industry.

#### REFRACTING HEALTH CARE RIGHTS THROUGH THE MEDICAL NECESSITY FRAMEWORK

Even if one has a civil right to gender-affirming care, they must navigate their health insurance to get it. My team interviewed twenty-four adults who identify as transgender and/or non-binary, had sought health care to be covered by insurance related to their transgender status in the last two years, had some kind of insurance coverage at the time, and were willing to talk about their insurance coverage in some detail.<sup>26</sup> Notably, the trans and non-binary people interviewed for this chapter had health insurance that ostensibly covered gender-affirming care. Not all trans people seek surgical care, but often they do, and not necessarily to move from one place on the gender binary to the other. Not everyone in this chapter was seeking a surgical intervention, either, though many were. Some interviewees did not have insurance for the care they sought because they were subject to an explicit exclusion. As I discuss in depth in the next chapter, Catholic healthcare institutions strongly resist performing any transgender-related care for both theological and political reasons. Joshua's doctors determined that a mastectomy was medically necessary, but he had to change jobs to get insurance coverage that would cover his care because his Catholic healthcare plan denied coverage. So while trans people have a range of needs and experiences, I'm focused here on a particular type of barrier that is still allowed even with health care civil rights laws in place: the internal wrangling over medical necessity for gender-affirming care. Medical necessity determinations can become the primary site of conflict in benefit plans that are on their face inclusive because, as one surgery scheduler told us, "Benefit exclusions are almost futile to appeal from a provider's standpoint. We can't do anything about that." Even if all categorical exclusions for gender-affirming care in every plan in the country were whisked away, these challenges would remain.

The trans people interviewed for this chapter were mostly properly *recognized* under health care civil rights, but the *provisioning* of those rights still needed to be secured. Although insurers have removed most outright exclusions for gender-transition care, health insurance policy language, interpretation, and implementation of what constitutes medically necessary gender-affirming care still makes insurance hard to use. Many of these difficulties would apply to anyone trying to use coverage for a complex or contested condition, but some are specific to trans people seeking gender-affirming procedures. This chapter reveals not just the power of insurance policy language but also how making insurance claims and getting them paid is a socially contested and negotiated process. The definition, discretion, and disputation around what constitutes medical necessity for gender



dysphoria (the official diagnosis for billing purposes) is the primary way that insurance refracts health care civil rights.

The same basic definition of medical necessity appears across the patient-facing document in health plans that offer gender-confirming care and those that exclude it. A standard definition of medically necessary services and supplies (from Cigna's 2019 health plan for Stanley Black & Decker) is: "Medically Necessary Covered Services and Supplies are those determined by the Medical Director to be: required to diagnose or treat an illness, injury, disease or its symptoms; in accordance with generally accepted standards of medical practice; clinically appropriate in terms of type, frequency, extent, site and duration; not primarily for the convenience of the patient, Physician or other health care provider; and rendered in the least intensive setting that is appropriate for the delivery of the services and supplies."<sup>27</sup> This plan explicitly excludes "transsexual surgery, including medical or psychological counseling and hormonal therapy in preparation for, or subsequent to, any such surgery." Adobe's health plan, administered by Aetna, covers gender-affirming care. Their plan's definition of medical necessity is not very different from the Black & Decker health plan above, which fully excludes gender-affirming care. Medically necessary care under this health plan also means what a prudent clinician would do according to generally accepted standards of what is clinically appropriate, not just for convenience, and so on. But just as the words of a statute do not necessarily tell us how the law works in practice, we found that these definitions explain very little about what happens when trans people and their professional allies argue for coverage.

#### TRANS SELF-ADVOCACY FOR COVERAGE

Malik, who is Black and transmasculine, identified medical necessity definitions as the linchpin of health insurance coverage determinations:

I think one thing that definitely needs to change is how we talk about gender-affirming procedures or surgeries or hormone replacement therapy. And how insurance companies see how these particular things are affecting individuals. Looking at things as medically necessary is super important because that changes how it's written in the policy and how it's talked about.

He continued:

I think what the problem is now is a lot of the health care that trans folks are seeking is trivialized and thought of as like something that is, you know, quote-un-quote "cosmetic," which is a way for them to say not necessary. And so if you change the language about it, you change how it's talked about and recognized, how these things are medically necessary—and how that affects the lives of trans folk, then that is the initial jumpstart that you need to get things changed within insurances at an

administrative policy level. Because then once the policy is changed, then they have a rule in place that they follow.

