Candidate number: 846006

Out of the Silence:

Women Protesting the AIDS Epidemic, 1980-2020

Emma Day

Pembroke College

Thesis Submitted for the degree of Doctor of Philosophy in History
at the University of Oxford

Supervised by

Dr Mara Keire and Professor Stephen Tuck

Hilary Term 2020

Word count: 94,578

Contents

1. Acknowledgements…….4

2. Abbreviations……..6

3. Short Abstract……10

4. Long Abstract……11

5. Prologue: The Beginning……..15

6. Introduction……...20

6.1. Scope and Structure……26

7. Chapter 1: AIDS is a Disaster, Women Die Faster: Women, Transmission, and the Early Response to AIDS, 1980 – 1993……...51

7.1 Discovering AIDS in Women……..….55
7.2 The Coercive State……...65
7.3 Fighting for Women's Sexual Rights……...72
7.4 Feminist Public Health Alternatives……....77
7.5 Shaping an International Platform……82
7.6 Conclusion……89

8. Chapter 2: Of Childbearing Age: The Reagan Administration, AIDS, and Reproduction, 1981 – 1994……...91

8.1. Maternal Concerns……..95
8.2. Dr Koop and the AIDS Question……..101
8.3. The Anti-Abortionist Surgeon General, and the Bureaucrat……....109
8.4. Boarder Babies with AIDS……...124
8.5. Conclusion……135

9. Chapter 3: Women's Fight for Safer Sex in the Culture Wars, 1989 – 1995…..……...137

9.1. Challenging the "Myth of Immunity" ……..142
9.2. The Safer Sex Handbook for Lesbians……....157
9.3. Do You Know Where Your Daughters Are?……....163
9.4. Conclusion……....176

10. Chapter 4: The Fire Inside: Women Protesting in Prison, 1990 – 2005……..…...179

10.1. Inside Prison Walls……184
10.2. Through Prison Walls……198
10.3. From the Cell to the Court……..212
10.4. Conclusion……..223

11. Chapter 5: The Fight to End AIDS, 1996 – 2020……..…….227

11.1.In the Hands of Women……..231
11.2. Preparing Women for the Prevention Agenda…….....244
11.3. Saving Title X in the Fight to End AIDS…….....254
11.4. Taking on Big Pharma…….....260
11.5. Conclusion……..273

12. Conclusion: New Beginnings……..276

13. List of Illustrations……..293

14. Bibliography……294

Acknowledgements

Researching and writing this thesis has been a life changing experience. I have many people to thank in supporting me along the way.

I could not have come this far without the wisdom, support, and guidance of my supervisors, Dr Mara Keire and Professor Stephen Tuck. I have learned so much from them both. Thanks also to my examiners, Professor Gareth Davies and Professor Jonathan Bell. Their expert insights and suggestions for taking the project forward have already proved invaluable.

I am grateful to Pembroke College, Oxford, and the British Arts and Humanities Research Council (AHRC) for funding my DPhil for three years. I am also grateful to the Rothermere American Institute (RAI) and Oxford History Faculty for funding my fourth year. The RAI especially has not only provided me with financial support over the years, but an academic home. Thanks to the other institutions and organisations that have awarded me funding in order to travel to the United States in order to write and carry out primary research.

My work has benefitted greatly from feedback I received at conferences organised by the Organization of American Historians (OAH), the Historians of the Twentieth Century United States (HOTCUS), the British Association of American Studies (BAAS), the Society for the History of Women in the Americas (SHAW), the American History Graduate Seminar at the RAI, Pembroke College, the Queen's College Queer Studies Symposium, the Centre for Gender, Identity and Subjectivity (CGIS), the Queer Studies Network, the History Faculty's LGBT History Month Workshop and others.

Thanks to my friends and family, especially my parents and Jamie, whose love and support has sustained me throughout.

Finally, I would like to acknowledge the women whose activism is the subject of this thesis and whose stories have compelled me to keep going. This thesis is dedicated to them.

Abbreviations

ACA—Patient Protection and Affordable Care Act

ACE—AIDS Counseling and Education

ACE-OUT—AIDS Counseling and Education on the Outside

ACLU—American Civil Liberties Union

ACTG—AIDS Clinical Trials Group

ACT UP—AIDS Coalition to Unleash Power

AHCA—American Health Care Act

AIA—Abandoned Infants Assistance Act

AIDS—Acquired Immunodeficiency Disease

AmFAR—American Medical Foundation for AIDS Research

APHA— American Public Health Association

ARC—AIDS Related Complex

ART—Antiretroviral Therapy

A.W.A.R.E—Association of Women for AIDS Research and Education

AZT—Azidothymidine

BWHBC—Boston Women's Health Book Collective

cART—Combination Antiretroviral Therapy

CCWF—Central California Women's Facility

CCWP—California Coalition for Women Prisoners

CDC—Centers for Disease Control and Prevention

CDCR—California Department of Corrections and Rehabilitation

CHANGE—Center for Health and Gender Equality

CIW—California Institute for Women

COYOTE—Call Off Your Old Tired Ethics

CSWPC—Coalition to Support Women Prisoners at Chowchilla

CWAA—Convicted Women Against Abuse

DES—Diethylstilbestrol

DHHS—Department of Health and Human Services

DOJ—Department of Justice

DPC—Domestic Policy Council

ELISA—Enzyme-linked immunosorbent assay

ERA—Equal Rights Amendment

FDA—Food and Drug Administration

FHI—Family Health International

GCM—Global Campaign for Microbicides

GMHC—Gay Men's Health Crisis

GRACE—Gender, Race, and Clinical Experience

HOOK—Hands Off Our Kids

HPTN—HIV Prevention Trials Network

HRT—Hormone Replacement Therapy

ICC—Incarceration Children's Center

ICU—In-Patient Care Unit

IPM—International Partnership for Microbicides

IUD—Intrauterine device

LAP—Lesbian AIDS Project

LC—Library of Congress

LHA—Lesbian Herstory Archive

LSPC—Legal Services for Prisoners with Children

MMWR—Morbidity and Mortality Weekly Report

MTA—Medical Technician Assistants

MTN—Microbicide Trials Network

N-9—Nonoxynol-9

NIAID—National Institute of Allery and Infectious Diseases

NIH—National Institute of Health

NJWAN—New Jersey Women and AIDS Network

NLM—National Library of Medicine

NOW—National Organization for Women

NYPL—New York Public Library

OCA—Oregon Citizens Alliance

PACHA—Presidential Advisory Council on HIV/AIDS

PEPFAR—President's Emergency Plan for AIDS Relief

PHS—Public Health Service

PLACE—Pleasanton AIDS Education and Counselling Programme

PrEP—Pre-exposure prophylaxis

PROVE—Parents for the Restoration of Values in Education

R&D—Research and Development

SHIPP—Sustainable Health Center Implementation PrEP Pilot Study

SHU—Special Housing Unit

SPLC—Southern Poverty Law Centre

SSA—Social Security Administration

SSI—Supplementary Security Income

TAF—Tenofovir alafenamide fumarate

TDF—Tenofovir disoproxil

UCSF—University of California San Francisco

UMDMJ—University of Medicine and Dentistry of New Jersey

UNAIDS—United Nations Program on HIV/AIDS

VSPW—Valley State Prison for Women

WAC—Women's Action Coalition

WAN—Women's AIDS Network

WARN—Women and AIDS Resource Network

WHAM!—Women's Health Action Mobilization

WHO—World Health Organization

ZDV—Zidovudine

Short Abstract

For women in the United States, the fight against AIDS has for the past forty years been a fight for autonomy, equality, and rights. During this period, activists have not only had to deal with the health crisis of the AIDS epidemic, but have had to battle with the US government and the pharmaceutical industry over the question of who is deserving, who is responsible, and who counts in the epidemic. These questions were particularly important in the 1980s, a decade during which ideas about who deserved welfare and support were at the top of the political agenda. Since then, the treatment environment has changed, but women's struggle to make themselves count as human beings, free from prescriptions about their bodies and lives, has continued to drive their activism in the twenty-first century.

This thesis traces the aims and actions of women struggling for autonomy, equality, and rights in the wake of the AIDS epidemic across a range of scenarios in the United States. It also centres women's fight for autonomy, equality, and rights in the AIDS epidemic within a series of other major historical developments from the 1980s to the present day; namely, abortion politics, the culture wars, the carceral state, and the US healthcare market. It shows that the efforts of the women in this thesis to carve out an autonomous space was not only a right in theory, but became a matter of life and death in the wake of the epidemic. Moreover, this thesis argues that the origins and evolution of activism in the twentieth and twenty-first century United States lie within a persisting tradition of women organising for control over their bodies and lives.

Long Abstract

For women in the United States, the fight against AIDS has for the past forty years been a fight for autonomy, equality, and rights. During this period, activists have not only had to deal with the health crisis of the AIDS epidemic, but have had to battle with the US government and the pharmaceutical industry over the question of who is deserving, who is responsible, and who counts in the epidemic. These questions were particularly important in the 1980s, a decade during which ideas about who deserved welfare and support were at the top of the political agenda. Since then, the treatment environment has changed, but women's struggle to make themselves count as individuals, free from prescriptions about their bodies and lives, has continued to drive their activism into the twenty-first century.

This thesis traces the aims and actions of women struggling for autonomy, equality, and rights across a range of scenarios in the United States. It also centres women's fight for autonomy, equality, and rights in the AIDS epidemic within a series of other major historical developments from the 1980s to the present day; namely, abortion politics, the culture wars, the carceral state, and the US healthcare market. It shows that the efforts of the women in this thesis to carve out an autonomous space was not only a right in theory, but became a matter of life and death in the wake of the epidemic. Moreover, this thesis argues that the origins and evolution of activism in the twentieth and twenty-first century United States lie within a persisting tradition of women organising for control over their bodies and lives.

The title of this thesis, *Out of the Silence: Women Protesting the AIDS Epidemic*, signifies the ways in which the dominant response to the AIDS epidemic at the time and its reconstruction in the historiography has often obscured the role and treatment of women. Moreover, it

highlights the ways in which women have broken the silence around women and AIDS in their twin demands for medical equality and bodily autonomy from the 1980s to the present day. It is a thematic study that moves chronologically through the epidemic's forty-year history. In particular, *Out of the Silence* charts five major themes, on transmission and recognition; motherhood, AIDS, and reproductive autonomy; lesbian organising and the culture wars; incarceration; and gender, economics, and healthcare through time. Each of these five themes maps onto five chronological, though overlapping, chapters, examining how they intersected with the history of AIDS in women. Looking through the forty-year history, each chapter focuses on a distinct gender-specific issue related to women and AIDS.

Chapter one of *Out of the Silence* shows that the discovery that AIDS could pass sexually between men and women and between women and their infants increased doctors' urgency to diagnose AIDS in women, with motherhood becoming the crux of women's inclusion in the epidemic. When public health officials began recognising the problem of AIDS in women, they also put on women the onus of preventing Human Immunodeficiency Virus (HIV, the virus that causes AIDS) transmission both sexually and reproductively. In response, a range of feminist activists sought to broaden the scope of how women counted in public health. By the mid-1990s, they had succeeded in shaping a broader, more inclusive public health consensus that treated women as human beings and not just as mothers.

Nonetheless, the AIDS epidemic emerged in the United States in an era of conservative politics and converged with an already high stakes debate about abortion and women's right to have children when and whether they chose. Chapter two shows how, despite the success of activists in shaping a broader public health consensus, the issue of reproductive rights remained dominant within political debate in the 1980s, with the scientific discovery of AIDS

in women complicating the existing debate. The public health and caring initiatives of Faye Wattleton, the President of Planned Parenthood Federation of America, in the most unexpected of alliances with Surgeon General C. Everett Koop, and First Lady Barbara Bush, offered ways to address the problem of perinatal transmission without compromising women's reproductive choices.

Chapter three explores how the debate over women and AIDS shifted to lesbian women in the 1990s, partly as a result of the onset of the culture wars, and partly as a result of the approval of the use of the antiretroviral azidothymidine (AZT) drug in pregnancy in 1994 which ended many of the political debates over prevention, abortion, and motherhood. Focusing on the activism of pro-sex radical Amber Hollibaugh and her organisation, the Lesbian AIDS Project (LAP), the chapter examines the impact that AIDS had on conceptions of what it meant to be a lesbian woman, especially as it related to sexual practice, and the impact that AIDS had on shaping the relationship between queer women and the state in this period.

The culture wars of the 1990s coincided with the rise of the carceral state. Chapter four outlines how the ramped-up carceral state of the late twentieth-century did not adequately prepare to deal with the reproductive and chronic illnesses that are common in women, and how women in prison struggled to access treatment through health delivery systems that were designed with men in mind. The chapter explores how women responded to this situation and attempted to achieve structural reform, drawing on the consciousness raising tradition of the feminist healthcare movement and culminating in the 1995 *Shumate v. Wilson* court case.

Chapter five shows that, whether in or out of prison, women with HIV have had to navigate a healthcare system that is made and modelled by and for men. From the mid-1990s onward, without the prospect of a vaccine or cure on the horizon, feminist scientists began developing an HIV prevention product that was woman-controlled and initiated. Tied to ongoing gendered problems with pharmaceutical research and development, private companies have not seen enough profit potential in a women-focussed transmission tool meaning that promising products have stalled due to a lack of money to take them forward. Instead, the drugs that have made it to market have been designed and marketed with a male focus and have often failed to reflect the needs of women. This situation has only been compounded by a right-wing, partisan health agenda that greatly restricts women's access to treatment, an agenda that activists are currently working to resist.

In summary, this thesis foregrounds the hopes, fears, energy, and dynamism of women organising against the AIDS epidemic in the United States. Doing so, it reframes how we write broader histories, not just of the fight for equality in the context of the AIDS epidemic but of other aspects of US history. What follows is a history of the power of women's persistent organising, even when the power of entrenched authority was against them.

The Beginning

On a wet afternoon in September 1979, 37-year-old Rick Wellikoff visited the office of Dr Linda Laubenstein at the New York University Medical Center for blood studies. Dr Laubenstein, who specialised in haematology and oncology, noted the generalised rash on Wellikoff's skin that resisted treatment, and the enlarged lymph nodes all over Wellikoff's body.

Laubenstein asked Kenneth B. Hymes, M.D., a fellow haematologist and colleague at the Medical Center, to take a look at Wellikoff. She showed him a large purple lesion on the back of the patient's neck and asked him what he thought it was. Hymes said he thought it was a pimple. Laubenstein told him that the biopsy showed Kaposi's sarcoma. Named after a nineteenth century Hungarian dermatologist, doctors knew Kaposi's sarcoma as an extremely rare, purple-coloured tumour that appeared most often on the skin of elderly men, and in patients who had received an organ transplant and who were severely immune-suppressed. The following week, when Hymes began his rotation at the Veterans Administration Hospital, he saw another young man with a purple lesion on his leg. Hymes called Laubenstein and arranged for a biopsy. The report confirmed Kaposi's sarcoma.

Two years later, in February 1981, Alvin E. Friedman-Kien, M.D., a professor of microbiology and dermatology and colleague of Laubenstein at the New York Medical University Center, saw two more cases of Kaposi's sarcoma. Friedman-Kien reached out to Laubenstein, and the two doctors exchanged stories of their patients who were all men, all gay, and who had all died. Unlike the previous iterations of Kaposi's sarcoma that were slow-

growing, the new cases appeared all over the bodies of these young men.[1] Laubenstein suggested that they do case histories.[2] Led by Dr Laubenstein and Dr Hymes, the March 1981 issue of the journal the *Lancet* reported eight cases of Kaposi's sarcoma in a cohort of men in New York, in the first article linking what would become known as AIDS with this rare form of cancer.[3]

Doctors on the other side of the country began noting the sudden appearance of an extremely rare pneumonia called *Pneumocystis carinii* pneumonia. Until this point, *Pneumocystis* pneumonia, like Kaposi's sarcoma, had only occurred in humans when the immune system was severely weakened. The disease had most commonly affected cancer patients whose chemotherapy treatment had decimated their white blood cells. In June 1981, investigators at the University of California, Los Angeles reported five cases of *Pneumocystis* pneumonia in young, previously healthy gay men to the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia. All the men had other unusual infections as well, indicating that their immune systems were not working. Two had already died by the time the report was published. The first official reporting of what became known as the AIDS epidemic happened that same month, when the CDC used its weekly journal, the *Morbidity and Mortality Weekly Report* (MMWR), to publish reports of an increased occurrence of Kaposi's sarcoma and *Pneumocystis carinii* pneumonia.[4]

[1] Siddhartha Mukherjee, *The Emperor of all Maladies: A Biography of Cancer* (London: Fourth Estate, 2011), 315.
[2] Meryl Gordon, "The Woman Who 'Discovered' AIDS: permanently crippled by childhood polio, Dr. Linda Laubenstein became a pioneer in treating AIDS cases—the patients nobody wanted," *McCall's*, May 1993, 110; Jeanie Russell Kasindorf, "The Plague," *New York Magazine*, undated; box 1, fol. Clippings & Articles, Linda Laubenstein papers, Arthur & Elizabeth Schlesinger Library on the History of Women in America, Harvard University, Boston. Hereafter: Schlesinger Library.
[3] Kenneth B. Hymes et al., "Kaposi's sarcoma in homosexual men—a report of eight cases," *Lancet* 318, no. 8247 (March 1981): 598-600, accessed February 2020, available at: https://doi.org/10.1016/s0140-6736(81)92740-9
[4] CDC, "*Pneumocystis* Pneumonia—Los Angeles," *MMWR* 30, no. 21 (June 5, 1981): 250-252.

By the late summer, the CDC had reported on additional cases of *Pneumocystis* pneumonia, Kaposi's sarcoma, cryptococcal meningitis, and rare lymphomas in New York City, San Francisco, and Los Angeles. Each of these diseases destroyed a person's immune system, leaving them susceptible to rare cancers and opportunistic infections that left the body incapable of defending itself.[5]

After receiving the initial reports, in June 1981 the CDC formed a Task Force on Kaposi's sarcoma and Opportunistic Infections to identify risk factors and to develop a case definition for national surveillance.[6] By the end of the year, the CDC had recorded a cumulative total of 270 reported cases of a near total collapse of the immune system among young gay men, and 121 of the patients had already died.[7]

The initial prevalence of the new disease in gay men led one writer for the *Lancet* to call it "gay compromise syndrome." The Public Health Service (PHS) originally called it "GRID" (gay-related immunodeficiency). Others called it "gay cancer".[8]

In her book *Dangerous Pregnancies*, historian Leslie J. Reagan has shown that the discovery of a disease is an ongoing process. A scientific discovery has to be researched and confirmed, questioned, and discovered again to be believed. Discovering a disease also entails identifying, defining, and naming that disease as well as winning acceptance of the evidence

[5] Opportunistic infections only cause diseases when a person's immune system is severely weakened.
[6] Harry W. Haverkos and James W. Curran, "The Current Outbreak of Kaposi's Sarcoma and Opportunistic Infections," *CA: A Cancer Journal for Clinicians* 32, no. 6 (November/December 1982): 330, accessed February 2020, available at: https://doi.org/10.3322/canjclin.32.6.330
[7] Avert, "History of HIV and AIDS Overview," last updated October 10, 2019, accessed February 2020, https://www.avert.org/professionals/history-hiv-aids/overview#footnote5_ig9n74j
[8] Mukherjee, *The Emperor of all Maladies*, 316.

and the name. This process was evident not only in German measles, Reagan's case study, but in AIDS, especially in the 1980s.[9]

First identified in 1979 as a disease in white, gay men, researchers at the CDC used the term Acquired Immune Deficiency Syndrome (AIDS) for the first time in September 1982, separating reported AIDS cases into groups based on four risk factors—homosexual or bisexual males, intravenous drug users, Haitians, and haemophiliacs.[10]

During this period, scientists assumed that AIDS was a uniquely male disease. In fact, it was a disproportionately male disease. But, in this moment of scientific discovery, silence pervaded the possibility that women could become infected too. It would take nearly three more years after scientists began reporting on immunodeficiency in men before scientists began noticing that women were also contracting the disease, and they often did so only after their infants and children began getting sick.

