

# INTRODUCTION

.....

IN HER HANDS tells the story of women who fought the state neglect of their health-care needs alongside the state intervention into their lives during the HIV/AIDS epidemic. When the health crisis of AIDS (acquired immunodeficiency syndrome) first emerged in the United States in the early 1980s, doctors, scientists, and public health professionals overlooked women in the response to a novel disease that they first associated with white, gay men. Throughout the decade, as the acknowledgment that women could contract the human immunodeficiency virus (HIV), the virus that causes AIDS, and die from it grew, women became vulnerable not only to a fatal new disease but government policies that threatened their health and rights. Women living with HIV/AIDS constantly navigated the tension between needing to access state-funded services and needing to protect themselves from state interference, as state recognition easily tipped to state coercion. State interference always

coexisted with state neglect to shape the experiences of women with HIV/AIDS.

In 1979, scientists discovered cases of immunodeficiency disorders in men.<sup>1</sup> Nearly three years passed before physicians began noticing similar symptoms in women, often after the infants and children of these women began getting sick.<sup>2</sup> As the US Centers for Disease Control and Prevention (CDC)—the federal public health agency responsible for addressing disease outbreaks—began receiving reports of the disease among groups who did not report male homosexuality, scientists expanded their conception of who AIDS affected, sorting the reported cases into four “at risk” groups: homosexual and bisexual males, heroin users, Haitians, and hemophiliacs.<sup>3</sup> What became known as the “4-H” club largely attributed a person’s vulnerability to infection to their sexual identity or, if Haitian, their perceived foreignness. Attributing risk to racial and sexual identity and associated behaviors, the 4-H categories gave the impression that the differing rates of AIDS among diverse racial, ethnic, sexual, and social groups arose not from the systemic factors that impact a person’s health but—in line with the advancing neoliberal politics of the period that shifted responsibility for addressing social problems from the state to private citizens—an individual’s supposedly “deviant” behavior.<sup>4</sup>

Women scholars mobilized to critique the resulting coverage that rendered some women invisible and others hyper-visible in the epidemic and which perpetuated existing sexist and racist tropes of certain women as the “carriers” of disease to men and children. Evelyn Hammonds, a Black lesbian feminist and historian of science, explained that the media’s association of Black women’s risk with sex work and drug use continued the stereotyping of all Black women as inherently immoral that dated back to slavery.<sup>5</sup> As the cultural theorists Paula Treichler and Cindy Patton similarly observed, the vilification of Black and Latina women as the “vectors” of HIV, rather than as individuals requiring treatment and care for themselves, contrasted with the sym-

pathetic portrayal of white, middle-class women as “inefficient” and “incompetent” transmitters of the virus who became sick through circumstances seemingly beyond their control.<sup>6</sup> Treating AIDS as a disease predominantly among those in stigmatized “risk groups,” the Reagan administration, which came to power as the epidemic began devastating communities across the United States in the early 1980s, intervened to regulate the lives of marginalized groups already vulnerable to attack from the new government without mounting the robust, systematic, and egalitarian political and public health response required to meet the crisis. Racism, sexism, homophobia, and classism coalesced to blunt the government response to HIV/AIDS.

Like other scholars who have examined the discriminatory effects of diseases, Hammonds predicted that society’s understanding of HIV/AIDS would determine “who lives and who dies.”<sup>7</sup> Just as Ronald Reagan and other conservative lawmakers maligned Black women who used state aid as “welfare queens” and those requiring state support as the crack mothers of crack babies to justify their anti-welfare, tough-on-crime agenda, the assumption that AIDS mostly affected apparently deviant women similarly legitimized simultaneously neglectful and discriminatory AIDS policy.<sup>8</sup> The media’s simultaneous objectification and marginalization of women dovetailed with the CDC’s initial refusal to acknowledge women’s symptoms as indicators of HIV, which led to misdiagnosis and early death, and denied women access to lifesaving housing, disability, and medical services and benefits. At the same time, the designation of multiply marginalized HIV-positive women—those whose identities and social status placed them at the intersection of more than one form of discrimination with limited access to traditional power structures, and who therefore experienced HIV as what Celeste Watkins-Hayes described as an “injury of inequality”—as unfit mothers by some lawmakers, journalists, and public health officials, fueled the assumption that HIV-positive women should not have children, which led to interventions that undermined their health and rights.<sup>9</sup>

As the early work of Hammonds and other feminist intellectuals attest, women did not accept mistreatment passively. They rejected and subverted harmful stereotypes and demanded that officials and communities center their collective needs and demands within the multifaceted response to AIDS. Women employed various strategies and tactics, from media campaigns and direct-action protests to class-action lawsuits, and organized across multiple settings, from prison cells to the courts. *In Her Hands* tells the story of women who, in the life and death context of the new epidemic, fought to save each other's lives. The question of how, when, and on what terms they succeeded in securing state recognition for the sake of accessing nondiscriminatory state support animates this book.