Malik was just twenty-two years old at the time of this interview, but he had become an expert on how health insurance works and how rules, language, and administrative power matter for rights. Trans people, even with employer-sponsored health insurance that is supposedly nondiscriminatory, struggled with numerous barriers to gaining coverage. These barriers, operating with this meso-level of corporate insurance business control, are permitted under Section 1557's gender-identity protections because decisions about medical necessity are explicitly left to the insurer.

Even when gender-affirming care was covered, insurance companies demanded people prove themselves worthy of services. One interviewee detailed how after living as a trans man for ten years, his insurance company (Molina) required a six-month period of verification in therapy before it would approve any medications or services. Merely being in counseling for six months was even rarely sufficient for coverage to start. For Phoenix, who is white and non-binary, the six-month requirement dragged out much longer because it was just a first step to making many arguments with his insurer:

I go to Molina and Molina won't cover it unless, you know, for sure this is something that is a definite yes. And in order to find out if it's definite yes, you have to go through intensive counseling, for like six months. Then you get two psychologists to sign off on paper stating, yes, this person is suffering identity dysphoria, they do not belong in the body that they have. It was I'd say two years before I can finally get Molina to agree [to pay for surgery], even though I had those consents.

A medical provider's letter insisting that services were medically necessary was often insufficient for the insurance company, which had an unwritten and opaque internal process for how it determined medical necessity. Phoenix also had endometriosis and their doctor had determined that a hysterectomy was medically necessary on that basis but also wrote to the insurer that "this will help with [Phoenix's] transition." Phoenix was thus presenting two different accounts of medical necessity (both valid), but their multiple diagnoses caused significant challenges with the insurance company. The insurance company initially denied coverage for the hysterectomy with endometriosis because Phoenix was also transitioning. Phoenix's case shows how someone who does not meet the profile of the binary trans person with no other health issues runs into additional obstacles.

Just as researchers cannot systematically study what is in our nation's health insurance plans, beneficiaries themselves often find that their insurance company does not have to disclose how it makes necessity determinations. "I would say the number one thing [that was the hardest in getting care] was, from the get-go, not

having a clear definition of what is considered medically necessary by my plan,” Adrian said. Adrian, who is white and non-binary, was seeking services for speech therapy, which their speech therapist identified as medically necessary, and their employer agreed would be covered. When they reached out to his insurance company, it told them that it was not legally required to share information about what it deemed medically necessary. “So there was a lot, and I mean a lot, of back and forth between my employer’s HR department who were saying this, and my insurance company basically saying, trying to find out what is actually covered by insurance.” All Adrian wanted to know was, “What does this new insurance policy consider medically necessary versus not?” Their employer had a self-funded plan run by a third-party administrator (TPA). In practice, that meant each could blame the other for conflicting views of medical necessity. Adrian was caught in the middle. It was “just an awful back-and-forth experience of finger pointing,” they recounted, with “the insurance company saying, ‘Well, my employer puts this policy together and agents provide the services for it,’ whereas from my employer would say, ‘Well, we pay the insurance company to do this.’” Adrian ended up spending eight months and six thousand dollars of their own money for services that their HR department had said would be covered in a memo to all employees. Finally, the insurance company provided sufficient documentation to the hospital to stop billing them.

Trans people seeking care read their plan documents very carefully and put in many hours of labor trying to use them for coverage. Adrian still found themselves trapped between their employer and the employer’s TPA in a cycle of obfuscation. Others found confusion and ignorance on the other end of the phone at the insurance company. Insurance company staff tasked with answering questions often lacked sufficient information to answer questions about coverage for gender-affirming care. For example, after learning from a pharmacist that hormones would be covered with prior authorization, Billy, who is white, looked more closely at his health insurance plan, trying to plan for the full scope of care he hoped to get. “I was interested in pursuing surgeries and I knew that documentation would be needed obviously to try and obtain an authorization,” he said. He called his insurance company and spoke to four different people, but no one could help him figure out how to start obtaining those authorizations.

I said can you please give me some direction as to what I may need? Would I need to go see someone specifically, a special type of doctor? Or would you need a letter from my primary care? Would you need one from my neurologist? And they couldn’t direct me, give me any type of guidance. It was useless.

Black trans people with distinctively Black names such as LeVar and Malik encountered microaggressions and dismissals as insurance company staff tasked with helping people understand their benefits and problem-solve instead treated their requests as trivial or funny.