This was the case for Elizabeth Glaser. Doctors learned that Glaser, an actress from New York, had HIV after her daughter, Ariel, began suffering from a series of unexplained illnesses and tested positive for HIV in 1985. Working backwards, scientists realised that Glaser had contracted the virus through a blood transfusion in 1981 and had transmitted the virus to Ariel through breastfeeding.[11]

[9] Leslie J. Reagan, *Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America* (Berkeley: University of California Press, 2010), 22.
[10] CDC, "Current Trends Update on Acquired Immune Deficiency Syndrome (AIDS)—United States," *MMWR* 31, no. 37 (September 24, 1982): 507-508, 513-514. The risk group categories remained until 1986.
[11] Randy Kennedy, "Elizabeth Glaser Dies at 47; Crusader for Pediatric AIDS," *New York Times*, December 4, 1994.

Following reports of immunodeficiency in infants in 1982, scientists had begun publishing studies speculating that whatever was causing immunodeficiency in men and infants was infecting women too.[12] In the following months and years, as doctors realised that the viral agent that caused AIDS could pass sexually between men and women and between women and their infants, a range of actors and activists raced to keep up with the latest scientific findings in order to assert credible knowledge about its risks and reach, and to shape the official response. In particular, women activists worked to influence how the state responded to AIDS not only as a male disease or a disease that affected women as mothers, but as an epidemic that impacted women as human beings with complex healthcare needs who mattered.

The 43 reports that the CDC received of previously healthy women who had developed *Pneumocystis carinii* pneumonia and other opportunistic infections between 1981 and 1983 would challenge the agency, the US government, and society at large to reconceptualise the disease as one not only of men, but of women.[13] By the end of the decade, rates of AIDS cases among women continued to climb. Despite the noted increase, scientists did not know exactly how many women were affected, as the diagnosis of AIDS depended on a person having symptoms that were based on how Human Immunodeficiency Virus (HIV, the virus that causes AIDS), manifested in men.[14] Understudied scientifically in the early 1980s, and understudied historiographically since, out of this silence, women protested the AIDS epidemic.

[12] CDC, "Unexplained Immunodeficiency and Opportunistic Infections in Infants—New York, New Jersey, California," *MMWR* 31, no. 49 (December 17, 1982): 665-667.
[13] CDC, "Epidemiologic Notes and Reports Immunodeficiency among Female Sexual Partners of Males with Acquired Immune Deficiency Syndrome (AIDS)—New York," *MMWR* 31, no. 52 (January 7, 1983): 697-8.
[14] Between 1981-2000, the percentage of women with AIDS rose from 8.0% to 22.6%. See Table 1. "Number and percentage of persons with AIDS, by selected characteristics and period of report—United States, 1981-2000," in CDC, "HIV and AIDS—United States, 1981-2000," *MMWR* 50, no. 21 (June 1, 2001): 43-434.

Introduction

Five women join hands and form a closed circle as they crouch down on the floor, all their faces bar one obscured by the angle of the camera hovering above them. Four out of the five women in the photograph hide their faces, wishing to remain anonymous. "If you show my face, I will lose my kids," one woman says.[15]

Documentary photographer Ann P. Meredith took this picture in the summer of 1987 at a women's support group for HIV/AIDS in San Francisco. For over twenty years, Meredith had documented the lives and culture of women, lesbians, and girls. But now, concerned about the growing health crisis of AIDS, she assumed that she would need to broaden her focus to engage with male subjects in order to document the epidemic. In March 1987, Meredith attended her first workshop on AIDS at the Eye Photography Gallery in San Francisco along with several other photographers. Within fifteen minutes of the workshop, she realised that women were also living and dying with AIDS.

A participant at the workshop on AIDS stood up and recounted the story of Meredith Miller, a woman, and a mother who had the disease. They spoke of how Miller was forced to give up her two children and was struggling as one of the few known infected women. Meredith Miller was not alone. Newspapers reported on cases where social services had removed children from a woman's custody following a child abuse or child neglect charge, while others gave up their children for adoption.[16] Journalists related the stories of women who

[15] Ann P. Meredith, "If You Show My Face, I Will Lose My Kids," 1987, from the collection *Until That Last Breath!*, Ann P. Meredith papers, box 45, fol. 3, Schlesinger Library.
[16] Cynthia Chris, "Reviews: Women and AIDS," newspaper unknown, Summer 1989, 1; Kay Longcope, "A wide-angle view of AIDS: Exhibit sheds light on women, the epidemic's 'invisible population,'" *The Boston Globe*, April 12, 1990; Photographs by Ann Meredith, "Until That Last Breath: Women with AIDS," 23, Meredith papers, box 45, fol. 47.3, Schlesinger Library.

themselves worried, "Who will take care of the children?" if they were to die.[17] Rhoda, a single mother of three, who had felt lucky when she had found an experimental drug trial that accepted women, tried not to worry that researchers had belatedly discovered that the drug caused vaginal cancer in mice, but did worry about what might happen to her children in the future.[18] Despite this coverage, Meredith Miller was the first woman Ann Meredith had heard of who had the disease. Her story prompted Meredith to commit to contributing to the fight against AIDS by curating a visual document of women who she would later describe as the "hidden population" of the epidemic.[19] She planned to create a travelling exhibition of portraits and words gathered from oral history and videotaped interviews that would enable her to relate each woman's story to a public audience. But first, she had to meet the women and achieve their consent to be photographed.

One day in 1987, Meredith received a phone call. A young woman called Joan Baker had contacted her to let her know that she could take her picture. Baker was twenty years old and had tested positive for HIV two years earlier in 1985. The next day, Meredith visited Baker at a hotel in the Tenderloin district of San Francisco where she was living. She listened as Baker explained that her family had rejected her when they learned of her HIV-positive status. Baker then left her home in Riverside, California, to move to the Bay Area, seeking a surrogate community.[20] After photographing Baker, Ann Meredith began connecting with other HIV-positive women through the burgeoning feminist networks that women had begun developing in response to the epidemic. She met women through the first AIDS support group for women available at the San Francisco AIDS Foundation under the direction of

[17] Suvan Geer, "Exhibit Gives AIDS Human Face—a Woman's," *Los Angeles Times*, July 28, 1989, Meredith papers, box 45, fol. 47.3, Schlesinger Library.
[18] Chris Norwood, "The Silent Minority," *The Discovery Channel*, February 1990, 13, fol. Subject file: AIDS, Lesbian Herstory Archive, Brooklyn, New York. Hereafter: LHA.
[19] Ann P. Meredith, "Essay Untitled," undated, 14, box 45, fol. 47.1, Meredith papers, Schlesinger Library.
[20] Meredith, "Essay Untitled," 14.

Catherine Maier, and with Gloria Weissman, a lesbian programme officer for the National Institute of Drug Abuse, whom she accompanied on trips to Mexico and Puerto Rico. She fundraised with the San Francisco Commission on the Status of Women and worked with Nancy Shaw, a feminist activist who in 1983 co-founded the Women's AIDS Network (WAN), one of the first women's AIDS advocacy groups in the country. It was through these networks that Meredith found women courageously willing to have their pictures taken, and in some cases, the pictures of their partners, families, and friends.[21]

Meredith's first exhibition, *Until that Last Breath!*, opened at the Somar Gallery in San Francisco in 1988 to a crowd of 1,500, and travelled the country, showing in Los Angeles, New York, New Haven, and Boston. The travelling exhibition combined portraits, videos, and text. The wall text adjacent to the photographs detailed each woman's age, diagnosis, sexual preference, sometimes multiple modes of HIV transmission, and the latest statistics on the epidemic. She printed statements women had written about the impact that AIDS had had on their lives alongside their portrait to explain how an individual image related to the broader history of the disease. Pictures showed women navigating their illness alongside protests they attended that challenged the gender inequities that exacerbated the epidemic in women. In "The Chemo Room will be Closed on Thursday," 32-year-old Paulette, a black lesbian and mother of two, sits at a women's waiting room in the San Francisco General Hospital. The portrait of a 30-year-old woman and her five-year-old son taken in San Francisco featured on the front cover of the 1993 edition of the magazine *The Body Positive*

[21] Letter from Ann P. Meredith to Nancy Shaw, July 27, 1987, 1-2, box 2, fol. 538, Call Off Your Old Tired Ethics (Coyote) records, Schlesinger Library.

as an example of the "changing portrait" of AIDS.[22] By the end of the tour, most of the women Meredith had originally photographed had died.[23]

Presenting women, with their children, in hospital, at home, and in the streets, the pictures did not announce illness in the way that the concurrent portraits of emaciated men did.[24] The physical manifestations of HIV virus in women are often invisible, with death frequently coming from opportunistic infections such as cervical cancer and other, related non-visible diseases. Instead, the portraits and statements offered a multiplicity of perspectives that challenged viewers to consider what it was like to live as a woman with a life-threatening illness. Meredith's photographs had the intersectional ability to include multiple narratives that reflected the reach of the crisis across race, gender, sexuality, region, and class. The presentation of some in their role as mothers provided a powerful alternative to the growing mainstream portrayal of women, not as sick individuals in their own right, but as a risk factor for HIV in children.

This thesis moves the historical understanding of the effect that the AIDS epidemic has had on women's bodies and lives beyond their exclusion from the initial medical response and the important role women played in the epidemic as the supporters and carers of gay men. Instead, it historicises a series of other gender-specific issues that women have struggled against since the early 1980s, some of which Ann P. Meredith documented in her photographs. These are issues that have persisted into the twenty-first century and that are less well-documented and still understudied today: motherhood, and the restrictions placed

[22] Jameson Currier, "The Images of AIDS: A Changing Portrait," *The Body Positive*, December 1993, 9-16, box 45, fol. 47.3, Meredith papers, Schlesinger Library.
[23] Meredith, "Essay Untitled," 13-14.
[24] See, for example, photographer Alon Reininger's portraits of Kenneth Meeks. See Unprocessed PR 13 CN 1992:149 and Unprocessed PR 13 CN 1991:022. Library of Congress Prints and Photographs Division Washington, D.C. Hereafter: LC.

on an HIV-positive woman's reproductive autonomy; the persistent under-representation of women in biomedical research; the challenge of having to navigate health delivery systems that are made by and for men; gender-based violence; sexual silencing in the public sphere; and the criminalisation of HIV transmission.

Just as Meredith noticed and brought the stories of HIV-positive women to the public sphere in the 1980s and early 1990s, this thesis centres women in the AIDS epidemic and concurrent political debates. Doing so, it takes a new approach to the study of the epidemic and the broader history of the late twentieth and early twenty-first century United States; revealing the underappreciated impact of AIDS on women and their role in framing the fight against the disease. The title of this thesis, *Out of the Silence: Women Protesting the AIDS Epidemic*, signifies the ways in which the dominant response to the AIDS epidemic at the time and its reconstruction in the historiography has often obscured the role and treatment of women. Moreover, it highlights the ways in which women have broken the silence around women and AIDS in their twin demands for medical equality and bodily autonomy from the 1980s to the present day.

Feminist critic Rebecca Solnit has observed that silencing takes many forms, and that violence against women is often against their voices and their stories. For Solnit, to speak, to be heard, and to be believed are crucial parts of membership in a community and a society.[25] In the wake of the AIDS epidemic, public health professionals, members of the US

[25] Rebecca Solnit, "A Short History of Silence," in *The Mother of All Questions: Further Feminisms* (London: Granta Publications, 2017), 19, 20. For more on the theory of silence and silencing, see Michel Foucault, *The Will to Knowledge: The History of Sexuality: Volume One* (London: Penguin Books, c. 1976, 1998); Audre Lorde, "The Transformation of Silence into Language and Action," in *Sister Outsider: Essays and Speeches* (Berkeley: Crossing Press, c. 1984, 2007), 40-44; Kevin Quashie, *The Sovereignty of Quiet: Beyond Resistance in Black Culture* (New Brunswick, N.J.: Rutgers University Press, 2012); Kate Manne, *Down Girl: The Logic of Misogyny* (New York: Oxford University Press, 2018), 4-7, 18; Andrea Dworkin, "I Want a Twenty-Four-Hour Truce During Which There is No Rape (1983)" in *Last Days at Hot Slit: The Radical Feminism of Andrea Dworkin*, ed. Johanna Fateman and Amy Scholder (California: MIT Press, 2019), 200, 201.

government, and others in positions of authority repeatedly failed to listen to women and take their health concerns seriously. The fact that women frequently had to make space for themselves within systems that were built for men also fits with feminist author Caroline Criado Perez's assessment that designers, whether in government policy or medical research, frequently default to male and, as a result, "routinely forget to accommodate the female body."[26]

Women did not passively accept those in power actively denying their experiences or remaining ignorant of their needs either. They forced other groups to address their risk and put their needs at the centre of the multifaceted response to the political and human crisis of AIDS. Anger sat at the heart of their movement. As Michele Russell, a case manager at the Center for Special Studies at New York Hospital, explained in 1993, "The women talk a lot about anger. Sometimes they are angry at the powerlessness they feel in the face of the disease. However, often out of this anger also comes hope and a desire to overcome the disease."[27] Theirs was no small version of anger. It was a deep and rational anger, sustaining their fight for a more equitable form of humanity. Anger, like silencing, manifests itself in different ways. Often mixed with friendship and love, women's protests against AIDS happened differently in different spaces and places in response to the unique situations that women found themselves in. Their fight to "count"—to have their voices heard and, most importantly, their needs recognised and acted upon—was constant throughout.[28]

---

[26] Caroline Criado Perez, *Invisible Women: Exposing Data Bias in a World Designed for Men* (London: Chatto & Windus, 2018), 32.
[27] Michele Russell, "A Place Where Anything Can Be Said," *LAP Notes: Lesbian AIDS Project at GMHC. / New York, NY: Lesbian AIDS Project-GMHC*, Issue no. 1 (April 1993): 4, Boston Women's Health Book Collective records. Hereafter: (BWHBC), Schlesinger Library.
[28] For more on the uses of anger, see Adrienne Rich, "The Phenomenology of Anger" in *Driving into the Wreck: Poems 1971-1972* (New York: W. W. Norton & Company, Inc. c.1973, 2013), 27-29; Audre Lorde, "The Uses of Anger: Women Responding to Racism," in *Sister Outsider*, 124-133; Deborah Gould, *Moving Politics: Emotion and ACT UP's Fight Against AIDS* (Chicago: University of Chicago Press, 2009), 233-235; Rebecca Traister, *Good and Mad: The Revolutionary Power of Women's Anger* (New York: Simon & Schuster, 2018); Soraya L. Chemaly, *Rage Becomes Her: The Power of Women's Anger* (New York: Simon & Schuster, 2018).

Scope and Structure

Out of the Silence is a thematic study that moves chronologically through the epidemic's forty-year history. In particular, it charts five major themes, on transmission and recognition; motherhood, AIDS, and reproductive autonomy; lesbian organising and the culture wars; incarceration; and gender, economics, and healthcare through time. Each of these five themes maps onto five chronological, though overlapping chapters, examining how they intersected with the history of AIDS in women. Looking through the forty-year history, each chapter focuses on a distinct gender-specific issue related to women and AIDS. I do this to show how women responded to the AIDS epidemic even as they navigated four other major historical developments from the 1980s to the present day: the anti-abortion politics of the Reagan era, the political conservatism of the culture wars in the 1990s, the expansion of the carceral state, and the profiteering of the pharmaceutical industry in the twenty-first century. Throughout, I argue that state interference often co-existed with state neglect. In their twin demands for bodily autonomy and medical equality, women living with HIV fought both for the right to self-determination and the right to state recognition for treatment.

Throughout the thesis, I examine how these themes change over time and address the recurring tensions that existed between women needing recognition and resisting interference; between pragmatic public health and ideology; and between compassion and coercion. Specifically, I show that in the 1980s, the compassionate conservatism and pragmatic public health response to the problem of AIDS in women from individuals such as Surgeon General C. Everett Koop, counterbalanced many of the political right's more punitive, systemic proposals to bring the epidemic under control. With the onset of the culture wars and the expansion of the carceral state in the 1990s, the state's approach to

women's health, and the health of women with HIV specifically, became increasingly punitive—and remains so today.

In the next part of this introduction, I will consider the five key themes that are central to this thesis—transmission and recognition; motherhood, AIDS, and reproductive autonomy; lesbian organising and the culture wars; incarceration; and gender, economics, and healthcare. These themes ground each chapter in turn. I will reflect on how the history of AIDS in women intersects with a series of other fields of twentieth-century US history in order to argue that a number of the larger political, institutional, and structural changes from the 1980s onwards can only be understood fully in their relation to the grassroots and federal responses to the problem of AIDS in women. In analysing late-twentieth and early twenty-first century US history through the lens of HIV and putting women at the centre of a narrative from which they are often excluded, I place the AIDS epidemic, and in particular women's resistance to it, at the centre of US politics, culture, and society and trace its prominence to the present day.

Transmission and Recognition

Chapter one explores how, in the 1980s, a range of activists fought for doctors to diagnose AIDS in women so that women would become eligible for treatment. Although scientists recorded the first cases of immunodeficiency in men in 1979, doctors were slower to diagnose AIDS in women. The chapter shows that the discovery that the so-called "AIDS agent" could pass sexually between men and women and between women and their infants increased doctors' urgency to diagnose AIDS in women, and motherhood became the crux of women's inclusion in the epidemic. In response, activists sought to broaden the scope of how

women counted in public health, not just as mothers but as women with complex health needs who mattered. But, as public health officials began recognising the problem of AIDS in women, they also began putting on them the onus of preventing HIV transmission both sexually and reproductively. Drawing on the records of feminist groups such as the Boston Women's Health Book Collective (BWHBC) and Call Off Your Old Tired Ethics (COYOTE) at the Schlesinger Library and the AIDS Coalition to Unleash Power (ACT UP) Women's Caucus located at both the Lesbian Herstory Archive and at the Tamiment Library at New York University, I show how feminists created their own public health publicity that emphasised the need to recognise women for treatment and to protect women's sexual autonomy and reproductive rights. By the mid-1990s, after taking their fight to secure recognition and protect women's autonomy to the largest international platform on AIDS, activists had succeeded in shaping a broader, more inclusive public health consensus that treated women as human beings and not just as mothers.

