

A NOTE ON METHODS

This book is a genealogy of AIDS told through the stories of feminist social movement actors that engaged in restructuring our understanding of AIDS and its outcomes.¹ I take genealogy to mean an “analysis that traces how contemporary practices and institutions emerged out of specific struggles, conflicts, alliances, and exercises of power, many of which are nowadays forgotten.”² How has the past created the conditions for our contemporary management of disease? My attempt, in keeping with scholarly undertakings of genealogy, is to show how transformations in law and science interact with and are coproduced by contingent and shifting claims of individuals and institutions.³ In the tradition of science and technology studies and critical legal theory, from where I draw much inspiration for this book, I offer an account which seeks to show how taken-for-granted ideas – science and law as objective and neutral sites of fact-finding – are disrupted to shift the material distribution of resources.⁴

This book is focused on social movement activism on AIDS from approximately 1982 until 2013. Though I am not a historian, much of my work for this book was conducted in the archive. Though for this project, the “archive” must be defined broadly. Not only did I visit traditional archives, cultivated by libraries and nonprofits, including the Harvard Schlesinger Library, Lesbian Herstory Archive, the Smithsonian Museum, Office of NIH (National Institutes of Health) History and Stetten Museum, the ACT-UP Oral History Project, and the Gay Men’s Health Crisis, I also spent time in the personal files of activists and advocates. I visited their offices and photocopied personal files and photographed pictures of memorabilia and images. I wanted to be sure I could capture the moments I was writing about with all of their complexity and contingency.

Because this book centers law and legal struggle, I have also read and drawn on hundreds of legal documents, including regulations of administrative agencies, party briefs filed to the court, amicus briefs,

court decisions, congressional hearings, regulations, and supplementary information to regulations spanning the course of at least fifty years.

I supplemented the archival and legal research with oral interviews with lawyers, members of ACT-UP, people living with HIV, and government officials. Where accounts of a moment in time differed between an individual account and one on paper, I have noted that in the footnotes. I also relied on the oral histories banks including the ACT-UP Oral History Project and the NIH Oral History Project.

When I began this book I was struck by the invisibility of women in the broader scholarly and public understandings of HIV and AIDS. In most accounts, AIDS was and is a disease of gay men, one that was bravely fought and won. A reader could be forgiven for walking away from this literature thinking that there were few women involved in AIDS activism and that AIDS was now a thing of the past. This sat in stark contrast to the world I was witnessing in which women and girls around me had HIV in large numbers, they had contracted HIV in recent years, they were still struggling to access basic care and treatment.

Contributing to the erasure of women from historical accounts of AIDS is their absence from the archive: Many women did not have the infrastructure necessary to save documents as they tried to survive. Most women diagnosed with HIV in the 1980s have now died; they are unable to give oral histories or tell their own stories. In writing this account, I often reflected on the work of Saidiya Hartman, who has written about absence of Black women and queer people, in the archive, the invisibility of people we knew existed, for whom we can only find “fragments of a life”.⁵

In this genealogy of AIDS, I have tried to recover those stories that are lost or are quickly being forgotten, to tell a history of AIDS that shows how the entire legal structures, of nations, of cities, of agencies, and the scientific rationalities of risk that underpin them, were transformed by groups of unexpected people whose activism reverberates through the global response to HIV and AIDS.