LeVar described how his insurance company repeatedly sent him his insurance card using his former name. This created problems because his insurance card would not match the information submitted for services. Racism compounded barriers for trans people of color. When he called the insurance company, he usually got the “runaround” and felt like “it was a joke” to them. Malik recounted a very similar experience with insurance staff after changing his name:

It didn't seem at all that they have any sort of policy or training or anything about that, how to go about updating that in the system. So when I went to the offices and gave them the proper documentation to show that I've changed my name, the guy just wrote it down on a piece of paper and said, “Yeah. I'm not sure what we're supposed to do about that, but I'll get back to you.” And then nothing ever came of it.

While white trans people described painstaking processes to navigate insurance company mistakes and structural barriers, few conveyed the same sense of invalidation that Black trans people expressed.

#### DIFFERING PROFESSIONAL PERSPECTIVES ON MEDICAL NECESSITY

Doctors and insurers mobilize the medical necessity framework in different ways. Insurers deem a medical procedure as medically necessary if there is a physical, functional benefit. As one surgeon we'll call Dr. Fischer noted, “We get into this debate about what's medically necessary and what's not. The insurance companies tend to say unless [insurers] are going to see improved physical functioning or reduced cost of medical burden going forward, that is not a medically necessary operation.” Other providers noted that insurers consider a procedure medically necessary if the effectiveness of the procedure is grounded in evidence-based research or consistent with international and national consensus.

Surgeons and social workers who work with trans people seeking care take a broader view. They think that medical necessity should be determined by whether a procedure improves the well-being and quality of life for the person, including improving the mental health of a group of people with a very high risk of suicide. Dr. Fischer described how insurers go back and forth over functionality and the required evidence base, where sometimes one factor is present but the other is lacking:

It's not a hard-and-fast thing. If there's clear functional benefit, it's not difficult. If there is data available to show clear quality of life, mental health, you know, functioning-in-society data, that's not hard. It's in the gray zone where you really can't perceive a definite functional benefit, there's not real data to show a lot of quality-of-life benefit. Then it becomes hard. A good example is body contouring after massive weight loss. So insurance companies, if you've lost one hundred pounds, they will, without a whole lot of argument, pay for your abdominal body contouring. They rarely or

never pay for arms or breasts or thighs, even though the people would clearly benefit sometimes not only in terms of quality of life but in terms of functioning.

Surgeons may see some ordinary, nonsurgical procedures as much more medically necessary than insurance companies do. It is typical for surgeons to require laser hair removal from the genital area before surgery so that the result does not leave hair growing in undesirable places. Electrolysis services are difficult to bring into the insurance context because they are not a medically elite service with billing to insurance already set up (since hair removal is not part of other medical services). Barriers to coverage extend from insurance denial out to the mundane, such as whether the electrologist has the required secure fax machine to transmit patient information.<sup>28</sup> The impacts on trans people who are poor, elderly, or disabled are especially harsh as Dr. Pace, a psychologist, explained: “There’s people who have Medicare and Medicaid or are on disability can’t get their surgery, and they can’t do it because they can’t do the hair removal.” Jill, a clinical social worker who works with trans people seeking care, highlighted the frustration of a narrow construction of medical necessity:

Hair removal. This is huge. So genital surgeries are often covered. But what is not covered or treated as medically necessary is hair removal at the surgical site. So that is bonkers, like straight up. It’s a part of the medically necessary surgery, but I cannot think of any insurance companies right now that [are] covering it. Our plastic surgeons write a lot of letters saying it’s a part of a medically necessary surgery. You guys need to cover this!

Doctors believed the context in which the procedure is performed matters for whether it is medically necessary. They see it as based on the medical condition or diagnosis, not the procedure, even in the case of breast implants, which are nearly always considered cosmetic. “The distinction for me,” says Dr. Pielson, “between the cisgender woman and a transgender woman is the medical condition.” He continues: “I would argue that there’s no particular procedure that’s inherently cosmetic or reconstructive, it’s the diagnosis for which that procedure is being performed. Insurance companies have simply chosen to view the issue of gender dysphoria as cosmetic.” This doctor views medical necessity based on the diagnosis, one that accounts for the quality-of-life needs of the patient seeking such care, while the insurer applies a more uniformly restrictive approach (e.g., breast implants are always cosmetic except for post-mastectomy reconstruction after cancer treatment as required by the Women’s Health and Cancer Rights Act).