One of women's biggest obstacles to medical recognition came from the fact that the diagnosis of AIDS depended not only upon demonstrated infection with HIV—the presence of antibodies to the virus in a person's blood—but also upon how those infected became sick. Because the first people recorded with immunodeficiency were almost exclusively men, the CDC's official case definition of AIDS was based on how the disease manifested in that group. This meant that widely reported gynaecological conditions specific to women, such as pelvic inflammatory diseases, vaginal yeast infections, and cervical cancer, were not officially counted as manifestations of HIV infection. A common assumption among doctors

that women were not an at-risk population resulted in regular misdiagnosis, and women on average died faster of AIDS-related conditions than men.[29]

Some of the earliest scholarship on women in the AIDS epidemic addressed how the medical exclusion of women erased them from discussions of AIDS in society at large. In her seminal essay, "AIDS, Homophobia, and Biomedical Discourse" (1987), and subsequent publications, cultural studies scholar Paula Treichler argued that the media's relative silence on the topic of women and AIDS in the early 1980s followed the assumption of most scientists that AIDS was a "gay disease" and a "male disease."[30] It was no wonder that many people, including women themselves, were unaware that AIDS affected them too. Janet Mitchell, an African American physician working at the Harlem Hospital Centre in New York observed in 1988, "no matter how many conferences on HIV infection one attends or how many articles one reads, the space allotted to women is minuscule."[31] For feminist writer Gena Corea, the assumption that AIDS was a disease of men meant that by the end of the 1980s, it had also become an "invisible epidemic" in women.[32] A number of feminist scholars and commentators writing in the 1980s and early 1990s therefore noted how the medical professions' slowness to trace the disease in women resulted in the failure on the part of society at large to address women's needs in terms of their own risk and unique problems.[33]

[29] Chris Norwood, "Alarming Rise in Deaths: Are Women Showing New AIDS Symptoms?" *The Ms. Reporter*, July 1988, 66-67, box 139, fol. 10, BWHBC records, Schlesinger Library.
[30] Paula A. Treichler, "AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification," *October* 43 (Winter, 1987): 48-49; Treichler, *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS* (Durham: Duke University Press, 1999), 42.
[31] Janet Mitchell, "What About the Mothers of HIV infected Babies?" *NAN Multi-Cultural Notes on AIDS Education and Service* 1, no. 10, April 1988: 1, fol. Subject file: AIDS, LHA.
[32] Gena Corea, *The Invisible Epidemic: The Story of Women with AIDS* (New York: HarperCollins, 1992).
[33] Evelynn Hammonds, "Race, sex, AIDS the construction of 'Other,'" *Radical America* 20, no. 6 (September 1987): 28; Cindy Patton, *Last Served?: Gendering the HIV Pandemic* (London: Taylor & Francis Group, 1994); Beth E. Schneider and Nancy E. Stoller, *Women Resisting AIDS: Feminist Strategies of Empowerment* (Philadelphia: Temple University Press,1995); Nancy Goldstein and Jennifer L. Manlowe, *The Gender Politics*

Existing accounts of the epidemic still tend to focus on the history of AIDS in men, although some historians have also recognised the role of women in the epidemic. Addressing the contribution women made to the grassroots response to AIDS as the supporters and carers of gay men has been central to this historiographical shift. For example, in his book *The Dividends of Dissent* (2008), historian Amin Ghaziani observed that many lesbian women were motivated to act because of the personal ties of friendship and feelings of political solidarity with the lesbian and gay movement.[34]

Other historians, in particular Jennifer Brier, Tamar W. Carroll, and Jonathan Bell have addressed the contributions of the women who led the campaign to change the CDC's official definition of AIDS to include opportunistic infections pertaining to women in the 1980s.[35] They showed how women in the organisation ACT UP launched a class-action lawsuit against the Social Security Administration (SSA) and the CDC and pressured the National Institute of Health (NIH) to organise a conference on women and AIDS following a sit-in they carried out at the institute. Carroll also showed how members of ACT UP New York built coalitions with the Women's Health Action Mobilization (WHAM!), who both challenged the shame some in society made people with AIDS feel, and connected this to the shame some in society made women feel for expressing their sexuality and controlling their

of HIV/AIDS in Women (New York: New York University Press, 1997); Nancy E. Stoller, *Lessons from The Damned: Queers, Whores, and Junkies Respond to AIDS* (Routledge: New York, 1998).

[34] Amin Ghaziani, *The Dividends of Dissent: How Conflict and Culture Work in Lesbian and Gay Marches on Washington* (Chicago: The University of Chicago Press, 2008), 83. See also, Sara M. Evans, *Tidal Wave: How Women Changed America at Century's End* (New York: The Free Press, 2003), 208. For a more recent account of the work straight women did in the epidemic as the advocates of gay men, see activist Victoria Noe's study, *Fag Hags, Divas and Moms: The Legacy of Straight Women in the AIDS Community* (Chicago: King Company Publishing, 2019).

[35] Jennifer Brier, *Infectious Ideas: U.S. Political Responses to the AIDS Crisis* (Chapel Hill: University of North Carolina Press, 2009), 171-179; Tamar W. Carroll, *Mobilizing New York: AIDS, Antipoverty, and Feminist Activism* (Chapel Hill: University of North Carolina Press, 2015), 131-135; Jonathan Bell, "Rethinking the 'Straight State': Welfare Politics, Health Care, and Public Policy in the Shadow of AIDS," *Journal of American History* 104, no. 4 (March 2018): 947.

reproduction.[36] The efforts of these activists culminated in the CDC's expansion of its AIDS definition to include cervical cancer in 1993, which granted more women access to benefits and services. As sociologist Alexis Shotwell observed, women's struggle for inclusion in the CDC definition was also in part a battle for historical memory. Since HIV-positive women were not counted as having AIDS when they died, they were not remembered as having died of AIDS.[37]

In this chapter, I build on the existing historiography by showing that not only did diagnosticians and federal agencies put the onus of recognition on women, but public health agencies also placed the onus of preventing transmission both sexually and reproductively on women, even at a time when the small-state, anti-abortion politics of the Reagan era limited women's autonomy and rights. Doing so, I show that activists' goal in the first decade and a half of the epidemic was to make women count in healthcare in a way that did not also undermine their sexual autonomy and reproductive rights. Whereas chapter one is broad, focusing on the discovery of AIDS in women, and the tension that emerged between public health agencies and activists seeking to address that discovery, the second chapter narrows to the issue of AIDS and reproduction in government policy. The next chapter will show that despite the success of activists in shaping a broader public health consensus in the post-1989

[36] Carroll, *Mobilizing New York*, 20. Carroll did not, however, consider how the onset of the AIDS epidemic directly impacted the reproductive choices of women living with HIV and AIDS.
[37] Alexis Shotwell, "'Women Don't Get AIDS, They Just Die From It': Memory, Classification, and the Campaign to Change the Definition of AIDS," *Hypatia* 29, no. 2 (Spring 2014): 521. Shotwell's article is part of a rich literature on the politics of memory in the AIDS crisis. See, in particular, Marita Sturken, *Tangled Memories: The Vietnam War, the AIDS Epidemic, and The Politics of Remembering* (Berkeley: University of California Press, 1997); Ann Cvetkovich, *An Archive of Feelings: Trauma, Sexuality, and Lesbian Public Cultures* (Durham, North Carolina: Duke University Press, 2003); José Muñoz, *Cruising Utopia: The Then and There of Queer Futurity* (New York: NYU Press, 2009); Charles E. Morris III, *Remembering the AIDS Quilt* (East Lansing: Michigan State University Press, 2011); Christopher Castiglia and Christopher Reed, *If Memory Serves: Gay Men, AIDS, and the Promise of the Queer Past* (Minneapolis: University of Minnesota Press, 2012); Thomas R. Dunn, *Queerly Remembered: Rhetorics for Representing the GLBTQ Past* (Columbia: University of South Carolina Press, 2016).

period, the issue of reproductive rights remained dominant within political debate in the 1980s, with the scientific discovery of AIDS in women complicating the existing debate.

Motherhood, AIDS, and Reproductive Autonomy

The AIDS epidemic emerged in the United States in an era of conservative politics and converged with an already high stakes debate about abortion and women's right to have children when and whether they chose. Throughout the twentieth century, the outbreak of diseases that caused congenital disorders raised questions about who had the jurisdiction to determine whether a woman could plan for, terminate, or continue a pregnancy. As the historical literatures on AIDS and abortion are typically treated separately, the question of how the discovery of AIDS in women again threatened women's reproductive autonomy—especially within government policymaking—is underexplored.[38] Chapter two argues that the public health agendas of Faye Wattleton, the President of Planned Parenthood Federation of America, in alliance with Surgeon General C. Everett Koop, and the caregiving initiatives of First Lady Barbara Bush, offered ways to address the problem of perinatal HIV transmission without compromising women's reproductive choices.

[38] For histories that deal with the government response to AIDS, especially within the Reagan administration, see Randy Shilts, *And the Band Played On Politics, People, and the AIDS Epidemic* (New York: St. Martin's Press, 1987), 600; Cathy J. Cohen, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics* (Chicago: University of Chicago Press, 1999), 83-84; William B. Turner, "Mirror Images: Lesbian/Gay Civil Rights in the Carter and Reagan Administrations," in *Creating Change: Sexuality, Public Policy, and Civil Rights*, ed. John D'Emilio and William B. Turner (New York: St. Martin's Press, 2000), 5; Ghaziani, *The Dividends of Dissent*, 77; James T. Patterson, *Restless Giant: The United States from Watergate to Bush v. Gore* (New York: Oxford University Press), 179-182; Sean Wilentz, *The Age of Reagan: A History, 1974-2008* (New York: HarperCollins, 2008), 185-186; Brier, *Infectious Ideas*, esp. chapter 3, 78-121; Doug Rossinow, *The Reagan Era: A History of the 1980s* (New York: Oxford University Press, 2015), 129-34, 212-215. For histories that deal with abortion politics in the same period, see Rickie Solinger, *Abortion Wars: A Half Century of Struggle, 1950-2000* (Berkeley: University of California Press, 1998); Solinger, *Pregnancy and Power: A Short History of Reproductive Politics in America* (New York: New York University Press, c. 2005, 2019); Sara Dubow, *Ourselves Unborn: A History of the Fetus in Modern America* (New York: Oxford University Press, 2011) esp. chapters 4 and 5, 112-152, 153-183; Mary Ziegler, *After Roe: The Lost History of the Abortion Debate* (Cambridge, Mass.: Harvard University Press, 2015); Charlie Jeffries, "Adolescent Women and the Antiabortion Politics in the Reagan Administration," *Journal of American Studies* 52, no. 1 (2018): 193-213.

Historians writing on the nexus between reproduction and disease have examined how the political response to diseases that caused birth defects have had different implications for women's autonomy and rights. According to historian Allan M. Brandt, beginning in the Progressive era—a period that roughly spanned the 1890s to the 1920s—after physicians and reformers highlighted the damaging reproductive effects of syphilis and gonorrhoea, many states passed laws mandating premarital and prenatal testing for venereal diseases.[39] These laws intended to save both babies from a series of health complications and the nation from the cost of caring for seriously ill children, but they were most forcefully directed at women and African Americans, with their implementation often grounded more in social convention and ideologies of race and respectability than epidemiological reality. In her book, *Dangerous Pregnancies* (2010), historian Leslie J. Reagan showed that the political and medical responses to the German measles outbreak of the 1960s were similarly rooted in ideas about race, class, and respectability, but served to liberalise attitudes about abortion. According to Reagan, in the presence of foetal defects, many doctors, religious leaders, and politicians came to see the necessity of abortion and the cruelty of forcing women to bear sick children. Reagan argued that the perception that German measles mostly affected white, seemingly well-meaning, middle-class families helped to shift attitudes, making abortion appear more respectable.[40]

Conservatives in Ronald Reagan's administration who wanted to prevent the birth of HIV-positive infants while limiting women's access to safe and legal abortion called for the same measures that the state had used to address diseases in the past to combat HIV. As addressed

[39] Allan M. Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880* (New York: Oxford University Press, c.1985, 1987), 150. See also, Ruth Clifford Engs, *The Progressive Era's Health Reform Movement: A Historical Dictionary* (Connecticut: Greenwood Publishing Group, 2003), 345.
[40] Reagan, *Dangerous Pregnancies*, 6.

in an extensive historical literature on reproductive justice, a woman's control over her body is as much about the right to have children as to choose an abortion. In practices that dated back to slavery, the United States government regularly worked to control and police the reproductive lives of non-white women. Throughout the twentieth century, the federal government continued experimenting on the bodies of Black, Latina, Native American, and low-income women for the sake of reproductive control, only stopping in the 1970s after organisations such as Southern Poverty Law Centre (SPLC) exposed these inhumane practices.[41] The emergence of AIDS in the 1980s once again threatened the reproductive choices of women in the United States, as some public figures began calling for the mandatory mass testing of all women of "childbearing age," with the aim to advise those who tested positive to abort their pregnancies, or to refrain from conceiving in the future. In the context of an administration working to outlaw abortion, women's health advocates worried that the goal of preventing the birth of infants who might carry HIV could only be achieved if HIV-positive women never had children.

Chapter two combines government papers with medical records, memoirs, and news reports to show how the public health pragmatism of Surgeon General Koop, in surprising alliance with Faye Wattleton and Planned Parenthood, counterbalanced a number of the extreme measures that some on the political right proposed to force or coerce HIV-positive women into making unwanted decisions about their pregnancies for the sake of preventing perinatal transmission. Instead, Koop and Wattleton's promotion of condoms and safer sex education

[41] Dorothy Roberts, *Killing The Black Body: Race, Reproduction and the Meaning of Liberty* (New York: Vintage Books, 1999); Jennifer M. Nelson, *Women of Color and the Reproductive Rights Movement* (New York: NYU Press, 2003); Solinger, *Pregnancy and Power*; Harriet Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonia Times to the Present* (New York: Doubleday, 2006); Mary Ziegler, "The Framing of a Right to Choose: Roe v. Wade and the Changing Debate on Abortion Law," *Law and History Review* 27, no. 2 (Summer, 2009), 281-330; Danielle L. McGuire, *At The Dark End of the Street: Black Women, Rape, and Resistance—A New History of the Civil Rights Movement from Rosa Parks to the Rise of Black Power* (New York: Alfred A. Knopf, 2010); Tina K. Sacks, *Invisible Visits: Black Middle-Class Women in the American Healthcare System* (New York: Oxford University Press, 2019).

as a means to prevent unwanted pregnancies, and endorsement of abortion as a medically viable option in cases where women were already pregnant and wanted the procedure, kept women's reproductive options open.

Moreover, I show that in her support of AIDS Houses founded to care for the rising number of infants born with HIV and AIDS in the 1980s and early 1990s, First Lady Barbara Bush offered a solution to the question of what to do with infants not prevented nor aborted but born with AIDS. In providing a third way to those who opposed abortion but wanted to deal with the reality of perinatal transmission, Bush embodied the traditional, caregiving strand of the Republican party. While historians of the "New Right" have often homogenised the politics of conservative women in the Reagan and Bush eras as anti-feminist—embodied in the anti-Equal Rights Amendment (ERA) activism of Phyllis Schlafly—Bush instead represented the Republican women who wanted to maintain women's reproductive autonomy in this period.[42] Working with Wattleton and Planned Parenthood, Koop's two-fold approach to AIDS and abortion, and Bush's third way, served to protect women's reproductive choices in the wake of the AIDS epidemic. A focus on their actions reveals the fundamental realignment that took place within both political parties and political factions in this period, especially over women's reproductive rights.

The approval of the use of the antiretroviral drug azidothymidine (AZT) in pregnancy in 1994 essentially resolved the issue of mother-to-child transmission. While the overlapping

[42] First introduced in Congress in 1923, the Equal Rights Amendment (ERA) is a proposed amendment to the US Constitution designed to guarantee equal legal rights for all American citizens, regardless of sex. For more on the activism of Phyllis Schlafly, see William C. Berman, *America's right turn: from Nixon to Clinton* (Baltimore, Md.: Johns Hopkins University Press, 1998), 9, 19, 79; Donald T. Critchlow, *Phyllis Schlafly and Grassroots Conservatism* (Princeton, N.J.: Princeton University Press, 2005); Lisa McGirr, *Suburban Warriors: The Origins of the New American Right* (Princeton, N.J.: Princeton University Press, c. 2001, 2015), 233-234; Laura Kalman, *Right Star Rising*: *A New Politics, 1974-1980* (New York: W. W. Norton & Company, Inc., 2010), 72.

politics of abortion and the issue of reproductive justice are underexplored in the historiography of the US AIDS epidemic, chapter two shows that before the introduction of treatment for HIV in pregnancy, the government could not address the issue of AIDS without also addressing the issue of abortion.[43] Moreover, although historians have outlined how the introduction of AZT marked a turning point in the treatment of HIV more generally, my research shows that the introduction of AZT also ended many of the debates over AIDS and abortion, even as the development of the culture wars intensified the ideological commitments and increased the coercive approach to women's health on the part of the state.[44] It is to this that I turn in chapter three.

Lesbian Organising and the Culture Wars

The end of the Reagan era marked the beginning of the culture wars, during which some on the political right increased their attacks on LGBTQ individuals and the anti-abortion movement sought to further restrict women's access to legal abortion. As the political right did not view lesbian women's bodies as a threat to HIV in children, they instead co-opted and weaponised their educational materials—designed to overcome the lack of thorough and accessible medical information on women and HIV—as dangerous homosexual propaganda in need of censorship for the sake of symbolically protecting America's children.

[43] Historian Jennifer Brier used the Ford Foundation as a case study to address the issue of reproductive rights in the context of HIV in the Global South but did not examine how the issue of HIV in women informed the abortion debate and battle over reproductive justice for women in the United States. See Brier, *Infectious Ideas*, chap. 4, 122-155. In her book, *More Than Medicine*, historian Jennifer Nelson also briefly addressed the HIV/AIDS work of reproductive justice advocate Dázon Dixon Diallo and the Atlanta Feminist Women's Health Center. See Nelson, *More Than Medicine: A History of the Feminist Healthcare Movement* (New York: NYU Press, 2015), 157-168.

[44] For accounts of the battles between activists and the pharmaceutical industry in the development and marketing of AZT, see Gould, *Moving Politics*, 403-419; David France, *How to Survive a Plague: The Inside Story of How Citizens and Science Tamed AIDS* (New York: Alfred A. Knopf, 2016), 476; Anthony M. Petro, *After the Wrath of God: AIDS, Sexuality, and American Religion* (New York: Oxford University Press, 2015), 144.

Chapter three examines the impact AIDS had on conceptions of what it meant to be a lesbian woman in the wake of the AIDS epidemic, especially as it related to sexual practice, as well as the impact AIDS had on shaping the relationship between queer women and the state in the context of the culture wars. In the chapter, I examine how lesbian activists such as pro-sex radical Amber Hollibaugh created safer sex materials that challenged the "myth of lesbian immunity" which implied that sex between women could not transmit HIV and that self-identified lesbian women did not engage in other behaviours that put them at risk. Instead, Hollibaugh, through her organisation, the Lesbian AIDS Project (LAP), used sex education as a way to articulate a more realistic and less ideological vision of their identities that acknowledged that some women who identified as lesbian also had sex with men and used drugs. The popularity of the LAP's 1993 safer sex brochure, the *Safer Sex Handbook for Lesbians*, which was intentionally radical in tone, drew a backlash from the political right. Their campaign to censor the brochure served to silence lesbian women's right to sexual self-determination in the public sphere.

