CONCLUSION

Governing the Unknown: Legal–Scientific Settlements

On January 31, 2020, the US government issued an emergency declaration about a new public health emergency: COVID. This new pandemic raised old questions in the contemporary moment.[1] How do we determine legal rules to stop the spread of disease in the face of scientific uncertainty? How do knowledge claims – around disease, illness, health – shape the distribution of material resources?

This conclusion offers the frame of *legal–scientific settlements* as a way to understand the interactions between law, science, and social movements in public health crises.[2] The term legal–scientific settlement describes how the stabilization of particular truth-claims results in new legal and regulatory regimes. I use the term "settlement" to reflect the contingency and possibility for disruption. In these moments of legal–scientific settlement, law and science are coproductive of new facts and new knowledge ecosystems that are then generative of distributional outcomes.[3] Legal–scientific settlements reflect negotiations between law and new scientific and epidemiological claims refracted through the political and economic context in which they are developed. As reflected by the story of feminist AIDS activists, legal–scientific settlements are important *because* they have distributional effects: material, social, and cultural.[4]

REMAKING LAW, REMAKING SCIENCE

As HIV travelled from person to person lawmakers struggled to govern in a moment of scientific uncertainty. The virus spread as the idea of

personal responsibility further entrenched itself into the politics and economics of healthcare: People ought to take care of their own health. As personal responsibility narratives took hold, so did the idea that the state does not owe a duty to provide necessary healthcare services, especially to those who do not deserve them.[5] The stigma around gay sex and drug use moved people who had HIV quickly into the category of undeserving. A growing emphasis on criminal law would result in a crime control paradigm for many of the groups deemed at risk for HIV and harm-reduction programs were de-emphasized. [6] The result was sickness and death.

Who would be deemed as most in need and deserving of healthcare in a floundering public health system? A technocratic approach might suggest that this would be scientifically determined by the epidemiological data. This data would presumably be collected in a methodologically thorough and neutral way scientifically revealing how services and funding should be prioritized. In these accounts, as scientists and epidemiologists gained more knowledge, legislators and regulators were able to transform laws accordingly to better target the epidemic.

Studying feminist social movement activism in the AIDS response reveals the deep obfuscation of activism's role in shaping public health responses in technocratic accounts. This book remedies this erasure by showing how activists and lawyers helped shape a new legal order that would alter how scientists and public health institutions responded to AIDS. This shifted how money, resources, and power are distributed within the ideological framework offered by the current political and economic frameworks.

Feminists saw an inextricable connection in how the legal rules on disability were making and reinforcing the scientific vision of who has AIDS. It was a legal–scientific settlement that excluded women and needed to be disrupted. As the AIDS epidemic roiled on feminists saw that shifting science and law could create opportunities for remaking the world according to a feminist imaginary. As this book documents, whether it was the Centers for Disease Control and Prevention (CDC) definition of AIDS or mobilizing evidence in the context of harm and consent in sex work and trafficking, feminist advocates successfully transformed the ideas and institutions that produced knowledge about risk and vulnerability to HIV. Reflecting what Janet Halley and her co-authors have called governance feminism, they remade the world from both inside and outside institutions.[7] The focus on science and epidemiology was intentional. The goals of feminist reformers were not

only to change what we know – they were to alter the material distribution of resources in the context of a withering welfare state. They fought the ideology of individual responsibility that repeatedly failed women during the AIDS epidemic.

Feminists were not the first, nor the last, to take on legal–scientific settlements in service of redistributing resources through altering legal rules. The idea of challenging legal–scientific settlements has many origins, not least W. E. B. DuBois' 1906 book *The Health and Physique of the Negro American*. DuBois questioned the belief held by experts of the day that there was something specific to African Americans that made them less healthy and more likely to die of illnesses like tuberculosis that were circulating rapidly through the American population. He challenged the racialized science that was increasingly taking hold in medicine in the early 1900s, arguing that "[t]he Negro death rate and sickness are largely matters of [social and economic] condition[s] and not due to racial traits and tendencies." DuBois saw that to change the distribution of services and provide more healthcare for African Americans, it was necessary to take on a legal–scientific settlement dictating that the problem of poor health was innate to Black people. This idea justified denying healthcare and maintained a race and class hierarchy.

From DuBois to the Black Panthers and the New Left, feminists continued a tradition that sought to remake institutions and ideas, based on a recognition that the distribution of resources flows from law and knowledge being intertwined, one legitimating the other.[8] The critique of experts, DuBois and beyond, would inspire and motivate scholars and activists to disrupt political–scientific settlements for at least over a century.

In the context of AIDS, despite a shared sense that it was necessary to disrupt legal–scientific settlements, feminists were not always unified in their strategy or goals. Feminists often disagreed, holding competing theories of how to best address women's subordination. There were, and are, deep feminist disagreements about harm reduction and public health, about sex and sexuality, and about race and gender. At the heart of these disagreements was often the question of how to accurately portray the subjugation of women and how to understand liberation. The debates on sex work and trafficking in Chapter 5 clearly illustrate this point. Competing camps of feminists, each with their own feminist projects, fought for recognition of their own worldview in order to shape the distribution of resources to one ideological project or

another. At stake was not only money, but life and death, and a virus that moved more quickly where resources to prevent and manage its transmission were scarce.

Feminists engaged in the project, and sometimes competing projects, of defining who women are, what puts them at risk, and how we ought to understand a disease as a phenomenon related to sex and gender. In "Making Up People," philosopher of science Ian Hacking shows how a diagnosis not only gives a preexisting issue a label, it has the effect of producing people: "Who we are is not only what we did, do, and will do but also what we might have done and may do. Making up people changes the space of possibilities for personhood."[9] To make people anew, to make them "at risk," can be an act of resistance and world-making. Feminist advocates pushed to remake the science of women in a fight for material resources.