Focusing on the underappreciated impact of AIDS on women and their role in framing the fight against the disease, *In Her Hands* centers women in both the history of the AIDS epidemic and the broader history of the twentieth- and twenty-first-century United States. Shifting the focus of the history of HIV/AIDS in the US both chronologically and thematically, it chronicles women's struggle against the disease from the early 1980s to the present day and explores five distinct, yet overlapping, arenas of women's activism related to the epidemic: transmission and recognition, reproductive justice, safer sex campaigns for women who have sex with women (WSW), the carceral state, and the economics of health-care access around HIV prevention and treatment.<sup>10</sup> Centering women within the AIDS epidemic and concurrent political debates, *In Her Hands* opens avenues to explore the relationship between the state and women's status in modern America.

The examples of activism by multiply marginalized women unable to leverage race and class privilege to access health and social services in the same way as some white, gay men highlight the numerous, mutually reinforcing forms of discrimination in US politics. The privilege of whiteness failed to protect women like Joan Baker, a lesbian woman who died of AIDS in 1993, from experiencing government

neglect on account of her gender and sexual identity. While men with relative class and race privilege also encountered debilitating discrimination as a result of the deepening homophobia of this period, the women whose stories are the subject of this book often came second to men in terms of setting AIDS policy, receiving health care, and accessing new health technologies.<sup>11</sup> Women like Baker found it even more difficult to access equal treatment and care when they rejected the politics of respectability that demanded they adhere to strict standards of normative social and sexual behavior to win sympathy and support.

The historian Evelyn Brooks Higginbotham coined the term “respectability politics” in 1993 to signify how Black women in the Progressive era modified their behavior to counter harmful stereotypes of them as hypersexual and uncivilized. Instead, they presented themselves as polite and pure, seeking to conform to ideals of middle-class whiteness, heterosexuality, and femininity to win acceptance from, and assimilation into, mainstream society.<sup>12</sup> Throughout the twentieth century, people on the margins of society similarly adhered to and manipulated dominant notions of respectable behavior in their fight for equality, freedom, and rights, including—with the outbreak of AIDS in the 1980s—women with HIV. Nonetheless, unlike singly oppressed groups that sometimes downplayed aspects of their identities to win legitimacy in and beyond the AIDS crisis, multiply marginalized women often chose not to place their arguments in a framework of racialized and gendered respectability politics out of the necessity of their interventions and political choice.<sup>13</sup> For instance, the safer sex materials of the Lesbian AIDS Project (LAP), which outlined in explicit detail nonnormative sexual practices between women, reflected the group’s dual agenda to save lives and promote pro-sex lesbian erotics. Like Black feminist scholars such as Hammonds and Cathy Cohen, who critiqued discriminatory representations of Black women with HIV in the 1980s and 1990s, multiply marginalized women were alert to the impact of inequality that informed their demand for political

change and justice.<sup>14</sup> In challenging the terms on which those in power considered their lives worthy of sympathy and state support, women's AIDS activism often embodied Cohen's theory of transformative queer politics—one in which those on the margins of state-sanctioned, white, middle-class heterosexual society rejected dominant sexual norms.<sup>15</sup> While this book primarily focuses on women's experiences of and resistance to HIV/AIDS, it also acknowledges that women and men on the margins of respectability often worked in coalition to challenge the power structures fueling the discriminatory effects of HIV/AIDS.

Race, class, gender, health status, and positionality to power therefore shaped whether people fought for specific gains to tackle HIV/AIDS or petitioned for transformative justice. Like men who experienced AIDS alongside the structural oppressions with which it converged, multiply marginalized women fought for transformative changes that both addressed the roots of inequality, such as universal health care and prison abolition, and treated AIDS as one health crisis among many. As the prisoner-rights advocate Judy Greenspan articulated, women AIDS activists in prison fought not for more money to fund “unworkable prison medical systems” but to end mass incarceration.<sup>16</sup> Moreover, with limited access to elite power structures, they struggled to not only access existing services but change the terms of that access, free from prescription and risk. Activists' ability to secure distinct wins, such as expanding the CDC's AIDS definition and gaining access to experimental research, underscores Beatrix Hoffman's conclusion about different health-care movements throughout the twentieth century, namely, that people found it easier to win changes that did not challenge the governing principle in America that health care is a privilege and not a right.<sup>17</sup> The challenges they faced in realizing an alternative, more just, and humane vision of society also reflected the political moment that saw public health become increasingly privatized and politicized at the onset of the AIDS crisis.