This chapter contributes to an extensive literature that charts how the categories of homosexuality and heterosexuality are not essential or fixed, but evolve over time in relation to different forces.[45] Scholars of lesbian culture have examined how the convergence of such forces as economics, labour, and scientific knowledge have shaped the social meaning of

[45] For a sampling of the historical literature on the social construction of identities and sexualities through time, see, John D'Emilio and Estelle B. Freedman, *Intimate Matters: A History of Sexuality in America* (Chicago: University of Chicago Press, c.1988, 1997, 2012); George Chauncey, *Gay New York: The Making of the Gay Male World* (New York: Basic Books, 1994); Estelle B. Freedman, "The Prison Lesbian: Race, Class and the Construction of the Aggressive Female Homosexual, 1915-1965," *Feminist Studies* 22, no. 2 (Summer 1996): 397-415; George Chauncey, "'What Gay Studies Taught the Court': The Historians' Amicus Brief in *Lawrence V. Texas*," *GLQ: A Journal of Lesbian and Gay Studies* 10, no. 3 (2004): 510; Margot Canaday, *The Straight State: Sexuality and Citizenship in Twentieth-Century America* (Princeton: Princeton University Press, 2009); Kevin Mumford, "The Trouble with Gay Rights: Race and the Politics of Sexual Orientation in Philadelphia," *Journal of American History* 98, no. 1 (June 2011): 49-72; Dan Healy, *Russian Homophobia from Stalin to Sochi* (London: Bloomsbury Academic, 2017).

lesbian identities over the course of the twentieth century, along with the terminology used to signify lesbian life. For example, scholars such as Lillian Faderman, Elizabeth Lapovsky Kennedy, and Madeline D. Davis have shown that shifts in what society has understood as lesbianism have ranged from the "romantic friendships" of women who felt passion for other women in the early twentieth century, to the butch-femme categories prominent in the working-class, lesbian bar culture at mid-century.[46] As historian Alice Echols recounted in her book *Daring to be Bad* (1989), beginning in the 1970s, a faction of lesbian-feminists who felt frustrated at their marginalised position within the broader women's liberation movement called for a movement for lesbian separatism that worked to detach sexual practice from lesbian identities.[47] Prominent members of the lesbian-feminist movement advanced the argument that women should be willing to consider other women as life as well as sexual partners in order to overcome sexual and gender oppression. This understanding of lesbian identity necessitated neither the need to have sexual relations with nor sexual attractions to other women; the choice to partner with other women was as much a political as a personal act.[48]

My analysis brings existing studies of lesbian life that chart the changing categorisation of lesbian identities throughout the twentieth century beyond the lesbian separatist movement of the 1970s, and highlights how the onset of AIDS in the 1980s drove prominent members of

[46] Lillian Faderman, *Surpassing the Love of Men: Romantic Friendship and Love Between Women from the Renaissance to the Present* (New York: Morrow, 1981); Elizabeth Lapovsky Kennedy and Madeline D. Davis, *Books of Leather, Slippers of Gold: The History of a Lesbian Community* (New York: Routledge, c. 1993, 2014)
[47] Alice Echols, *Daring to be Bad: Radical Feminism in America, 1967-1975* (Minneapolis: University of Minnesota Press, 1989), 238.
[48] Radical Lesbians, "The Woman Identified Woman Manifesto," 1970, accessed February 2020, https://www.historyisaweapon.com/defcon1/radicalesbianswoman.html; Adrienne Rich, "Compulsory Heterosexuality and Lesbian Existence," *Signs* 5, no. 4 (Summer, 1980): 631-660; Sarah Lucia Hoagland, "Lesbian Separatism: An Empowering Reality," *Sinister Wisdom* 34 (Spring 1988), 23-34, LC Periodical PS 508 W7 S54; Lillian Faderman, *Odd Girls and Twilight Lovers: A History of Lesbian Life in 20th-Century America* (New York: Columbia University Press, 1991), 218; Christina Rousseau, "Wages Due Lesbians: Visibility and Feminist Organizing in 1970s Canada," *Gender, Work & Organization* 22, no. 4 (July 2015): 364-374.

the lesbian-feminist movement, such as Amber Hollibaugh, to argue against prescriptive ideas about what it meant to be a lesbian woman. According to Hollibaugh, these ideas lent a false sense of security to some whose membership in the lesbian community led them to believe they were at low risk from HIV, regardless of their actions. Instead, Hollibaugh wanted to move away from political definitions and address lived experiences; to not focus on idealised lesbian communities in ways some in the feminist movement had done before the AIDS outbreak, but to come to terms with what women who had sex with other women were also doing, engaging in behaviours that put them beyond the boundaries of middle-class lesbian-feminism. She, along with other lesbian AIDS activists such as Joan Baker, worked to broaden the definition of the term "lesbian" to recognise not only women who self-identified as a lesbian woman, but those who engaged in sexual activities with both women and men, who asserted a sexual desire for women but did not self-identify as a lesbian, and those who may have had a sexual experience with another woman.

The efforts on the part of lesbian activists to raise lesbian women's visibility sparked a backlash from the political right, who co-opted their safer sex materials as evidence of the symbolic threat members of the LGBTQ community posed to America's children. Queer theorists such as Lee Edelman and Jack Halberstam have long addressed the power of the "protect the children" arguments on the silencing of public discussions of sexuality.[49] Queer women had evaded many of the more punitive measures directed at gay men for the sake of symbolically protecting America's children throughout much of the twentieth century.[50]

[49] Lee Edelman, *No Future: Queer Theory and the Death Drive* (Durham: Duke University Press, 2004); Jack Halberstam, *Gaga Feminism: Sex, Gender, and the End of Normal* (Boston: Beacon Press, 2012), xx. Historian Dagmar Herzog has also noted the persistence of the battles over homosexuality, especially in the context of school curricular, in the 1990s through the 2000s. See Dagmar Herzog, *Sex in Crisis: The New Sexual Revolution and the Future of American Politics* (New York: Basic Books, 2008), 83-84.
[50] Stacy Braukman, "'Nothing Else Matters but Sex': Cold War Narratives of Deviance and the Search for Lesbian Teachers in Florida, 1959-1963," *Feminist Studies* 27, no. 3 (Autumn, 2001): 555.

Historian Margot Canaday has argued that the state targeted male homosexuality more readily in the first half of the twentieth century because federal officials were slower to decide that homosexuality among women was a problem that deserved federal attention, doing so only when women became fully integrated into the military at mid-century. According to Canaday, "male perverts mattered so much to the state" in the early twentieth century "because male citizens did."[51] As scholars of gay, lesbian, and queer history such as Miriam Frank have also noted, the "protect the children" arguments gained particular prominence in the post-1960s period, when in 1977 actress Anita Bryant, under the banner "Save Our Children," launched a campaign to repeal a Florida ordinance which prohibited discrimination on the basis of sexual orientation.[52] The following year, State Senator John Briggs sponsored an ultimately unsuccessful initiative, also known as Proposition 6, seeking to prevent gay individuals or those who supported gay rights from working in public schools in the state of California.[53] Prior to the 1990s, much of the debate over lesbian lifestyles and identities had taken place within the lesbian community.[54] Now, as lesbian activists sought to raise the visibility of queer women for the sake of receiving life-saving treatment in the wake of the epidemic, and the political right reiterated the need to "protect the children," AIDS brought renewed focus to the lives and sexualities of queer women who played a central role in the culture wars.

[51] Canaday, *The Straight State*, 12-13.
[52] Dudley Clendinen and Adam Nagourney, *Out for Good: The Struggle to Build a Gay Rights Movement in America* (New York: Simon and Schuster, 1999), 299-311; Fred Fejes, *Gay Rights and Moral Panic: The Origins of America's Debate on Homosexuality* (New York: Palgrave, 2008), 110-112; Miriam Frank, *Out in the Union: A Labor History of Queer America* (Philadelphia: Temple University Press, 2014), 86-87.
[53] Craig A. Rimmerman, *From Identity to Politics: The Lesbian and Gay Movements in the United States* (Philadelphia: Temple University Press, 2002), 129-131.
[54] For more on the origins and evolution of these debates within the women's movement, see Jane Gerhard, *Desiring Revolution: Second Wave Feminism and the Rewriting of American Sexual Thought, 1920 to 1982* (New York: Columbia University Press, 2001).

Chapter three outlines how the political right punished lesbian women for not conforming to prescribed gender roles, which played out overtly with the attacks on lesbian sex education. Drawing on the feminist theory of Victoria Law, Kate Manne, and Soraya Chemaly who have similarly considered how society treats women seen to have violated societal expectations of femininity, I show that the punishment of women who did not conform to societal expectations went even further than recognised in the history of the feminist movement.[55] Shifting the focus to prison, chapter four reveals that women with AIDS were not just silenced in the public sphere but removed from it altogether.

Incarceration

The culture wars of the 1990s coincided with the rise of the carceral state. Chapter four outlines how the ramped-up carceral state of the late twentieth-century was not adequately prepared to deal with the reproductive and chronic illnesses that are common in women. As a result, women in prison struggled to access treatment through health delivery systems that were designed with men in mind. The chapter explores how women responded to this situation, setting up prison support groups that drew on the consciousness raising tradition of the feminist healthcare movement at correctional facilities such as Bedford Hills in New York. The protests of women at the Central California Women's Facility (CCWF) in Chowchilla, California, went even further than seeking to self-educate about the disease, attempting to achieve structural reform through their 1995 *Shumate v. Wilson* court case. Much of the women's ability to bring the lawsuit rested on their success in connecting with outside support. While mistreatment and death would continue largely unabated at women's

[55] Victoria Law, *Resistance Behind Bars: The Struggles of Incarcerated Women* (Oakland: PM Press, 2009), 5; Chemaly, *Rage Becomes Her*, xviii; Manne, *Down Girl*, 282.

prisons in California, *Shumate* marked a turning point in using the mistreatment of women prisoners, especially those with HIV, to call into question the inhumanity of the entire carceral system in the United States.

As a result of the field-defining work of scholars such as Michelle Alexander, an extensive literature now exists outlining how "tough on crime" laws and punishment campaigns, implemented across federal, state, and local levels from the 1980s onwards, resulted in the United States incarcerating a greater proportion of its citizens than any other country in the world.[56] Criminal justice scholars have also highlighted the racial disparities of the law enforcement strategies propping up what the federal government called its "war on drugs," and more recently on the intersections between the systemic violence against women and the expansion of a what criminal justice scholar Beth E. Richie has termed "America's prison nation."[57]

The seminal work of feminist criminal justice scholars such as Beth Richie, Victoria Law, Kimberlé Crenshaw, and Angela Davis has prompted society to focus on the problem of women's incarceration more now than ever before. Despite this shift, accounts of women protesting against AIDS in prison often received less public attention than how male

[56] Ruth Wilson Gilmore, *Golden Gulag: Prisons, Surplus, Crisis, and Opposition In Globalizing California* (Berkeley: University of California Press, 2006); Heather Ann Thompson, "Why Mass Incarceration Matters: Rethinking Crisis, Decline, and Transformation in Postwar American History," *Journal of American History* 97, no. 3 (December 1, 2010): 703-734; Michelle Alexander, *The New Jim Crow: Mass Incarceration in the Age of Colorblindness* (New York: New Press, 2012); Elizabeth Hinton, *From the War on Poverty to the War on Crime* (Cambridge: Harvard University Press, 2016).

[57] Angela Davis and Cassandra Shaylor, "Race, Gender, and the Prison Industrial Complex: California and Beyond," *Meridians* 2, no. 1 (2001): 1-25; Silja A. Talvi, *Women Behind Bars: The Crisis of Women in the U.S. Prison System* (Seattle: Seal Press, 2007); Law, *Resistance Behind Bars*, Kali N. Gross, "African American Women, Mass Incarceration, and the Politics of Protection," *Journal of American History* 102, no. 1 (June 2015): 25-33; Beth E. Richie, *Arrested Justice: Black Women, Violence, and America's Prison Nation* (New York: New York University Press, 2012). For more on Kimberlé Crenshaw's work addressing police violence against black women, see, The African American Policy Forum, "#SayHerName: Resisting Brutality Against Black Women," accessed February 2020, https://aapf.org/sayhernamereport

prisoners, prison authorities, and policymakers responded to AIDS in men's prisons and, as the field of criminal justice history continues to expand, there is a danger that the focus on men at the time will be recapitulated in the historiography.[58] Drawing on the legal records, correspondence, and newsletters of women prisoners in the Judy Greenspan papers at the LGBT Community Center and Nancy E. Stoller papers at University of California San Francisco (UCSF), chapter four contributes to the recent work on women in the criminal justice system by examining the efforts on the part of women living with HIV to reform the carceral state. Shifting the historical focus to AIDS reveals how women's organising in prison often differed to that of men. Moreover, women's prison activism is an example of the remarkable power of ordinary women, facing serious mortality issues and living in institutions cut off from networks of support, to take on entrenched power, despite what little power such women had to effect change.

Whether in or out of prison, women with HIV have had to navigate a healthcare system that is made and modelled for men. As Perez has argued, women's health will continue to suffer as long as designers in medical research take the male model of health as normative.[59] Chapter five shows that, in the twenty-first century, in a new treatment era, many of the new ways of dealing with old problems continue to perpetuate gender inequities.

Gender, Economics, and Healthcare

In chapter five, I show how, in the mid-1990s, without the prospect of a vaccine or cure on the horizon, scientists began developing new tools that could help prevent HIV infections and

[58] In the epilogue to her study of sexuality in prison, historian Regina Kunzel explained that studies of AIDS in prison in the 1980s "nearly uniformly focused on men." See Regina Kunzel, *Criminal Intimacy: Prison and the Uneven History of Modern American Sexuality* (Chicago: The University of Chicago Press, 2008), 235.
[59] Perez, *Invisible Women*, 32.

bring the epidemic under control as it entered its third decade. Aware of the power imbalance that exists in condom negotiation, activists from the fields of women's health, contraceptive research and development, and HIV/AIDS called for prevention options that—unlike the male condom—women could use without a partner's active involvement. The escalating evidence of women's vulnerability to HIV—both biologically and socially—compelled feminist scientists to take up activists' call to develop a prevention option specifically for women. Tied into ongoing gendered problems with pharmaceutical research and development, private companies did not see enough profit potential in a woman-controlled tool to underwrite medical research, and promising products stalled for lack of money to take them forward. The drugs that did make it to market were new medicines, but with old problems. Compounding the medical research and cultural messaging that associated the new medicine with male sexuality and health, the efforts on the part of the Trump administration and political right to repeal the Obama-era Patient Protection and Affordable Care Act (also known as the Affordable Care Act; ACA) and the non-profit health spaces where women receive information and treatment has put available prevention options further out of the reach of women with real public health effects.

The latest iteration in the fight to end AIDS offers insight into the operation of the modern US health market. The current conversation over the cost of new HIV medicines are part of the larger debate in US society on who should finance healthcare. As scholars such as Peter Cohen and more recently historian Jonathan Bell have argued, debates over health benefits and cost were central to the early history of the epidemic, as the high price of treatment put services beyond the reach of many living with the virus.[60] During the 1980s, Medicaid—the

[60] Peter F. Cohen, '"All They Needed': AIDS, Consumption, and the Politics of Class," *Journal of the History of Sexuality* 8, no. 1 (July 1997): 86-115; Bell, "Rethinking the 'Straight State'"; Bell, "Between Private and Public: AIDS, Health Care Capitalism, and the Politics of Respectability in 1980s America," *Journal of American Studies* 54, no. 1 (2020): 159-183.

government sponsored programme that helps with medical costs for some people with low income—was limited to those in certain "dependent" categories, such as pregnant women or women caring for children aged eighteen and younger. In 1987, the SSA categorised people who had progressed to AIDS and were unable to work, i.e. disabled, as eligible for Medicaid insurance, although this did not apply to those with early stage HIV disease.[61] As outlined in chapter one, the requirement that a doctor count a person's illness as a disability in order for them to receive benefits was particularly burdensome for women, as the CDC did not diagnose woman-specific manifestations of HIV as AIDS until the agency broadened its definition of the disease in 1993. Prior to the passage of ACA in 2010, many women had to pay out-of-pocket for basic preventative healthcare services, and millions of women were denied coverage because of "pre-existing conditions" such as HIV and domestic abuse.[62] Ending the exclusion of some pre-existing conditions; allowing individual states to eliminate categorical requirements (e.g. pregnant women or children); and broadening Medicaid eligibility to most low income adults, ACA was a historic change in health care law for women and other people living with HIV.[63] This thesis shifts the historical perspective of the US health system to the underappreciated specifics of women's chronic ailments, and brings that history to the present day. Doing so, it demonstrates the persistent challenges of women living with HIV in an evolving treatment environment.

Chapter five also puts the existing historiography of the particularities of the US healthcare system, including the influence of the pharmaceutical industry, in conversation with the

[61] Bell, "Rethinking the 'Straight State,'" 942-943.
[62] Samantha Kahn, "The End of Gender Rating: Women's Insurance Under the ACA," *Wharton Public Policy Initiative*, August 4, 2015, accessed September 2019, https://publicpolicy.wharton.upenn.edu/live/news/819-the-end-of-gender-rating-womens-insurance-under
[63] Timothy M. Westmoreland, "The Affordable Care Act in the United States and HIV Disease: Past, Present, and Future," *Topics in Antiviral Medicine* 24, no. 2 (July-August 2016): 98-102, accessed February 2020, available at: https://www.ncbi.nlm.nih.gov/pubmed/27841980

historiography of the feminist healthcare movement.[64] Since the 1970s, the work of the feminist health movement has sought to democratise the operation of the US healthcare system, especially for women. Specifically, organisations such as the BWHBC, who were unhappy with the "capitalist, patriarchal medical establishment," worked to remove the onus that medical professionals placed on women to prevent unwanted pregnancies and stop the spread of diseases without providing them with accurate information about their bodies or adequate access to healthcare services.[65] Focusing on how activists currently fighting for cheaper medicines are building on the earlier work of groups such as the BWHBC, my research brings the history of the women's health movement into our contemporary moment, demonstrating that the fight over autonomy that framed the feminist health movement in the 1970s has driven women's response to AIDS from the 1980s to the present day. Women's AIDS activism therefore reveals the evolution and continuities in women's fight for equality in healthcare, which included maintaining women's autonomy in the life and death context of the AIDS epidemic, from the mid-twentieth to the early-twenty-first century.[66]

Chapter five shows the extent to which the gendered dynamics of the healthcare system have become increasingly punitive toward women since the end of the Reagan era. It examines the

[64] For histories of the US healthcare system, including the pharmaceutical industry, see Charles Rosenberg, *The Care of Strangers: The Rise of America's Hospital System* (New York: Basic Books, 1987); David M. Oshinsky, *Polio: An American Story* (New York: Oxford University Press, 2005); Jonathan Engel, *Poor People's Medicine: Medicaid and American Charity Care Since 1965* (Durham: Duke University Press, 2006); Joseph M. Gabriel, *Medical Monopoly: Intellectual Property Rights and the Origins of the Modern Pharmaceutical Industry* (Chicago: The University of Chicago Press, 2014); Nancy Tomes, *Remaking the American Patient: How Madison Avenue and Modern Medicine Turned Patients into Consumers* (Chapel Hill: University of North Carolina Press, 2016).

[65] Amber Jamilla Musser, "From Our Body to Yourselves: The Boston Women's Health Book Collective and Changing Notions of Subjectivity, 1969-1973," *Women's Studies Quarterly* 35, no. 1/2 (Spring-Summer, 2007): 93.