New Illness, New Formations, New Legal–Scientific Settlement

COVID further revealed the severe effects that decades of state restructuring that depleted the welfare and public health systems would have on the management of a new pandemic. As COVID surged, there was limited state/public health capacity to effectively collect and aggregate data on COVID infections for epidemiological analysis, and little to no infrastructure to roll out basic services, including COVID testing.

AIDS activism laid the groundwork for the social movement response to COVID. As before, government failure to appropriately respond to the COVID pandemic resulted in social movement activism. Activists recognized that the fight for redistribution of resources would require questioning/challenging how scientific questions were being framed by experts. They feared a legal–scientific settlement that would obscure the realities of the COVID pandemic.

The movement of Long COVID activists has parallels to the feminist struggles of the 1980s. Long COVID advocates were afflicted by a condition that was being dismissed.[10] They pushed back against the notion that COVID was a simple illness like the flu or pneumonia that would last no more than two weeks. By organizing patient groups and using first-person accounts, Long COVID sufferers published their stories in medical journals.[11] Others recognized themselves in the first-person accounts and began to make the case that they, too, had been suffering for weeks or months after a prior COVID infection. News media then began to pick up on these accounts.

Patient advocates and their allies knew that without the declaration of a medical condition that had been validated by science, necessary legal protections would not be afforded to them.[12] Being classified as having a chronic condition could help people access medical care and treatment, receive insurance coverage, and claim disability benefits. As with AIDS, the scientific and epidemiological understandings of COVID directly related to the distribution of material resources.

In November 2020, Anthony Fauci, Director of the National Institutes of Allergy and Infectious Diseases during AIDS and COVID, noted that it was time to begin exploring a new condition that describes physical consequences that continue from a COVID infection. This development reflected months of advocacy by patient groups, and a burgeoning scholarly and medical literature. Feminists, activated in this context, and with data that women report Long COVID symptoms more frequently than men, called for greater attention to women in the study of Long COVID, while cautioning against the biologization of gender through research on women.[13]

To be sure, while some stakeholders and social movements mobilized basic science and epidemiology to demand a more robust public health response, from vaccines to social welfare support, challenges to scientific authority would also come from individuals and organizations with conflicting ideological projects. Many stakeholders set out to disrupt legal–scientific settlements from mask efficacy to vaccine safety and reliability by claiming the preservation of liberty and freedom. Their redistributionist impulse diverged from advocates who sought more state services and care. Corporate entities, like Delta Airlines, sought to boost business. It worked to rewind the ten-day quarantine period to five days and sought to reduce postinfection isolation times to address worker shortages and keep individuals traveling.[14] Along with other players, and against the flight attendants' union, it lobbied the CDC to change the rules around quarantine and isolation.[15] Masking was portrayed by some activists as an act of state overreach and control, despite evidence that face coverings effectively prevented disease transmission.[16] A successful campaign to challenge public health authority seemed inspired by a desire to galvanize voters in the name of liberty and freedom. It is still not possible to assess the true impact of these rule shifts: Did more people contract COVID? Did more people die from COVID? As various actors step into fray, scientific uncertainty produces opportunities to legally govern in a way that redistributes the losses and gains of a crisis.

Though this book focuses on how feminists utilized science and epidemiology in service of law reform for women's health during AIDS, the reality is that competing projects to remake scientific and epidemiological settlements long predate COVID as well. In the early 2000s, for example, the George W. Bush administration directed the CDC to emphasize the failure rates of condoms and the positive role of abstinence in stopping the spread of HIV and sexually transmitted infections (STIs).[17] There were political benefits to pushing this perspective: It justified providing greater resources to the faith-based organizations who were willing to work on an abstinence-only agenda and sated the appetites of social conservatives who long advocated for abstinence.

These fights to disrupt legal–scientific settlements, either from the left or the right, have all been similarly erased from narratives of disease management that foreground apolitical scientific discovery. The occlusion of the political contributes to the contemporary sensibility that the politics of scientific disruption that are taking place during COVID are a new phenomenon and that they are only counterproductive to scientific and social progress.

The World Health Organization pronounced the COVID pandemic over on May 5, 2023. Though bodies no longer pile up in freezers near major city hospitals in the United States, the virus continues to travel rapidly from person to person. As this book is published, some newspapers continue to publish weekly death counts. Most of the world remains unvaccinated and many people continue to fall sick. In January 2023, a *New York Times* headline announced that "scientists see a diminished threat" in the newest surge of COVID cases. "We are in good shape," an expert on COVID reassured readers. A few paragraphs later the article offers a statistic without comment: 1,200 people die of COVID each week. This is not a viral state of nature; it is the outcome of a legal–scientific settlement that distributes disability and death.

HIV also continues to spread. Forty years into AIDS, public health institutions have yet to declare that the epidemic is over. There is no vaccine or cure. Alarming statistics tell a troubling story: As of 2023, 17 percent of the South African population aged 15–49 are testing positive for HIV. In the United States, one in two gay Black men will be diagnosed with HIV in his lifetime and girls aged thirteen to nineteen constitute the majority of new AIDS cases.

We await the next pandemic even as we cannot escape the current ones. Each impending public health crisis brings new legal–scientific settlements. Social movements, with competing political and material interests, will continue to challenge the notion that law and science reflect the deepest commitment to reason. The outcomes of these struggles will dictate who will survive and how.