This disagreement also helps explain disputes over facial procedures. A transwoman may have facial features—hairline, jaw, Adam’s apple, brow ridge—that are perfectly functional for breathing and eating but present as masculine. These are among the most difficult to obtain coverage for, perhaps because they are not focused on genital organs or secondary sex characteristics and may involve making

a person more conventionally attractive as well as more feminine or masculine. More problematically, these procedures also involve making a person more white-looking.<sup>29</sup> That is, decisions about what surgical procedures are medically necessary for one's proper gender presentation to the world are also decisions about racial presentation, an illustration of the feminist argument that race and gender mutually constitute each other.<sup>30</sup> Providers repeatedly expressed frustration at the lack of coverage for facial-confirmation procedures despite insurers announcing that they cover gender-affirming surgeries.

Interviewees thought that insurance company interpretation of medical necessity ignores that the stakes of personal appearance are much higher for trans people, especially binary-identified transwomen. People seeking gender-affirming surgery often view facial procedures as vital to their life (since after all, we see each other's faces, not our genitals, in everyday life). The suicide attempt rate for transgender and non-binary persons is significantly higher than for cisgender people, reported in the 2015 Transgender Survey to be forty percent of respondents or nine times the rate in the US population.<sup>31</sup> Facial-confirmation procedures or breast reduction or augmentation do not feel "elective" or "cosmetic" for the trans people who seek them but vital to their mental and physical security and to decreasing the chance of discrimination, stigma, and violence against them. Providers argued that even if randomized controlled trials cannot really be done to show the benefit of these procedures across a large population of trans people (as they cannot be done with surgeries generally), medical necessity should be determined by whether a procedure improves the well-being and quality of life for a particular person in their care. That means improving the mental health of someone who is part of a group with a high risk of suicide.

#### ALLIED PROFESSIONALS PUSH BACK

The doctors who treat trans people bill their insurance companies, and they are part of the process of wrangling the insurer to pay. The surgeons we spoke to employ office staff to schedule surgeries. The first step is to make sure all the steps to secure coverage have been completed. Just as the grievance handlers shape the experience of rights on the ground for people trying to complain about injustices in hospitals, these office staff manage the tumultuous process of insurance coverage and are the ones to deliver the news to patients about whether the insurer will pay or not. They want the person to receive their care, so they push back against hoops and initial denials. In addition to the professionals in the medical offices who work with insurers, other professionals such as social workers and therapists also mobilize to help with coverage because there are additional requirements for trans people to access care.

Medically necessary care is not simply a list of covered procedures but, as Phoenix described, it also includes fulfillment of other criteria to demonstrate

worthiness and readiness. Health insurers impose a series of rules that a patient must satisfy to qualify for medically necessary treatment of gender dysphoria.<sup>32</sup> These rules may be laid out in the plan's list of coverages and exclusions or they may be found in the insurer's interpretation of the prevailing professional association guidelines and tucked away in a medical policy document. While many insurers claim that they cover gender-affirming surgeries, the details reveal insurers cover far less because these rules give many more occasions to deny or delay. These requirements may include two referral letters from mental health professionals, reaching the age of eighteen, all other health concerns being reasonably well controlled, twelve months of continuous hormone therapy, and twelve months of "real life experience" or living in the congruent gender identity.

Additional requirements that go beyond the World Professional Association for Transgender Health (WPATH) guidelines and recommendations were the among the most frustrating things insurers did according to health care professionals whom we interviewed. These additional obstacles lead to denials of coverage that providers view as simply excessive and not medically necessary. As Jill, the clinical social worker, explained:

For example, some insurers require that trans men who want a mastectomy are on hormones for twelve continuous months at least. That is not part of the WPATH standards of care. That is just one insurance company saying, "This is what we want." It's silly. It's not medically necessary. It's just the insurance company sort of deciding that this is what they want. It's not based on anything real.

These providers were highly aware that an informed consent model for care would grant trans people the same level of autonomy that other patients receive and that even the WPATH standards are regarded as overly restrictive.<sup>33</sup> Nonetheless, these healthcare providers must use them as an externally valid benchmark to bargain down what insurance companies demand, which is even more restrictive.

The number of mental health letters required to have procedures performed was a particular source of contention. Angela, a surgery scheduler, explains how adding extra requirements works:

Sometimes the criteria don't necessarily align with the WPATH criteria. The insurance criteria for surgery, they model it by the WPATH, but they don't follow it exactly. I recently had a patient for chest reconstruction. The WPATH criteria is that they need one letter of referral from a mental health specialist. I've had two Blue Crosses now say that we actually need two, two letters. We've tried fighting that that's not medically necessary.