[66] For a sampling of the historiography of the feminist health movement, some of which briefly addresses AIDS, see Sheryl B. Ruzek, *The Women's Health Movement: Feminist Alternatives to Medical Control* (New York: Praeger, 1978); Sandra Morgen, *Into Our Own Hands: The Women's Health Movement in the United States, 1969-1990* (New Brunswick: Rutgers University Press, 2002); Kathy Davis, *The Making of Our Bodies, Ourselves: How Feminism Travels Across Borders* (Durham, North Carolina: Duke University Press, 2007); Wendy Kline, *Bodies of Knowledge: Sexuality, Reproduction, and Women's Health in the Second Wave* (Chicago: University of Chicago Press, 2010); Nelson, *More Than Medicine*.

competing actions and perspectives of microbicide advocates such as feminist scientist Zeda Rosenberg, the research and development agenda of major pharmaceutical companies such as Gilead Sciences, Inc., and the activism of women such as Emily Sanderson and Brenda Goodrow to lower the cost of life-saving medication. Doing so, it reveals that, even with the recognition that women get AIDS and live with AIDS, the state still overlooks women in their efforts to prevent, medicate, and care for people with the disease. Despite progress in treatment, the gender bias in medical research and the politics of healthcare has meant that women continue to experience persistent discrimination.

***

There is no teleology for diseases without cures. Diseases for which vaccines and cures do exist resurge and persist anyway, complicating the assumption that their invention automatically signals the end of an illness. Acknowledging that gendered problems persist in the way women suffer from medical issues to do with living with HIV and, equally, that women continue to resist those problems on the ground, compels historians of the AIDS epidemic and other diseases to resist neat endings following scientific discoveries.[67] In this thesis, I have sought to subvert easy closure by chronicling women's struggle against HIV from the 1980s to the present day.

[67] For examples of histories of disease that deal with disease "endings," see Brandt, *No Magic Bullet*; Susan Sontag, *Illness as Metaphor and AIDS and its Metaphors* (London: Penguin, 1991); David Oshinsky, *Polio: An American Story*; William H. Foege, *House on Fire: The Fight to Eradicate Smallpox* (Berkeley: University of California Press, 2011); Gareth Millwood, *Vaccinating Britain: Mass Vaccination and the Public Since the Second World War* (Manchester: Manchester University Press, 2019). For examples of AIDS histories that end by the turn of the twenty-first century, see Brier, *Infectious Ideas*; Gould, *Moving Politics*; Petro, *The Wrath of God*; France, *How to Survive a Plague*; Richard A. McKay, *Patient Zero and the Making of the AIDS Epidemic* (Chicago: University of Chicago Press, 2017).

By placing women at the centre of the AIDS epidemic and a series of other major historical developments, this thesis takes a new approach to the study of the epidemic and the broader history of the late twentieth and early twenty-first century United States. Focusing on the underappreciated impact of AIDS on women and their role in framing the fight against the disease and concurrent political debates offers five lessons.

First, since the epidemic's outset, women have constantly fought for recognition in the male-oriented medical-political complex. From activists who challenged the original definition of AIDS that depended on clinical symptoms of HIV in men in the 1980s, to women who sought to reform the health delivery systems that were designed for men within the carceral state, and the feminist scientists fighting to bring to market a woman-controlled prevention option now, women activists have persistently fought to make space for women within systems and structures that defaulted to male.

Second, securing state recognition always brought the risk of state interference. The political recognition that women got AIDS sparked debate over how to prevent perinatal transmission that converged with an already fraught debate about abortion. Individuals such as Surgeon General Koop, who saw the state as more supportive, counterbalanced the more punitive public health policy proposals that threatened women's reproductive choices. Moreover, the efforts of lesbian activists to raise queer women's visibility in the epidemic clashed with the efforts of the political right to silence them in the public sphere. Throughout the thesis, women have navigated the tension between needing state-funded treatment while at the same time needing to protect their autonomy from state interference, as state support easily tipped to state coercion.

Third, the diverse, constant risks that came with state recognition are why women have organised in multiple settings, in multiple groups, and with a multiple, intersectional focus. The prolific organising efforts of groups such as the BWHBC, the ACT UP Women's Caucus, the Lesbian AIDS Project, the Lesbian Avengers, the California Coalition for Women Prisoners (CCWP); of advocates such as Faye Wattleton, Judy Greenspan, Zeda Rosenberg; and of women living with HIV and AIDS such as Joan Walker, Katrina Haslip, and Brenda Goodrow informs the entire thesis.

Fourth, every time the women in this thesis organised, a backlash followed. In the 1980s, this came from individuals within the Reagan administration such as Robert "Bob" Sweet who worked to undermine the reproductive rights of all women, including women with HIV. With the coalescing of the rising political right in the culture wars of the 1990s, others such as Congressmen Mel Hancock (R-MO) similarly censored and, by extension, silenced, women's right to self-determination in the public sphere. The misogyny of the carceral state not only silenced HIV-positive women in the public sphere but removed them altogether. The efforts of the Trump administration and some members of the Republican party to reverse ACA and restrict women's access to non-profit treatment spaces represent the latest iteration in the longstanding attacks on women's health and women's autonomy over the course of the epidemic.

Finally, this thesis shows that, throughout it all, women have met attacks and responded to backlash with persistence and friendship. Building communities, self-educating, and coming together for support, women's fight against AIDS reveals women's expansive vision of autonomy, friendship, community, and rights as seen throughout the twentieth century. In sum, *Out of the Silence* shows the power of women's persistent organising, even when the

power of entrenched authority was against them. Protesting the AIDS epidemic, women not only changed themselves, but took on the state for the sake of shaping a more equitable and humane form of society.

***

Chapter One

AIDS is a Disaster, Women Die Faster:

Women, Transmission, and the Early Response to AIDS, 1980-1993

At the fifth International AIDS conference in Montreal in 1989 and sixth meeting in San Francisco in 1990, chants of "AIDS is a disaster, women die faster," "they do nothing, women die," and "AIDS definition needs correction" reverberated around the crowds.[68] Women attendees were protesting the lack of scientific and state recognition of women as individuals at risk from and infected with HIV during the first decade of the AIDS epidemic. This lack of recognition came from the fact that in the 1980s, the diagnosis of AIDS depended not only upon demonstrated infection with HIV, but upon the ways in which those infected became sick. As the CDC's original official case definition of AIDS was based on how the disease manifested in men, widely reported gynaecological conditions, such as pelvic inflammatory diseases, vaginal yeast infections, and cervical cancer, were not counted as manifestations of HIV infection.[69] A common assumption that women were not an at-risk population resulted in regular misdiagnosis and swift deaths from AIDS-related diseases that the CDC did not count in its official definition. According to Risa Denenberg, ACT UP Book Group member and family nurse practitioner at Bronx Lebanon Hospital, a woman with HIV who lived in Newark, New Jersey, lived an average of 15.5 weeks following a diagnosis of AIDS, while a white gay male in the northeast region of the United States with HIV lived an

[68] San Francisco International AIDS Conference Tape #2: Women's demonstration 1990 June 00:60:00. AIDS Activist Videotape Collection, Manuscripts and Archives Division, The New York Public Library, Astor, Lenox and Tilden Foundations, New York City, New York. Hereafter: NYPL Manuscripts and Archives division.
[69] The CDC originally defined AIDS by the presence of at least one of twenty-three symptoms indicating that an individual's immune system was not working. A rare lung infection, *Pneumocystis* carinii pneumonia, and a rare, unusually aggressive, cancer, Kaposi's sarcoma, were the first reported opportunistic infections that would become associated with AIDS. CDC, "*Pneumocystis* Pneumonia—Los Angeles," *MMWR* 30, no. 21 (June 5, 1981): 250-252.

average of 20.8 months.[70] A preliminary body of research showed that many more women than previously thought had contracted HIV and died of AIDS-related illnesses without a doctor ever diagnosing them.[71]

In 1983, 32-year-old Sunnye Sherman from Washington, D.C., became one of the first women diagnosed with AIDS. She suffered regular bouts of the rare pneumonia, *pneumocystis carinii*, and died in 1986 of brain damage related to HIV.[72] As Sherman's death attests, it took approximately four years after the first reports of AIDS infections in men in 1979 for women to enter the AIDS narrative; when they did, it was most frequently as mothers and potential mothers. Reports of infants with AIDS-related infections in 1981 followed by the discovery that HIV could pass heterosexually in 1983 prompted scientists to recognise that whatever was infecting and making infants and men sick was probably infecting women too.[73]

In this chapter, I argue that the scientific discovery that HIV transmission was not just about sex, but reproduction, increased the public health urgency to address AIDS in women. Throughout the first decade of the AIDS epidemic, women with HIV were not only excluded from the initial medical response to AIDS because doctors and diagnosticians focused on the disease in white, gay men; they were ignored as women because they were first seen and counted as reproductive agents. The bias toward seeing women as mothers in the AIDS

[70] Risa Dennenberg, "Pregnant Women and HIV," in Marion Banzhaf et al., *Women, AIDS, and Activism by the ACT UP/NY Women and AIDS Handbook Group* (Boston: South End Press, 1999), 31.
[71] Norwood, "Alarming Rise in Deaths," 66-67; Norwood, "The Silent Minority," 13.
[72] Sandra G. Boodman, "Covering the AIDS Beat: Fear, Compassion, Duty," *Washington Post*, August 14, 1988; Lou Ziegler, "Women: The other Face of AIDS," *USA Today*, undated; Don Colburn, "I Just Started Crying," *Washington Post*, September 4, 1985; Bart Barnes, "Obituaries," *Washington Post*, August 12, 1986.
[73] CDC, "Epidemiologic Notes and Reports Possible Transfusion-Associated Acquired Immune Deficiency Syndrome (AIDS)—California," *MMWR* 31, no. 48 (December 10, 1982): 652-4; CDC, "Epidemiologic Notes and Reports Immunodeficiency among Female Sexual Partners of Males with Acquired Immune Deficiency Syndrome (AIDS)—New York," *MMWR* 31, no. 52 (January 7, 1983): 697-8.

epidemic was representative of the historic treatment of women as disease carriers.[74] It also spoke to the larger monitoring of women as mothers in the Reagan era, a period in which ideas of who was deserving of state welfare and support were also particularly important.[75]

In the early 1980s, a range of activists fought first for the diagnosis of women with AIDS so that women would be eligible for treatment programmes. When scientists began diagnosing AIDS in increasing numbers of women and increasing numbers of women began qualifying for clinical trials, researchers enrolled women in those trials as mothers. Activists not only sought the medical recognition that women got AIDS too but wanted to make sure that the design of clinical trials did not compromise women's autonomy, or the autonomy of their infants. In sum, their goal throughout the decade was to secure recognition in a way that maintained women's autonomy, and to get women treatment not just as mothers but as individuals with complex health needs.

Women were not only responsible for getting themselves recognised as individuals who contracted AIDS in the 1980s, as outlined in the existing historiography.[76] They also became

[74] Brandt, *No Magic Bullet*, 21, 32, 92, 94, 168; Sander L. Gilman, "AIDS and Syphilis: The Iconography of Disease," *October* 43 (Winter, 1987): 93-98, 107; Evelynn Hammonds, "Missing Persons: African American Women, AIDS and the History of Disease," *Radical America* 24, no. 2 (July 1992): 9-10; Treichler, *How to Have Theory in an Epidemic*, chap. 2, esp. 42-45, 65; Reagan, *Dangerous Pregnancies*, 225-241; Dubow, *Ourselves Unborn*, chap. 4, esp. 112-117.

[75] For histories that examine the monitoring of women as mothers and the gendered nature of welfare politics prior to and under the Reagan administration, see Theda Skocpol, *Protecting Soldiers and Mothers: The Political Origins of Social Policy in the United States* (Cambridge, MA: Belknap Press of Harvard University Press, 1992); Linda Gordon, *Pitied but Not Entitled: Single Mothers and the History of Welfare* (New York: Free Press, 1994); Gareth Davies, "The Welfare State," in *The Reagan Presidency: Pragmatic Conservatism and Its Legacies*, ed. W. Elliot Brownlee and Hugh David Graham (Lawrence: University Press of Kansas, 2003), 209-232; Michael Schaller, *Right Turn: American Life in the Reagan-Bush Era, 1980-1992* (New York: Oxford University Press, 2007), 41-42; Marisa Chappell, *The War on Welfare: Family, Poverty, and Politics in Modern America* (Philadelphia: University of Pennsylvania Press, 2010), 204; Karen M. Tani, *States of Dependency: Welfare, Rights, and American Governance, 1935-1972* (New York: University of Cambridge Press, 2016); Evans, *Tidal Wave*, 176; Alexander, *The New Jim Crow*, 48-49; Carroll, *Mobilizing New York*, 19; Charlie Jeffries, "Adolescent Women and the Antiabortion Politics in the Reagan Administration," *Journal of American Studies* 52, no.1 (2018): 193-213.

[76] A number of scholars have written about activists' campaign to petition the CDC to broaden its definition of AIDS to better reflect the impact of the disease on women and injection drug users in the 1980s. See Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (Berkeley: University of California

responsible for preventing transmission both sexually and reproductively as public health officials began counting women as sexual as well as reproductive agents. Women's fight for inclusion therefore revolved around a number of tensions: between seeing women as women and women as mothers; between activists and doctors and diagnosticians; between activists and public health officials; and between seeing women as sexual versus reproductive beings.

This chapter will address these tensions and examine how a range of activists fought to expand what it meant to "count" in healthcare in the 1980s and early 1990s—for the state to recognise women not just as mothers but as individuals with complex health needs who mattered. In the first section, I show that as women fought for the diagnosis of women with AIDS, motherhood became the crux of women's inclusion in the epidemic. In the second section, I then examine the largely unsuccessful, systemic attempts on the part of some right-wing political commentators to deal with the discovery of AIDS in women and the problem of HIV transmission. In section three, I argue that the state-wide, voluntary public health initiatives that put the onus of prevention on women were more in line with the neoliberal politics of the era and therefore had greater reach.[77] In section four, I show how feminist campaigners challenged this burden of prevention, creating alternative public health publicity that emphasised the need to recognise women for treatment, provide women with accurate information, and protect women's sexual rights. In section five, I explore how activists succeeded in shaping a broader, more inclusive public health consensus in the post-1989

Press, 1996), 287-290; Brier, *Infectious Ideas*, 171-179; Shotwell, "'Women Don't Get AIDS, They Just Die From It,'" 509-525; Carroll, *Mobilizing New York*, 131-135; Bell, "Rethinking the 'Straight State,'" 945-95.

[77] For an overview of the impact of neoliberal politics, especially what she termed the "ethos of individualism" on President Reagan's response to AIDS, see Brier, "Reagan and AIDS," in *A Companion to Ronald Reagan*, ed. Andrew L. Johns, (Malden, MA.: Wiley Blackwell, 2015), 228-229. For examples of how the rhetoric of individualism and responsibility played into HIV prevention strategies within the gay male community, see Douglas Crimp, *Melancholia and Moralism: Essays on AIDS and Queer Politics* (Cambridge: MIT Press, 2002), 3-6; Petro, *After the Wrath of God*, 9; Brier, *Infectious Ideas*, 11-44.

period after taking their fight to secure recognition and protect women's autonomy to the largest international platform on AIDS.

Discovering AIDS in Women

In early December 1982, the CDC reported on a case of a 20-month old infant infected with AIDS through a blood transfusion in San Francisco.[78] One week later, the CDC reported on Kaposi's sarcoma and other AIDS-related opportunistic infections found in small groups of infants in New York, New Jersey, and California. Speculating on how these infants became infected, the editor noted that "transmission of an 'AIDS agent' from mother to child, either in utero or shortly after birth, could account for the early onset of immunodeficiency in these infants."[79] The editor did not speculate on how the mothers of the infants became infected, beyond noting that they had histories of intravenous drug use. A report published one month later, in January 1983, on the first reported cases of heterosexual transmission of AIDS from men to women led to further speculation that the unknown "AIDS agent" may "occur among both heterosexual and male homosexual couples."[80] Approximately four years after the first reported AIDS cases in men in 1979, diagnosticians and doctors were starting to recognise that whatever was infecting infants and men was infecting women too.

Despite reports of immunodeficiency in women, the state was reluctant to recognise women as deserving of welfare and support in the early years of the epidemic. In line with efforts on the part of the Reagan administration to remove people from the Social Security disability

[78] CDC, "Epidemiologic Notes and Reports Possible Transfusion-Associated Acquired Immune Deficiency Syndrome (AIDS)—California," *MMWR* 31, no. 48 (December 10, 1982): 652-4.
[79] CDC, "Unexplained Immunodeficiency and Opportunistic Infections in Infants—New York, New Jersey, California," *MMWR* 31, no. 49 (December 17, 1982): 665-667.
[80] CDC, "Epidemiologic Notes and Reports Immunodeficiency among Female Sexual Partners of Males with Acquired Immune Deficiency Syndrome (AIDS)—New York," *MMWR* 31, no. 52 (January 7, 1983): 697-8.

rolls, the CDC were initially slow to conduct epidemiological testing in women and amend its definition to include increasingly reported AIDS-related conditions in its formal definition, such as the vaginal yeast infection, candidiasis. According to historian Jonathan Bell, this reluctance came from a disinclination on the part of the government to spend more money. As illnesses found in women "were common (unlike Kaposi's sarcoma), their inclusion would inevitably commit federal agencies to a major intervention in what, until that point, had been portrayed as a problem only in stigmatized 'risk groups.'"[81] As the Supplementary Security Income (SSI) welfare programme based its disability benefits eligibility on the CDC's official AIDS definition, federal agencies used the definition not only as a way to track the disease, but as a gateway to health services and disability benefits. The SSI denied those with HIV infection who were not designated as having AIDS assistance to which they should have been entitled on the basis of their illness. As the manifestations of HIV in women did not match a national medical list that the CDC originally established for gay men with the disease, many women failed to qualify for benefits as federal bureaucrats were determined not to expand welfare eligibility to women in the 1980s.[82] Women infected with HIV in this decade were therefore let down by a welfare system that was expanding to provide support to some gay men, but did not yet count them as deserving.[83]

The discovery of the Human Immunodeficiency Virus, or HIV, as the cause of AIDS in the spring of 1984 by scientists in Washington D.C., and Paris marked a turning point in

[81] Bell, "Rethinking the 'Straight State.'" 948.
[82] Other agencies at the federal, state, and local level also relied on information from the CDC for planning the allocation of funds, services, the content of prevention and research programmes, which meant that services specifically designed for women were virtually non-existent. Norwood, *The Silent Minority*, 13.
[83] According to Bell, despite the Reagan administration's attempts to purge people from the rolls of the Supplementary Security Income (SSI) programme that served as a disability benefit, it generally kept pace with inflation and the number of the disabled receiving SSI increased yearly by an average of about 3 percent. He examined how some white gay men with AIDS-related opportunistic infections managed to gain a seat at the health and welfare table as their access to the private health system diminished in the 1980s. Women, in contrast, struggled to access an altered welfare system that Bell argued expanded in this decade to incorporate white gay men in the context of AIDS. Bell, "Rethinking the 'Straight State,'" 935.

recognising women in the epidemic, especially as mothers. It led to a slight broadening of the AIDS case definition in 1985, making it scientifically clear that the virus could infect groups other than those originally identified, including women.[84] In 1985, scientists discovered that women could transmit HIV during pregnancy and childbirth, and in 1986, scientists in Boston and San Francisco reported discovering HIV in the vaginal and cervical secretions of twenty-one women.[85] According to one of the scientists who worked on that case, Dr Martin D. Hirsch of the Massachusetts General Hospital, their research suggested not only that the "virus present in the birth canal could be transmitted to new-borns during delivery" but that women could infect men as well as men infecting women. The discovery of mother-to-child transmission and the realisation that transmission was not just about sex, but reproduction, made the need to address AIDS in women particularly urgent. As public health physician Wendy Chavkin noted in 1990, public health officials began aggressively targeting women considered in relation to their reproductive capacities in the 1980s.[86]