AIDS emerged at a moment of political backlash to women's rights, including the right to plan for, terminate, or bring a pregnancy to term. After the US Supreme Court upheld a woman's constitutional right to abortion in the 1973 case *Roe v. Wade*, conservatives immediately mobilized to overturn the decision. Establishing that a fetus is a human being with moral and legal rights equal to a woman became central to their strategy. Immediately after the *Roe* decision, conservative members of Congress began introducing statutes and amendments to the constitution declaring that life began at conception, thereby equating abortion with murder.<sup>18</sup> As attempts at a national ban on abortion failed, antiabortion activists pursued other options, passing in 1976 the Hyde Amendment, which banned the use of Medicaid to fund abortions.<sup>19</sup> As Congress succeeded in making abortion less accessible to low-income women, the language of fetal rights began informing abortion restrictions at the state level.<sup>20</sup> The fight to establish fetal personhood also advanced with the "war" on drug use, which in the 1980s disproportionately impacted communities of color, as medics began testing and reporting to law enforcement mostly pregnant Black and Native American women suspected of using substances that allegedly harmed their fetuses.<sup>21</sup> The same argument that the state should intervene to protect fetuses from the behaviors of supposedly "irresponsible" women, and society from the financial and social costs of providing for the care of sick and apparently "undesirable" children, similarly legitimized and overlapped with the testing, reporting, and punishment of HIV-positive women in connection with their pregnancies. *In Her Hands* adds AIDS to the battle over reproductive justice, which centers on the right to both have and to not have children.

The assault on reproductive justice symbolized the punitive turn that accompanied the advance of neoliberalism in American politics at the end of the twentieth century. In the 1970s, lawmakers proposed competing visions of the causes of and solutions to the challenges facing the country following the social, economic, and political upheavals

of the previous decades. Those calling to cut welfare support for the supposedly “nonworking” poor tapped into deep-seated racial and gender prejudices that attributed poverty and social unrest in certain racial communities to their perceived pathology, especially the apparent shortcomings of single, non-white women. Instead of addressing the deep-seated inequalities that underpinned social disparities by, for example, investing in public health care, conservative policy makers shifted the responsibility of supporting marginalized communities from state agencies to private organizations and the white, heterosexual, middle-class, male-headed nuclear family that they framed as the regulator of acceptable private behavior. The shrinking of the welfare state, and emphasis on the family and private sector as the guarantors of public order, did not signal a reduction in government size, capacity, or will. Instead, the state “mutated” and “redeployed” its administrative power, increasing funding to law-enforcement agencies and building new prisons to survey and punish those seen to have violated the strict standards of normative behavior prescribed by the rising “family values politics” of the period.<sup>22</sup> With the retrenchment of the welfare state and expansion of the carceral state that underpinned the development of neoliberalism in the late twentieth century, conservative lawmakers framed the state as the “protector” of “innocent” citizens from the supposedly “immoral” lifestyles of those who fell outside the bounds of normative society, including—from the 1980s onward—marginalized women with HIV.<sup>23</sup> *In Her Hands* reveals the contradictory nature of neoliberalism, with its proponents advocating for nongovernmental action while implementing laws and policies that reach into the most intimate parts of people’s lives. It joins a body of scholarship that uses HIV/AIDS as a lens to explore how, when, why, and to what effect the state decided to flex its administrative power at the close of the twentieth and onset of the twenty-first century.<sup>24</sup>

With the power to direct where money goes and how it is spent, successive Republican governments since the 1980s have used federal

funding as a wedge to advance a health agenda that undermines women's sexual rights and reproductive freedoms both at home and abroad, keeping the health of women—especially those reliant on state aid—precarious in the process.<sup>25</sup> The fact that women of color disproportionately rely on public coverage means that the persistent political assault on public health care and women's nonprofit treatment spaces, as detailed in this book—seen recently in the actions of President Donald Trump to limit the scope of the Affordable Care Act (ACA) of 2010 and reform Title X of the Public Health Service Act—impacts women of color particularly negatively.<sup>26</sup> Affording medications is also more difficult without health coverage. The ability of the pharmaceutical industry to set and raise drug prices free from government regulation has also put lifesaving HIV prevention and treatment medicine beyond the reach of many.<sup>27</sup> Just as Keeanga-Yamahtta Taylor showed that housing policies aimed at profit reproduced and reinforced racial discrimination in the postwar period, the profiteering of the pharmaceutical industry that became increasingly politically protected with the advance of neoliberalism in the 1980s and 1990s has similarly compounded existing health inequalities, resulting in disproportionately adverse health outcomes for women of color.<sup>28</sup> While this book is primarily concerned with examining the underexplored story of how women confronting HIV/AIDS in the US accepted, navigated, resisted, and subverted state power, it also acknowledges that many of these struggles transcended national borders and places them in a global context. The neoliberal response to HIV/AIDS that put profit before public good threw into sharp relief whose life the state valued and considered worthy of support.

Speaking to the politicization of fetuses and children in the 1980s, the state responded more readily to women's needs and demands when they involved infants and children. The pattern of the state responding proactively to women as mothers played out in the early medical and political response to HIV, as many diagnosticians and doctors first