Insurance companies also selectively reject letters if the therapist does not hold a PhD (so excluding MSW-degreed social workers) or the right kind of PhD. The lack of doctors and mental health professionals available to treat transgender and non-binary people in particular geographic areas makes it difficult for people to

get the appointments they need to fulfill these requirements. Dr. Pace, a psychologist in a gender services clinic who is trans, noted that some of his trans clients drove six hours each way to attend a therapy appointment with him. Rather than contest the additional hurdle like a second letter, people often “lump” their losses and just do as the insurer requires, as Angela recounts:

Ultimately it was decided that it would take less time for the patient to go to another therapist and get another referral letter. That was the patient’s decision, of course. You meet criteria, but their criteria states that you need another letter. We can fight based on, you know, [the insurer] not meeting WPATH criteria, or you can appease them and sort of dance the dance.

Rather than fight the requirements, people choose the path of least resistance to obtaining coverage, even when the insurer is adding requirements that go against the consensus standard of care. But sometimes it is still not enough. Dr. Barker, an ob-gyn physician, after saying how much the insurance coverage situation had improved in recent years, went on to say moments later that she had just had someone cancel a surgery because they had not been able to get two letters in time.

We saw how allied professionals pointed out the much higher suicide risk for trans people when arguing for facial-confirmation surgery coverage. They also argued in these terms for seventeen year olds to obtain gender-affirming procedures, which are not recommended for minors except in some cases. Doctors and therapists would like to maintain control of this discretion for treatment at the cusp of adulthood when they think their patient’s mental health is at stake and they are capable of giving consent. Despite the impression that conservative opponents try to create that young children are eligible for gender-affirming surgeries, the fact is that insurance policies typically do not cover procedures before age eighteen, and some restrict until age twenty-one. Dr. Pace, the psychologist, described a case of a seventeen-year-old trans boy seeking chest surgery who had gone through therapy and secured the necessary letter.

The surgeon said, “Yep, I’ll do your surgery.” They went to do the pre-authorization with the insurance company, and the insurance company denied it. And when I talked to the person at the insurance company she said, “There’s no research evidence to show that this is helpful.” Okay. So just correct me if I’m wrong. We know that the suicide rate, the suicide attempt rate—not suicidal ideation, not completed suicides, but the rate of people who attempted suicide, is forty-one percent of transgender people. This person’s seventeen, they’re not eighteen. Do we really think they have a lower suicide rate because they’re seventeen and not eighteen? I don’t think so. Here’s the insurance company. They’re supposed to be helping their members get the services they need so that they’re healthy. I think it’s a ruse, I think it’s a cover. I think they’ll do anything they can not to pay.

Refracting rights through insurance disrupts health care rights expansions for trans people in ways that are hard to see because they scatter through tedious,



bureaucratic, and mostly private disputes in the context of ongoing yet interrupted care.<sup>34</sup> Rights blockages may not take the form of outright exclusion of transgender coverage but rather emerge through a rigid construction of medical necessity and a series of barriers put up by insurers. Trans people find the process of trying to use their supposedly nondiscriminatory health insurance exhausting, expensive, and insulting.

Allied professionals contest terms like *medically necessary* with alternative views of what the medical interventions mean for a trans person's life, raising points like heightened suicide risks. As I discuss in chapter 5, sometimes insurance rights are realized and some of these arguments and frameworks secure coverage for care. But any approach to health care civil rights must take seriously the fact that insurance companies still control decision-making about coverage with considerable industry autonomy from regulation. Not only do regulatory civil rights carve-outs protect insurance-industry management practices, but the whole private employer-based health insurance system remains fundamentally disconnected from federal health care civil rights regulation. If we thought of the tax breaks companies receive for providing health benefits as federal funding for health care, then all Section 1557 civil rights protections would apply.<sup>35</sup> Instead we maintain a healthcare system in which private employers broker care for the majority of working age adults and their families through insurance that is obscured for research, managed for insurer's profits, and yet quietly subsidized by our government.

Insurance companies are what I have called the mesolevel of health care civil rights governance, removed from the patient interactions in a care setting to a more distant institutional level but not yet as high as the executive level of government or the prevailing legal interpretation of the Supreme Court. All these three levels still shape people's lives, so by "removed" I do not mean less impactful. Moving across these levels has helped me explain and sort all the different ways that health care civil rights are refracted rights and to specify the frameworks and mechanisms that scatter them. In chapter 4, I move to the national level of organized political and legal disputing about health care civil rights. I focus on religious conservative opponents of health care civil rights on the basis of gender identity, arguing that one critical way that antidiscrimination law fails patients is when discrimination against trans people is allowed, defended, and even celebrated.