It would take almost three more years before some popular press outlets reported on the discovery of AIDS in women. In December 1985, Dr John Langone had claimed that AIDS was not a threat to women as "the rugged vagina (built to be abused by such blunt instruments as penises and small babies) provides too tough a barrier for the AIDS virus to

[84] CDC, "Provisional Public Health Service Inter-Agency Recommendations for Screening Donated Blood and Plasma for Antibody to the Virus Causing Acquired Immunodeficiency Syndrome," *MMWR* 32, no. 1 (January 11, 1985): 1-16.
[85] CDC, "Current Trends Recommendations for Assisting in the Prevention of Perinatal Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus and Acquired Immunodeficiency Syndrome," *MMWR* 34, no. 48 (December 6, 1985): 721-6, 731-2; Markus W. Vogt et al., "Isolation of HTLV-III/LAV from Cervical Secretions of Women at Risk for AIDS," *The Lancet* 327 no. 8480 (March 8, 1986): 525-527; Lawrence K. Altman, "AIDS Study Shows How Women Infect Men," *New York Times*, March 7, 1986; "Case of AIDS Is Traced to Vaginal Intercourse," *New York Times*, April 10, 1986, box 140, fol. 1; "aids," *off our backs* xvi, no. 4, April 1986, 1; Patricia Thomas, "Evidence Builds that AIDS Virus is Transmissible Heterosexually," *Ob.Gyn. News* 20, no. 12, 1985, 1, box 140, fol. 3; "Clue in the Spread of AIDS Virus Seen: Researchers Say Infection in Cervix Might Explain How Disease Hits Newborn," *New York Times*, March 4, 1988, box 139, fol. 10, BWHBC records, Schlesinger Library.
[86] Wendy Chavkin, "Preventing AIDS, Targeting Women," *Health/PAC Bulletin*, Spring 1990, 19, box 139, fol. 14, BWHBC, Schlesinger Library.

penetrate."[87] More alarming for women who wanted to challenge the misconception that women were not at risk were similar articles published not in niche medical journals but in widely read, popular women's magazines. In January 1988, Dr Robert Gould, Professor of psychiatry at New York Medical College, reassured the approximately 2.4 million readers of the magazine *Cosmopolitan* in the late 1980s that "ordinary sexual intercourse" posed no threat to American women.[88] Gould went on to claim that cases of heterosexual transmission in Africa were so high because "many men in Africa take their women in a brutal way, so that some heterosexual activity regarded as normal by them would be closer to rape by our standards."[89] He also failed to note that the latest scientific information available on heterosexual transmission showed that AIDS was the leading cause of death in women between the ages of 25 and 34 in New York City in 1988. The desire to correct Gould's article drove members of the ACT UP Women's Caucus to organize a protest outside *Cosmo*'s headquarters in Manhattan on 15th January 1988. Caucus members also met with Gould to ask him to retract his article, and when he refused, they sent hundreds of condoms a day to Helen Gurley Brown, the magazine's editor, until she published the first article in the magazine's history urging women to use condoms for safer sex two months later.[90] Gould's article and women's resistance to it revealed the contested ways in which different groups of actors and activists sought to assert credible knowledge about HIV in women and inform the popular understanding of the disease throughout the 1980s.

---

[87] John Langone, "AIDS: The Latest Scientific Facts," *Discover*, December 1985, quoted in Treichler, "AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification," *October*, 43 (Winter, 1987): 37.
[88] ACT UP/NY, "Action at Cosmopolitan Magazine January 15, 1988," in *The ACT UP Women's Caucus Women and AIDS Handbook*, ed. Maria Maggenti (March 1989), 91-92. Version of the handbook in the Women's Health Action and Mobilization (WHAM!) records, box 3, fol. ACT UP Women's Caucus and AIDS Handbook 1989, Tamiment Library and Robert F. Wagner Labor Archive, New York University, New York City. Hereafter: Tamiment Library; for estimated figures of Cosmopolitan readership see Carol Brennan, "Cosmopolitan," last updated January 24, 2020, accessed February 2020, https://www.encyclopedia.com/literature-and-arts/literature-english/american-literature/cosmopolitan
[89] Lisa Sabbage, "Fighting for Our Lives: Women & AIDS," *Broadsheet*, March 1989, 20, box 139, fol. 13, BWHBC records, Schlesinger Library.
[90] Maria Maggenti, interview by Sarah Schulman. Interview 010, January 20, 2003, transcript/ New York: ACT UP Oral History Project, 25-27; ACT UP/NY, "Action at Cosmopolitan Magazine January 15, 1988," 91-92.

At the same time that members of the ACT UP Women's Caucus and other feminist campaigners worked to correct articles published in women's magazines and educate women about their risk, advocates and activists were simultaneously working to shape the medical categorisation of AIDS in order to better reflect its reach in women. During the first half of the 1980s, community activists, activist medical groups, and supportive members of Congress such as Nancy Pelosi (D-CA) and Barbara Boxer (D-CA), had argued that the CDC's original definition of AIDS was too narrow and excluded many of those on the margins of society and invisible to CDC scientists.[91] In 1987, activists had succeeded in getting the CDC to amend its definition and the list of associated illnesses to include emaciation or wasting syndrome and dementia. The inclusion of wasting syndrome saw a sixty percent increase in the number of reported AIDS cases in women after 1987.[92] In a subsequent CDC study of twelve states, researchers projected that of those women already diagnosed with AIDS, nine to forty-three times more were also likely infected.[93] Efforts to shape the production of scientific-medical knowledge on the new disease and amend the CDC's official AIDS definition to more accurately reflect the actual number of persons with AIDS, especially among women and injection drug users, would continue into the 1990s.

By the end of the decade, scientists had come to understand AIDS not only as a disease in white, gay men, but as a virus that could pass sexually between men and women and, crucially, as a virus with a thirty-to-fifty percent chance of transmission from a woman to a

[91] Bell, "Rethinking the 'Straight State,'" 941-42.
[92] The increase of thirty percent of AIDS cases following the 1987 amendment led the agency to note that "compared with patients who meet the pre-1987 definition, a higher proportion of patients who meet only the 1987 definition were female, black or Hispanic or were intravenous drug users." CDC, "Current Trends Update: Acquired Immunodeficiency Syndrome—United States, 1981-1988," *MMWR* 39, no. 14 (April 14, 1989): 229-232, 234-236.
[93] Norwood, "The Silent Minority," 13.

child during pregnancy, childbirth, or breastfeeding.[94] These insights increased the urgency on the part of the medical community to diagnose women and include them in clinical research for the sake of addressing the possible transmission of HIV in women not only sexually but through reproduction.

Throughout the twentieth century, researchers had kept women out of many types of clinical trials out of concern that they might become pregnant while on a trial for an experimental drug that could turn out to harm the baby. Drug companies' and medical institutions' concern about financial liability for potential foetal damage provided an additional rationale for exclusion.[95] The thalidomide scandal of the 1960s heightened the pharmaceutical industry's concerns. During the 1960s, doctors began prescribing thalidomide to pregnant women who suffered from morning sickness. Researchers considered the drug, which had been available in many countries since the late 1950s, safe because its developers could not find a dose high enough to kill a rat. Although the drug did not kill rats, it did harm foetal development. Before the drug was taken off the market in 1962, thalidomide-related disabilities had affected the lives of over 10,000 children born around the world.[96] Women had also experienced the toxic effects of new drugs such as Diethylstilbestrol (DES) and contraceptive devices such as the copper 7 and Dalkon shield Intrauterine devices (IUDs).[97] Following the

[94] Mary Jo M. Dales, "Women with AIDS Antibodies Advised to Postpone Pregnancy," *Ob.Gyn. News* 20, no. 7, 1985, 30a, box 140, fol. 3; "As AIDS Spreads, Officials Face Tough Questions on Protection," *the nation's health*, October-November 1985; Dr David L. Heymann, "Mother to child," *World Health*, November-December 1990),13-15; Hernandez-Claire, "Paris Declaration: on women, children and the Acquired Immunodeficiency Syndrome (AIDS)," *World Health*, November-December 1990, 16-17; Professor Margaret C. Heagarty, "Psychological and Social Consequences," *World Health*, November-December 1990),18-19, box 139, fol. 13, BWHBC records, Schlesinger Library.
[95] Banzhaf et al., *Women, AIDS, and Activism*, 207.
[96] Brought to Life, "Thalidomide," accessed February 2020, http://broughttolife.sciencemuseum.org.uk/broughttolife/themes/controversies/thalidomide
[97] The experimental use of DES to prevent miscarriage in approximately three million pregnant women between 1945 and 1970 resulted in the appearance of rare vaginal cancer and death for thousands of their daughters, as well as testicular cancer in their sons. It took nearly as long to establish that the drug did not work as to reveal how dangerous it was. CDC, "About DES," accessed February 2020, https://www.cdc.gov/des/consumers/about/history.html

thalidomide scandal, in 1977 the US Food and Drug Administration (FDA) issued guidelines excluding women of childbearing age—which the CDC defines as between the ages of 16 and 49—from drug trials.[98]

Fear of causing "reproductive damage" provided the same rationale for women's exclusion from the early clinical trials for HIV. Before 1986, when the NIH formally changed its rules in response to protests, the agency excluded women of childbearing age from their trials outright.[99] Some researchers even barred women who could prove they were on permanent birth control, in other words had undergone sterilisation, thus preventing any possibility of pregnancy, from trials for experimental drugs. This included trials for AZT—also known as Zidovudine (ZDV)—the first antiretroviral drug that the FDA approved for sale in 1987.[100] The need for a woman to prove that she could not get pregnant also extended to women who self-identified as lesbians and who were not having sex with men, thereby reinforcing the heteronormative treatment of all women as potential mothers.

The fact that the safety and effectiveness of HIV medicine was based on research done with men spoke to a historic gender bias in biomedical research. Because women did not qualify for most of the FDA's clinical trials and drug experiments that the agency and other pharmaceutical manufacturers had designed to test newly developed drugs and treatments, little data existed on how the HIV virus and newly developed HIV drugs that may eventually be approved for sale acted differently in women's bodies. Potential differences included whether hormonal changes during the menstrual cycle affected women's risk of infection, or

[98] Ali Pattillo, "Sexist Science Makes Women's Reproductive Health a Guessing Game," *Inverse*, November 16, 2019, accessed February 2020, https://www.inverse.com/article/60989-gender-gap-research-and-womens-health
[99] Epstein, *Impure Science*, 260.
[100] The original studies of AZT in 282 patients included only 13 women. William M. Miley, *The Psychology of Well Being* (Westport, CT: Greenwood Publishing Group, 1999), 192-193; NOW Legal Defense and Education Fund, "Facts on Women and AIDS," June 1988, 2, box 139, fol. 14, BWHBC records, Schlesinger Library.

whether HIV medicines interfered with a woman's hormonal birth control.[101] Moreover, because of size, nutrition, and hormonal differences, women may have had lower tolerance to the drugs than men.[102] Whereas the government and pharmaceutical companies had excluded women from trials for the sake of protecting the foetus in the past, now they only included women for the sake of proving the efficacy of drugs to prevent mother-to-child transmission. As more women qualified for clinical trials, activists sought to ensure that their design did not undermine the autonomy of women or their infants.

In 1988, some researchers began proposing to test AZT—one of the only drugs available to treat HIV at that time—on HIV-positive pregnant women in the hope that it would reduce the chance of perinatal transmission.[103] In 1989, Burroughs-Wellcome, the manufacturer of the drug, announced that the drug caused cancer in the reproductive organs of female rats and mice.[104] Despite this announcement, the first federally run clinical trial for AZT that included women began three years later in 1993, which was thirteen years after the first reporting of AIDS to the CDC, and six years after the first clinical trial that enrolled mostly men.

In 1991, the AIDS Clinical Trials Group (ACTG)—established in 1987 to broaden the scope of the AIDS research effort of the National Institute of Allergy and Infectious Diseases (NIAID)—began recruiting women for a new treatment protocol, the 076 trial funded by the Department of Health and Human Services (DHHS), NIH, and NIAID. The designers of trial 076 were based at the University of Medicine and Dentistry of New Jersey (UMDMJ), the

[101] Michael Specter, "AIDS Infection and Birth Control Pills: Case of Nairobi Prostitutes Raises Question of Possible Risk Factors," *Washington Post*, June 2, 1987.
[102] Epstein, *Impure Science*, 260-261.
[103] Susan Okie, "Stopping it at the Source: Researchers Plan to Test AIDS During Pregnancy," *Washington Post National Weekly Edition,* October 10-16, 1988.
[104] Banzhaf et al., *Women, AIDS, Activism*, 206.

state with the highest proportion of women with AIDS in the country at that time.[105] The trial set out to prove the efficacy of AZT in preventing perinatal transmission of HIV if administered during the second and third trimesters of pregnancy and to the new-born for six days to two weeks. The three-year trial began in 1993 and involved over four hundred predominantly black and Latina pregnant women.

A number of women doctors and women-led organisations, caucuses, and committees hotly debated the ethics of the 076 AZT trial, which highlighted the conflict between a new-born's right to treatment and a woman's, especially as it related to the issue of race. Some women doctors, including Janet Mitchell, an African American doctor based at Harlem Hospital, wanted the trial to go ahead, arguing that it was a good thing for pregnant women who were eager to find a treatment that would stop them transmitting the virus to their babies. Activist Marion Banzhaf, a founding member of the ACT UP Women's Caucus and the coordinator of the New Jersey Women and AIDS Network (NJWAN), agreed that the trial was important as the African American pregnant women with HIV who she worked with had expressed their desire to help find an effective treatment, but noted that the trial also raised questions about the ethics of enrolling mostly African American women given the toxicity of AZT and the history of experimentation on black people in the United States. Banzhaf instead wanted to reform the trial, removing the placebo arm that would deny those women and infants access to potentially beneficial treatment, and to organise for the new-born arm to be optional too, so that the woman could decide whether or not she wanted to give her child the dose of the drug as its overall toxicities were still unclear.[106]

[105] Marion Banzhaf, interview by Sarah Shulman. Interview 070, April 18, 2007, transcript/ New York: ACT UP Oral History Project, 57.
[106] Marion Banzhaf, interview by Sarah Shulman, 56-63.

Others also raised concerns about the design of the trial. For one thing, the informed consent clause excluded factors such as a risk of vaginal tumours that had appeared in animal studies in the late 1980s. Because of this undisclosed risk, many in ACT UP rejected the trial outright, arguing that the study bypassed women's own medical needs. They also objected to the fact that participants were not guaranteed a continuation of treatment once the study concluded, and that without intervention a number of HIV-positive pregnant women already gave birth to HIV-negative children.[107] The ACT UP/People of Color caucus argued that "the US AIDS policy is racist, sexist, and genocidal as exemplified by the exploitation of communities of color for AZT placebo controlled trials."[108] Based on their objections, ACT UP disrupted a meeting where the principal investigators of the trial planned to discuss its design. According to Banzhaf, the ACT UP action prevented any meaningful conversation about reforming aspects of the trial to take place, and so it went ahead as originally designed. The results of the trial were ground-breaking for showing that the drug effectively reduced the risk for perinatal transmission by two-thirds—from 25 percent to less than 8 percent.[109] Based on the results of ACTG 076, the PHS issued recommendations for the use of AZT to reduce perinatal transmission in 1994. Discussed further in chapter two, the success of the 076 trial and the effectiveness of the PHS' subsequent recommendation in reducing rates of perinatal transmission helped to undermine the political calls to stop HIV-positive women from having children altogether for the sake of preventing cases of paediatric AIDS.

[107] Gould, *Moving Politics*, 356; Avram Finkelstein, *After Silence: A History of AIDS Through Its Images* (Berkeley: University of California Press, 2017), 179.
[108] ACT UP/People of Color Action Flyer, "Stop Murderous U.S. AID$ Imperialism," undated, box 4, fol. 7, LHA.
[109] For a more detailed account of the 076 trial, see Banzhaf Interview 070, 56-63. Based on the results of ACTGP 076, in April 1994, CDC issued provisional guidelines for AZT use to reduce perinatal transmission, and, in July 1994, FDA approved the drug for this use. In August 1994, the U.S. Public Health Service Task Force (USPSTF) and CDC issued consensus recommendations for use of this regimen to reduce perinatal HIV transmission. CDC, "Recommendations of the U.S. Public Health Service Task Force on the Use of Zidovudine to Reduce Perinatal Transmission of Human Immunodeficiency Virus," *MMWR* 43, no. RR-11 (August 5, 1994): 1-20.

As doctors diagnosed increasing numbers of women with HIV and increasing numbers of women qualified for clinical trials, activists wanted to ensure that, in treatment programmes, women's autonomy, and the autonomy of their infants, was protected. Activists were not only concerned by the fact that pharmaceutical companies largely saw women as reproductive agents and not as individuals needing treatment in their own right in this period, but measures that right-wing politicians and political commentators proposed to combat transmission in the 1980s also raised concern over women's autonomy and rights.

The Coercive State

Following the licensing of the first commercial blood test, ELISA, which stands for enzyme-linked immunosorbent assay, which not only made it possible to screen blood to preserve the quality of the blood supply, but to identify individuals who had come into contact with HIV, politicians began debating the efficacy of different forms of testing for the sake of curbing HIV transmission.[110] Many of the proposals for mandatory, mass testing were not dissimilar to the large-scale, institutional measures that the state had introduced to tackle diseases such as syphilis and gonorrhoea in the previous decades, including mandatory testing for marriage licenses.[111] However, in the post-sex revolution era, these proposals did not reflect the realities of how marriage functioned as an institution and largely failed to take off. In July 1987, long-time feminist and HIV advocate Cindy Patton explained that the suggestion that women "should just stop having sex outside of marriage" to prevent contracting HIV was sexist—and unrealistic.[112]

[110] Brandt, *No Magic Bullet*, 195.
[111] Engs, *The Progressive Era's Health Reform Movement*, 345.
[112] Cindy Patton, "Feminists Must Oppose Widespread Testing," *Sojourner: The Women's Forum*, July 1987, 3, box 140, fol. 1, BWHBC records, Schlesinger Library.

During the early years of the epidemic, a number of politicians and political commentators had called for mandatory AIDS testing and the tattooing, quarantining, and deportation of people who tested positive.[113] Because AIDS was first associated with gay men, conservatives most often made the gay male community the subject of their attacks.[114] In 1986, conservative commentator William Buckley had famously remarked that "everyone detected with AIDS should be tattooed in the upper forearm, to protect common needle users, and on the buttocks to prevent the victimization of other homosexuals."[115] Such punitive proposals were rooted not in the latest scientific information on the disease but instead stoked fears about how people with AIDS threatened the symbolic health of the nation. By 1988, a number of states had debated or passed into law AIDS testing for the purposes of surveillance and control. In Nevada, where prostitution was legal, women were not only advised to but required by law to use condoms during sex. In Orlando, Florida, Wendy Blakenship, a sex worker who reportedly "wouldn't tell her customers that she carried that AIDS virus," was charged with manslaughter, even though she used condoms with all her customers and all her customers tested HIV-negative. Blakenship's case inspired the Florida legislature to adopt a law in 1988 allowing health officials to "quarantine promiscuous AIDS carriers for up to four months."[116] Other measures included mandatory contact tracing—requiring people with AIDS to report the names of all their sexual partners to the government—in addition to the mandatory testing of people entering the military, persons in correctional systems, persons

[113] Keith Love, "GOP Rep. Dannemeyer Focuses on Family, Enters Senate Race," *Los Angeles Times*, December 10, 1985; Julie Rovner, "AIDS Fiery Debate, Senate Passes AIDS Bill," *CQ Health*, April 30, 1988, 1167-9; "When to Test for AIDS," *New York Times*, May 12, 1987; "Bush Appoints Dannemeyer Spokesman on AIDS," *New York Native*, October 10, 1988, box 148, fol. 42, C. Everett Koop papers, National Library of Medicine, Bethesda, Maryland. Hereafter: NLM.
[114] In May 1984, conservative commentator and former Nixon speechwriter Patrick J. Buchanan published an op-ed in the *New York Post* arguing that the AIDS epidemic was God's punishment of the gay community. Shilts, *And the Band Played On*, 311.
[115] William Buckley, "Crucial Steps in Combatting the Aids Epidemic; Identify All the Carriers," *New York Times*, March 18, 1986.
[116] Jeanne DeQuine, "Prostitute who told customers she was healthy dies of AIDS," *USA Today*, October 19, 1988, box 148, fol. 42, Koop papers, NLM.

admitted to hospitals, individuals applying for residency or citizenship, and couples requesting a marriage licence.[117]

Beginning in the Progressive era that spanned the 1890s to the 1920s, many states required applicants for a marriage licence to obtain a blood test. Laws for blood testing varied on a state by state basis, and these tests were for venereal diseases, most commonly syphilis, for genetic disorders, such as sickle-cell anaemia, or for rubella. By the end of 1938, twenty-six states had enacted provisions denying a marriage certificate if either party were found to have a communicable infection.[118] Proponents of premarital testing, such as Thomas Paran, the Surgeon General from 1936 to 1948, argued that testing was necessary to inform the potential marriage partner of the risk of contracting a communicable disease, and to reduce the risk of birth defects or genetic diseases associated with syphilis and rubella. In practice, many states passed laws that were grounded more in social convention than epidemiological reality, for example requiring only the examination of the bridegroom as mandatory testing affronted "pure" women. As a result, while the cost of premarital blood testing was very high the benefits were relatively low. In order to avoid the costly and invasive testing requirements, many couples simply chose to marry in states that did not have the mandates, or not to marry at all, a phenomenon bolstered by the mid-century second-wave feminist critique of the institution of marriage.[119] These same arguments over the efficacy of premarital testing framed the debates over HIV testing with the onset of AIDS in the early 1980s.

[117] US DHHS & PHS, "Information/Education Plan to Prevent and Control AIDS in the United States," January 1, 1987, 1-55, Richard A. Davis files, box 1, fol. 2; Memorandum from Otis R. Bowen to Beryl W. Sprinkel, Chairman, Council of Economic Advisors from the Secretary, "Assessing the Benefits of Testing for AIDS," July 20, 1987, Beryl W. Sprinkel files, box, fol. 2, 1-2, Ronald Reagan Presidential Library and Museum, Simi Valley, California. Hereafter: RRPL.
[118] Brandt, *No Magic Bullet*, 147.
[119] Brandt, *No Magic Bullet*, 147-149.

Throughout the 1980s, politicians and public health officials argued at length over whether to mandate states to offer AIDS testing to couples for marriage licenses.[120] In his first speech devoted exclusively to the growing epidemic at a gala for the American Medical Foundation for AIDS Research (AmFAR) in the summer of 1987, President Ronald Reagan called for a wide range of AIDS testing at the state and federal levels including the routine testing of applicants for marriage licenses in order to stop "AIDS surreptitiously spreading throughout our population."[121] Reagan's comments buoyed conservatives who embraced premarital testing as a means of curbing the spread of the virus among heterosexuals and preventing "at least some babies being born with AIDS."[122] Healthcare activists and many in the public health profession opposed policy proposals for compulsory premarital testing, arguing that it was an extremely expensive, largely ineffective measure that took resources away from more targeted AIDS prevention programmes and did more to deter marriage than to stop the spread of AIDS.[123] Moreover, as many social conservatives viewed HIV/AIDS as punishment for promiscuity before marriage, many critics also saw premarital blood testing as another ideologically driven proposal aimed at symbolically protecting the American family from infection. While a number of states debated requiring HIV testing for marriage licenses, only

[120] Domestic Policy Council to the President, "AIDS Testing," May 27, 1987, 1-6, box 1, fol. 2, T. Kenneth Cribb, Jr. files; Julie Rovner, "Sets Testing, Counseling Policy," *Congressional Quarterly Inc*., May 28, 1988, 1450-1451; Heather Shannon, House Committee on Health Care, Committee on Health Care Bill No.: S.432, S.435. Title: "An Act Relative to Testing for the Human Immunodeficiency Virus of Persons Filing Their Intentions to Marry." Sponsor: Sen. Kirby. Hearing Date: March 7, 1988, box 2, fol. 4, Kae K. Rairdin files, RRPL.

[121] Phillip M. Boffey, "Reagan Urges Wide AIDS Testing but Does Not Call for Compulsion," *New York Times,* June 1, 1987. As a number of commentators and historians have noted, Reagan was notoriously silent on the issue of AIDS in the early 1980s. Many have also noted that Reagan's budget called for a reduction in AIDS research, with Congress appropriating more funds to deal with AIDS than Reagan requested. See Shilts, *And the Band Played On*, 600; Cohen, *The Boundaries of Blackness*, 83-84; Turner, "Mirror Images," in *Creating Change*, 5; Ghaziani, *The Dividends of Dissent*, 77; Patterson, *Restless Giant*, 179.

[122] Phillip M. Boffey, "Reagan Urges Wide AIDS Testing but Does Not Call for Compulsion," *New York Times,* June 1, 1987.

[123] Paul D. Cleary et. al., "Compulsory Premarital Screening for the Human Immunodeficiency Virus: Technical and Public Health Considerations," *JAMA* 258, no. 13 (October 2, 1987): 1757, accessed February 2020, available at: https://jamanetwork.com/journals/jama/fullarticle/368468; "Analysis of Key AIDS-Related Legislative Proposals," April 1986, 2, AIDS Coalition to Identify Orange County Needs, box 15, Coyote records, Schlesinger Library.

two, Illinois and Louisiana, adopted and implemented these laws.[124] Because tests were expensive and identified few cases of HIV, Louisiana repealed the requirement one year later, in November 1988, followed by Illinois in September 1989.[125] Discussed further in chapter two, the proposals that state legislatures took more seriously were those to test all pregnant women and new-borns. Women's health advocates worried that routine or mandatory testing in prenatal clinics might lead to counselling that would encourage women who tested positive to have abortions, or the compulsory sterilisation of HIV-positive women.[126]

For women's advocates, these proposals had particularly worrisome implications for women of colour. Throughout the twentieth century, the movement for reproductive justice fought tirelessly to maintain the autonomy of diverse racial and ethnic groups of women in matters

[124] Texas adopted a law that triggered mandatory HIV testing based on prevalence in the general population (0.83%), but the state never reached the prevalence rate and repealed the law in 1989. Missouri passed a similar law that would have required such testing if the CDC recommended mandatory premarital testing. The law is no longer in effect. At least thirteen states require marriage licence applicants to receive information regarding HIV infection and testing. Memorandum for Dr Donald MacDonald from Kae Rairdin, "AIDS Legislation," July 14, 1988, 6, box 2, fol. 1, Rairdin files, RRPL.

[125] Referring to Illinois, journalist Sandra G. Boodman commented that "As of July 29, only 10 of more than 75,000 marriage licence applicants have tested positive for the AIDS virus…This year the total cost of the tests, which are paid for by couples, is expected to be $6 million, roughly half the amount the state legislature has allocated for AIDS prevention." Boodman, "Premarital AIDS Testing Annoying Many in Illinois," *Washington Post*, July 30, 1988; Kasey S. Buckles et al., "Changing the Price of Marriage: Evidence from Blood Test Requirements," *Journal of Human Resources* 46, no. 3 (July 2011): 539-567, accessed February 2020, available at: http://jhr.uwpress.org/cgi/reprint/46/3/539. According to a study in the *Journal of American Medical Association*, the number of marriage licenses declined in Illinois but went up in the surrounding states during that same time. B. J. Turnock and C. J. Kelly, "Mandatory premarital testing for human immunodeficiency virus: The Illinois experience," *Journal of American Medical Association* 261, no. 23, (1989): 3415, accessed February 2020, available at: https://jamanetwork.com/journals/jama/fullarticle/377684

[126] Women's health advocates became concerned following official public health recommendations advising HIV-positive women to delay or forgo pregnancy. In 1985, the CDC recommended that HIV-positive women be advised to "delay" or "prevent" pregnancy. CDC, "Recommendations for Assisting in the Prevention of Perinatal Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus and Acquired Immunodeficiency Syndrome," *MMWR* 34, no. 48 (December 6, 1985): 721-6, 731-2. In 1988, Curran also commented that "Someone who understands the disease and is logical will not want to be pregnant and will consider the test results when making family planning decisions," quoted in Fern Schumer Chapman, "Official Advocates AIDS Testing of Pregnant Women," *Washington Post*, September 20, 1988. In 1987, the American College of Obstetricians and Gynecologists (ACOG) similarly recommended that HIV-positive women be "strongly encouraged not to become pregnant." ACOG, "Prevention of Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome," ACOG Committee Statement, no. 53 (1987), quoted in Maxwell Gregg Bloche, "Beyond Autonomy: Coercion and Morality in Clinical Relationships," *Health Matrix* 6, no. 229 (1996): 232. See also Denenberg, "Pregnant Women and HIV," Banzhaf et al., *Women, AIDS, and Activism*, 159.

related to their reproductive health in the wake of state interference. In 1973, the Southern Poverty Law Center (SPLC) had discovered that for many decades, doctors had sterilised approximately 100,000 to 150,000 women using federal funds.[127] In addition to sterilisation abuses, the birth control pill that came to market in the United States in the 1960s followed a trial of 132 Puerto Rican women in which two women died and were then excluded from the study report.[128] By the 1980s, doctors had sterilised thirty-three percent of Puerto Rican women. During the 1960s and 1970s, the women's movement fought to restrict the widespread practice of coercive or forced sterilisation, and in the pre-Roe years, civil rights leaders often worried that abortion, as a means of population control, would be used to harm the interests of women of colour.[129] In 1974, the US DHHS issued guidelines that required informed consent and prohibited sterilisation of women under the age of twenty-one.[130] In the wake of the AIDS epidemic, women's health advocates again worried that the polices that federal agencies were developing to reduce perinatal transmission in the context of wanting to officially outlaw abortion might repeat the abuses of the past.

Others similarly expressed concern over potential sterilisation abuses. Prostitutes' rights activists of the organisation Call Off Your Old Tired Ethics (COYOTE) Barbara Santee and Carol Leigh argued that women "must be prepared to confront the challenges which will be thrown at reproductive freedom in the guise of 'protecting the public good from the threat of AIDS.'" Leigh worried that homophobic measures such as quarantining and tattooing might "be used to justify laws forcing infected persons to be sterilized against their wills or coerced

[127] Randall Hansen and Desmond King, *Sterilized by the State: Eugenics: Race, and the Population Scare in Twentieth-Century North America* (Cambridge: Cambridge University Press, 2013), 249.
[128] Sheryl Burt Ruzek, *The Women's Health Movement: Feminist Alternatives to Medical Control* (New York: Praeger Publishers, 1978), 37.
[129] *Roe v. Wade* was the 1973 Supreme Court ruling granting women the constitutional right to abortion. Ziegler, "The Framing of a Right to Choose," 239-330.
[130] McGuire, *At the Dark End of the Street*, 191-192; Rosalyn Baxandall and Linda Gordon, "Second Wave Feminism," in *A Companion to American Women's History*, ed. Nancy Hewitt (Malden, Mass.: Blackwell Publishing, 2002), 420.

into having unwanted abortions."[131] Members of other feminist groups including WAN, the Women's Global Network on Reproductive Rights, the Reproductive Rights Network, National Women's Health Network, the National Organization for Women (NOW), and the Association of Women for AIDS Research and Education (A.W.A.R.E) all spoke out against the potential for coerced abortion and sterilisation in cases where a pregnant woman received a positive test result instead of properly educating her to make a decision about the thirty percent chance of perinatal transmission.[132]

Physician Janet Mitchell of the Harlem Hospital Centre in New York aptly summarized the irony of the state ignoring women as individuals needing treatment on the one hand and targeting them for the sake of reducing perinatal transmission on the other when she observed that:

> With perinatal transmission of HIV on the increase, one would expect someone to be interested in the women bearing these children. Unfortunately, that has not been the case. Ironically, developing strategies to reduce perinatal transmission recently has become a priority with federal and public health agencies…The recommendation most often voiced is that HIV seropositive women should delay childbearing because of the estimated 50 percent chance that their child will develop AIDS.[133]

[131] Barbara Santee and Carol Leigh, "HIV-Positive Women Have Rights Too—and They're Often Denied," *On the Issue*, 1988, 11, box 139, fol. 10, BWHBC records, Schlesinger Library.
[132] Stephanie Poggi, "Women and AIDS," *Reproductive Rights Network Newsletter*, Spring 1987, 1-4, box 25, fol. 21; NOW Legal Defense and Education Fund, "Facts on Women and AIDS," June 1988, 2; BWHBC records; Letter from Nancy Stoller Shaw on behalf of WAN to Tom Mosmiller, Coordinator, AIDS Antibody Testing Program at the San Francisco Department of Public Health, November 13th, 1986, 1-3; Henri E. Norris, "Women and Reproductive Rights," 1987; Women's AIDS Network Meeting Minutes 11/4/86, box 2, fol. 538, Coyote records, Schlesinger Library.
[133] Mitchell, "What About the Mothers of HIV infected Babies?" 1.

The federal proposals to reduce HIV transmission, including marriage licence testing, were expensive, ineffective, and did not reflect the reality that in the 1980s, sex and motherhood often happened outside of the institution of marriage. Instead, with the shift toward neoliberal politics and ideas of personal responsibility in this period, the state-level, voluntary, and educational campaigns of distinct public health departments had a greater reach.

Throughout the 1980s, women had called for public health agencies to recognise them as whole, sexual beings and not only as reproductive agents. Such recognition brought prescriptions about motherhood and sexuality. Specifically, the campaigns encouraged women to seek treatment and services on behalf of their foetuses before seeking treatment and services for their own condition, and to modify their sexual behaviour for prevention, either engaging in abstinence or insisting on male condom use. These messages were particularly troubling given that they were created at the same time that the Reagan administration worked to slash tax-supported social programmes for improving health and undermine women's access to the very reproductive health services that helped them to plan for a pregnancy and seek medical care in the first place. The solutions offered were therefore individual rather than systemic.

Fighting for Women's Sexual Rights

In the first decade of the AIDS epidemic, HIV prevention strategies available to women included abstinence, condom use, and limiting sexual partners. Women's advocates noted that proponents of these methods often failed to recognise that many women lacked control over matters related to their sexuality. Although some scientists called for prevention options that would give women greater control in the epidemic during the 1980s, the FDA did not

approve the female condom until 1993, and public health campaigns continued to place the emphasis of prevention in this period on male condoms.[134] Ironically, although male condoms were not women-controlled, public health campaigns gave the impression that women were expected to control them.

In the 1980s and early 1990s, various national and state-wide public health departments ran publicity campaigns that perpetuated the historic trope of women as the vectors and transmitters of infection in infants.[135] They also perpetuated the historic, neoliberal trope that individuals should take greater personal responsibility in helping to prevent transmission of the virus. In an Oklahoma department of public health poster from 1990, entitled "No Time Bombs for Your Baby," the stomach of a faceless pregnant woman contains a foetus hugging a bomb. Instead of presenting women as individuals deeply concerned about their own health as well as the health of their child, the poster highlighted the threat that the woman's body posed to her baby and which grew the longer she left her condition untreated. The silhouetted woman, presented as a shadow and whose identity is thereby erased, was not encouraged to seek medical treatment for herself, only on behalf of her unborn child, who was the main focus of the poster.[136]

The Illinois department of public health produced a similar poster that encouraged women to "Take the HIV Test Before it's Time to Take a Pregnancy Test."[137] The message that women should get tested before considering pregnancy worried women's health advocates in light of

[134] Dick Thompson, "Packing Protection in a Purse: Condoms are becoming a part of a woman's sexual survival kit," *Time Magazine Health & Fitness*, September 15, 1988; Sabbage "Fighting for Our Lives," 21; Warren E. Leary, "Female Condom is Approved," *New York Times*, May 11, 1993.
[135] Brandt, *No Magic Bullet*, 21, 32, 92, 94, 168; Gilman, "AIDS and Syphilis," 93-98, 107; Hammonds, "Missing Persons," 9-10; Treichler, *How to Have Theory in an Epidemic*, chap. 2, esp. 42-45, 65; Reagan, *Dangerous Pregnancies*, 225-241; Dubow, *Ourselves Unborn*, chap. 4, esp. 112-117.
[136] Unprocessed PR 13 CN 1992:024, 1990. LC Prints and Photographs Division, Washington, D.C.
[137] Unprocessed PR 13 CN 1994:060, undated. LC Prints and Photographs Division Washington, D.C.

the public health guidelines advising women who tested positive for the virus to abort or forego pregnancy. In a CDC poster, a young woman looks concerned as she leans on an empty cot next to the caption, "I Didn't Know I had AIDS…Not Until my Baby was Born with it." The accompanying text reveals that the woman contracted AIDS from "her man," and that "had I known better, I would have made him use condoms, and if that didn't work, I'd have stopped being with him."[138] Not only was the woman responsible for protecting herself, she was also responsible for protecting her child. Despite the necessity of raising awareness of the issue of HIV-AIDS among women, the messaging urging women to modify their behaviour instead of acknowledging the need for systemic improvements in health insurance, health services, and prenatal care contained in these posters were harmful in placing the burden of reducing perinatal transmission solely on women.[139]

Public health agencies also ran campaigns that called on women to take greater responsibility in preventing heterosexual transmission of the virus. In a campaign designed to give women verbal strategies to encourage men to engage in safer sex in the wake of the epidemic, the CDC produced posters that read, "If he doesn't have a condom, you just have to take a deep breath and tell him to go and get one."[140] The condom segment of the film *Sex, Drugs & AIDS*, originally made for the New York City Board of Education, showed three girls chatting about where to buy male condoms and why they should use them.[141] Advertising companies and condom manufacturers also directed their safer sex campaign messages at women. The New York advertising executive Jerry Della Femina created a condom advert

[138] Atlanta, GA.: Centers for Disease Control, 1990. NLM, accessed February 2020, https://stacks.cdc.gov/view/cdc/34465
[139] Public health messaging that called on women to take personal responsibility to prevent the transmission of perinatal HIV echoed similar messages aimed at women to prevent mother-to-child transmission of rubella in the 1980s. See Reagan, *Dangerous Pregnancies*, 186-202.
[140] Atlanta, GA.: Centers for Disease Control, 1983. NLM, accessed February 2020, https://stacks.cdc.gov/view/cdc/34804
[141] Stuart Elliott, "Leaders of Anti-AIDS Effort See Good Progress So Far," *New York Times*, July 26, 1991.

titled "I enjoy sex, but I don't want to die for it" that featured a distressed woman discussing the virtues of male condom use as opposed to the importance of mutual responsibility.[142] The advertising firm Saatchi & Saatchi produced three adverts with similar themes. One depicted a couple kissing, and when the woman presented the man with a condom, he backed off, saying, "You don't want me to wear this?" Sensing he would not change his mind, the woman told him to "forget it" and walked out of the apartment, leaving him standing, puzzled, in the doorway.[143]

Many feminist commentators critiqued and, as seen in figure 1 below, satirised messages that put the onus of prevention on women. Created at a time when society was beginning to recognise the phenomenon of acquaintance rape, they were also tone-deaf about sexual violence.[144] Women's inability to use male condoms or control their use by men in a heterosexual relationship left Esther R. Rome of the BWHBC wondering "is what started out as a beneficial increase of awareness and comfort for women turning into another area of responsibility in which they have to convince a man to do something for his and her own good?"[145] Other women's health advocates were also quick to note the limitations of such campaigns for women.[146] "Since men are the ones with the penises, wouldn't it make better sense to require Johns to make sure condoms are worn during sex?" asked Women's Caucus

[142] Randall Rothenberg, "Condom Marketers Dropping Scare Tactics, *New York Times*, August 8, 1988.
[143] Nat Moss, "Safe sex is no sex on New York TV," *In these Times*, February 10-16, 1988.
[144] In 1982, Mary Koss, a clinical psychologist who had worked on "hidden rape" teamed up with *Ms*. Magazine to conduct a nationwide survey on sexual violence. In their study, they reported that one in four women on college campuses would experience rape or attempted rape by the time they graduate college. See Robin Warshaw, *I Never Called It Rape: The Ms. Report on Recognizing, Fighting, and Surviving Date and Acquaintance Rape* (New York, c.1988, 1994).
[145] Esther R. Rome, "Are Women Responsible for AIDS Prevention?", 2, box 25, fol. 21, BWHBC records, Schlesinger Library.
[146] Laura Giges, "AIDS: A Woman's Issue," *The Santa Cruz Women's Health Center* reprinted in *Women Wise*, 1985/1986, box 140, fol. 1; Rome, "AIDS burden falls on women," *Middlesex News*, June 8, 1987, 1, box 139, fol. 10; "Tests Confirm Condoms Block AIDS Virus," *Medical World News*, January 27, 1986, box 140, fol. 2; Anna Quindlen, "Life in the 30's: For women, the condom campaign is slightly tardy," *New York Times*, 17 June, 1987; Carol Emert, "Women and AIDS: The New Sexual Responsibility," *Second Century Radcliffe News*, June 1988, 8, box 140, fol. 1, BWHBC records, Schlesinger Library.

members Zoe Leonard and Polly Thistlethwaite.[147] Marie St. Cyr, director of the Women and AIDS Resource Network (WARN), noted that "heterosexual men aren't even asked to share responsibility. Over and over, the image projected is that it's a woman's own fault if she gets AIDS."[148] National AIDS prevention programme director Gloria Weissman highlighted the irony that "while women at risk repeatedly are told to use condoms, they're not the ones who have to put them on," and physicians Carole Marte and Kathryn Anastos concurred that "efforts to insert AIDS prevention activities into the context of pregnancy and heterosexual sex inevitably raises issues of women's subservience and empowerment."[149] Such campaigns failed to recognise the gender power imbalance in condom negotiation. Many men refuse—sometimes violently—to wear condoms when having sex with their partner. Moreover, many women did not have full control over matters related to their sexuality and it was often a woman's partners' behaviour rather than her own that put her at risk.

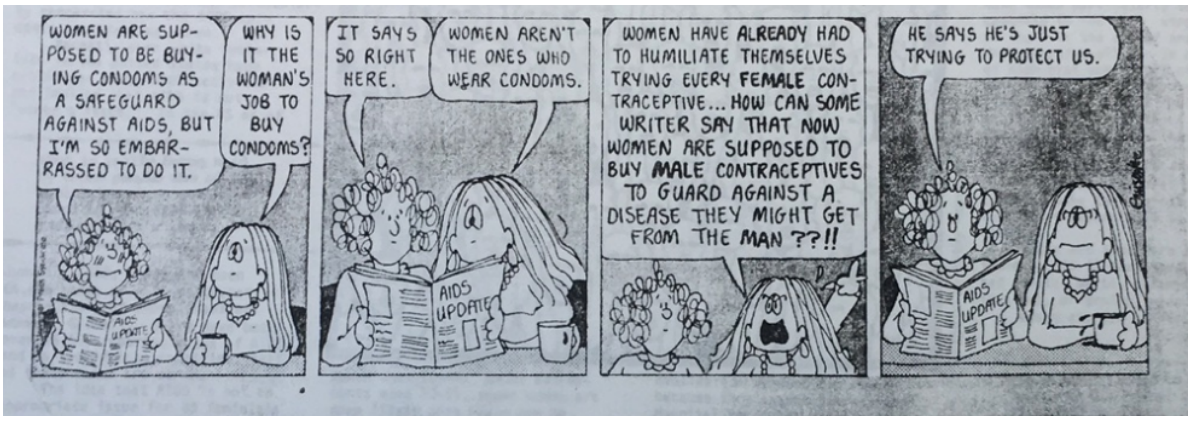


Figure 1. Cathy for *Glamour*, July 1987.[150]

[147] Banzhaf et al., *Women, AIDS, Activism*, 182.
[148] Quoted in Norwood, "The Silent Minority,"13.
[149] Kathryn Anastos and Carole Marte, "Women—The Missing Persons in the AIDS Epidemic," *Health/PAC Bulletin*, Winter 1989, 22, box 139, fol. 14, BWHBC records, Schlesinger Library.
[150] Christopher Norwood, "Is Preventing AIDS the Responsibility of Women? The Media Seem to Think So," *Glamour*, July 1987, 18, box 139, fol. 10, BWHBC records, Schlesinger Library.

The suggestion given in official public health campaigns, as well as commercial condom adverts, that women were the predominant carriers and preventors of HIV transmission both sexually and reproductively inspired activists to create their own feminist public health publicity. In books, pamphlets, journals, and through various other media, a range of feminist activists offered women accurate information on HIV and AIDS that also put the need to protect women's sexual and reproductive autonomy in the wake of the AIDS epidemic front and centre.

Feminist Public Health Alternatives

In the 1980s, Faye Wattleton, the youngest, first Black, and first woman President of the Planned Parenthood Federation of America fought tirelessly to expand Planned Parenthood's services to provide women with access to low-cost HIV testing and started the Planned Parenthood Action Fund to engage in public education and organise grassroots campaigns. In 1986, Wattleton published *How to Talk with Your Child About Sexuality*, a guidance book that spoke candidly about the need for parents to inform children about sexually transmitted diseases such as HIV.[151] In 1987, alongside the pioneering co-chairman of AmFAR Dr Mathilde Krim, she also appeared as a guest on the television show *Ask Dr. Ruth*, a half hour series hosted by sex therapist Dr Ruth Westheimer in which invited guests answered questions about HIV, sexuality, and sex education from a live and phone-in audience.[152]

[151] Faye Wattleton, *How to Talk With your Child About Sexuality* (New York: Doubleday & Company, Inc., Garden City, 1986), 87-90.
[152] Ask Dr. Ruth, Lucie Arnaz & Faye Wattleton / directed by David L. McGrail. United States: s.n., 1987. VAD 9879. Motion Picture and Television Reading Room. LC, Washington D.C.; Ask Dr. Ruth. Dr. Mathilde Krim, Ph.D. Part 1 & 2. /directed by David L. McGrail. United States: King Features Entertainment, 1987. VBF 0538. Motion Picture and Television Reading Room. LC, Washington D.C.

In March 1989, members of the ACT UP Women's Caucus ran a Women and AIDS teach-in in New York that culminated in the publication of a collection of essays exploring gendered aspects of the epidemic one year later. Originally entitled *The ACT UP Women's Caucus Women and AIDS Handbook,* and later published as ACT UP/NY Women & AIDS Book Group, eds., *Women, AIDS and Activism,* the authors modelled the anthology on the BWHBC's 1971 feminist bestseller, *Our Bodies, Ourselves.* The authors explained that it was their "primary objective to provide information and analyses as a context for understanding issues for women in the AIDS crisis."[153] The handbook was broad in scope, and, among other issues, highlighted the obstacles to safer sex for women, including male condom negotiation. In an essay entitled "Demanding a Condom," Kat Doud recalled how she had struggled to convince her male partner to use a condom as protection against AIDS:

> Max (not his real name) was putting a lot of pressure on me to get birth control pills for protection, only the only protection pills would offer would be for pregnancy—not AIDS. During this time, my fear of AIDS was growing. I was getting really paranoid, so I called the hotline. They talked a lot about condoms and safer sex. I went immediately to Max to tell him how I was feeling and that I wouldn't have sex with him without condoms. His reaction was horrible. He got very angry and full of contempt and accused me of having AIDS, and angry that I insinuated he did.[154]

The handbook also recounted past actions that members of the Women's Caucus had organised encouraging men to take greater responsibility in practicing safer sex.

[153] ACT UP/ NY, *Women and AIDS Handbook*, 1.
[154] ACT UP/ NY, *Women and AIDS Handbook*, 191.

The work of the BWHBC that had influenced members of the Women's Caucus continued beyond the publication of their landmark text in 1971. The authors regularly updated the original material and published new editions that addressed the latest issues in women's health. Since the 1970s, *Our Bodies, Ourselves*, has sold over four million copies and has been translated or adapted into 31 languages. In the United States, it has been updated and revised nine times, most recently in 2011, to include new information and perspectives.[155] The publication of multiple editions of *Our Bodies, Ourselves* over a number of years and across diverse platforms attests to its influence, reach, and impact, as well as the strength of the organisation to adapt their work to meet women's ongoing and changing healthcare needs.

For the 1992 edition, entitled the *New Our Bodies, Ourselves: A Book By and For Women*, original members of the BWHBC such as Jamie Penney collaborated with Women's Caucus members Marion Banzhaf and Risa Denenberg, and in the preface the authors explained that they had "added new topics such as AIDS, new birth control methods and special disorders that affect primarily women—subjects we did not cover in the 1984 edition."[156] Evidence that the BWHBC addressed AIDS as an issue related to reproductive health, both sections on "AIDS, HIV Infection and Women" and "Abortion" in the 1992 edition came under the section "Controlling Our Fertility."[157] Similar to the *Women, AIDS, Activism* handbook and other feminist books, articles, posters, and cartoons such as satirist Alison Bechdel's illustration seen in figure two, the information on AIDS in the *New Our Bodies, Ourselves*, also covered safer sex. "If a man refuses to use a condom and overpowers you into having

[155] Our Bodies, Ourselves: The Nine U.S. Editions, accessed February 2020, https://www.ourbodiesourselves.org/publications/the-nine-u-s-editions/
[156] Boston Women's Health Book Collective, *New Our Bodies, Our Selves: A Book By and For Women* (New York: Simon and Schuster, 1992), 11.
[157] BWHBC, *New Our Bodies, Our Selves*, 9.

intercourse, at least get some spermicide into your vagina, or use a female condom," the authors wrote.[158] Artists such as Alison Bechdel and Barbara Kruger similarly encouraged women to protect themselves through cartoons and posters. In 1992 Kruger created a broadside that read "Girl/ Don't Die for Love/ Do Safer Sex because AIDS Kills" for the art activist organisation Visual AIDS!'s awareness project.[159]



Figure 2. Alison Bechdel, *Making it a Woman's Guide to Sex in the Age of AIDS*, March 1989.[160]

The collaborative work of the Women's Caucus and the BWHBC, as manifested in the publication of both the *New Our Bodies, Ourselves*, and *Women, AIDS, and Activism*, demonstrated how the women's health movement of the 1970s continued with the movement to address the issue of AIDS in women in the 1980s, both groups linking women's medical treatment to women's oppression and shaping how AIDS was understood as a disease directly related to the politics of women's bodies. Both were guides written by and for women in order to demystify medical expertise and provide women with the basic information about HIV and AIDS that they found lacking in the available resources. Crucially, both books sought to empower women with the latest scientific information,

[158] BWHBC, *New Our Bodies, Our Selves*, 337-38.
[159] Barbara Kruger for Visual AIDS! (1992), fol. misc. Visual AIDS! Archive, Manhattan, New York.
[160] Reprinted in Sabbage, "Women & AIDS: Fighting for Our Lives," 20.

education, and resources to help them make informed decisions about their bodies with respect to their own condition, including over reproduction.

The authors of the two anthologies argued that, similar to past coercive medical policies and laws that resulted in high sterilisation rates for Native American, Puerto Rican, and low-income women, the link between HIV and pregnancy threatened a woman's reproductive rights. Marion Banzhaf, Tracy Morgan, and Karen Ramspacher of the Women and AIDS Book Group noted that "one of the primary reproductive rights issues for HIV-positive women is support for their right to have children if they so desire."[161] In the chapter "AIDS, HIV Infection and Women" the authors of the *New Our Bodies, Ourselves* similarly argued that public policy in response to AIDS, in particular the advice given to AIDS policymakers in legal and medical programmes to actively discourage all HIV-positive pregnant women from becoming pregnant and encourage pregnant HIV-positive women to terminate their pregnancies, "has greatly threatened the reproductive lives and choices of HIV+ women," putting a "HIV+ woman's right to decide whether to continue or terminate her pregnancy in serious jeopardy."[162] They argued that the advice to delay or forgo pregnancy was especially alarming given that "the medical evidence regarding the effects of pregnancy on the health of HIV+ women and the rates, methods and risk factors for transmission to the foetus are inadequate and inconclusive."[163] In *Women, AIDS, Activism*, Risa Denenberg similarly argued that because not enough was known at the time about the effect of HIV on pregnancy to provide comprehensive advice or counselling to HIV-positive women, "the rights of these women demand scrupulous protection. No situation has called more loudly for a feminist

[161] Marion Banzhaf at al., "Reproductive Rights and AIDS: The Connections," in Banzhaf et al., *Women, AIDS, Activism*, 207.
[162] BWHBC, *New Our Bodies, Our Selves*, 336.
[163] BWHBC, *New Our Bodies, Our Selves*, 336.

response."[164] Given the paucity of information available at the time, these women argued that the only acceptable counselling to pregnant women on questions of pregnancy would be full explanations of the available information, a nondirective approach, and complete medical and social support for the woman's decision.[165]

Throughout the 1980s, in publications such as those discussed above and through anthologies, articles, magazines, and on television, women's health advocates persistently articulated the need to educate women about HIV and to protect the autonomy of HIV positive women, including the reproductive choices of women who wanted to become pregnant and to carry a pregnancy to term or to terminate it. In addition, women's health advocates used the largest international platform on AIDS to call attention to the policies proposed to reduce transmission that threatened women's rights. As a result, their fight to have their voices heard and their needs taken seriously in the first decade of the epidemic also played out internationally. By the mid-1990s, their efforts had synthesised into public health policy that counted women as more than just mothers but as human beings with complex health needs.

Shaping an International Platform

During the 1980s and early 1990s, women's health advocates and activists regularly attended meetings of the International Conference on AIDS. The inaugural meeting took place in Arizona in 1985 and has served as the main international forum for exchanging scientific information about HIV and AIDS ever since. The World Health Organization (WHO), the US

[164] Denenberg, "Pregnant Women and HIV," in Banzhaf et al., *Women, AIDS, Activism*, 160.
[165] Denenberg, "Pregnant Women and HIV," in Banzhaf et al., *Women, AIDS, Activism*, 163.

DHHS, and other major research institutes organized and funded the first conference, with the early meetings focusing more on biomedical and epidemical research rather than the broader social, political, and behavioural issues that became prominent in later years.

Throughout the epidemic's forty-year history, the conferences have provided an index for changes in AIDS research and campaigning. Since its inception, women had used the conference as an international platform to counter the inadequate representation of women in the political and public health discussions of the complex issues and problems surrounding AIDS in women, except as vectors of transmission either prenatally or through prostitution. As the CDC's most visible platform, they also used the conferences to object to women's exclusion from the CDC's official AIDS case definition. As historian Emily K. Hobson has noted, "conference protests indicated a clear investment in a multi-issue politics and showed how proponents of a social action response to AIDS were turning ever greater attention to criminalization and poverty."[166] As the organising of the women at the conferences similarly attests to, women wanted to make sure that reproductive autonomy was part of a holistic approach to healthcare.

At the third International Conference on AIDS held in Washington, D.C., in June 1987, activists from the International Working Group on Women and AIDS wrote a two-page open letter to the planning committee that critiqued the current treatment of women in the HIV/AIDS epidemic. Beginning by asserting that "AIDS is a woman's issue," the letter to the planning committee stated that in the US women were proportionately the fastest growing group of people with AIDS; that in New York City, AIDS was the primary cause of death for

[166] Emily K. Hobson, *Lavender and Red: Liberation and Solidarity in the Gay and Lesbian Left* (Berkeley: University of California Press, 2016), 183.

women 25-29 years old; that women of colour carried a disproportionate burden of this disease; and that at least half of individuals with AIDS in Africa and the Caribbean were women:

> Of particular concern is the paternalistic and cavalier disregard for the reproductive rights of women at highest risk for HIV infection. Because historically, women of color have been repeatedly subject to forced sterilization and coerced family planning decisions, it is essential that all public health measures respect the dignity and autonomy of the pregnant woman. No meaningful reproductive options exist in the absence of adequate nutrition, prenatal and medical care, or without daycare, education and schooling for all children, including those born with disease or HIV positivity, and the availability of abortion on demand for women who choose it.[167]

As the International Working Group on Women and AIDS' letter attests to, women's health advocates saw the threat AIDS posed to the reproductive lives and choices of women not only in terms of the historical reproductive abuses women of colour had suffered in the past, but to the new struggles that women faced following the shrinking of domestic welfare programmes, particularly the Food Stamps programme, Medicaid, and Aid to Families with Dependent Children, in the Reagan era.[168]

Jamie Penney of the BWHBC travelled to the fifth conference held in Amsterdam in July 1992 and similarly tied the issue of AIDS among women to the question of reproductive

[167] International Working Group on Women and AIDS, "An Open Letter to the Planning Committees of the International Conference on AIDS," Distributed at AIDS Conference in Washington, D.C., week of June 1, 1987, 1-2, box 139, fol. 10, BWHBC records, Schlesinger Library.
[168] John O'Connor, "Us Social Welfare Policy: The Reagan Record and Legacy," *Journal of Social Policy* 7 no.1 (1998): 40; Davies, "Reagan and Welfare," 211-212, 225-227.

rights. Boston was meant to host the fifth conference in July 1992, but the organisers moved it to Amsterdam following the new travel and immigration restrictions the United States government had enacted against people with AIDS.[169] In an open letter to the conference organisers, she wrote that:

> AIDS is directly related to community health but also to reproductive rights. AIDS is a sexually-transmitted disease to which women are uniquely vulnerable. We are much more likely to become infected than to infect others. A woman's decision to use a contraceptive or not, which contraceptive to use, whether or not to have a child and whether or not to breastfeed that child will depend on the information she has about AIDS. AIDS will very quickly become a widespread heterosexual disease—all of us are vulnerable. We must demand that resources and information be made available to women's groups all over the world, and that governments and international organizations make information about women and AIDS widely available to us. Women are the only ones who can stop AIDS, we are the ones who will have to do the work.[170]

Through these open letters, women's health advocates used the largest international platform on AIDS to argue that women needed both sexual and reproductive healthcare, as well as accurate information, education, and resources on HIV and AIDS. As the publication of *Women, AIDS, Activism* and *New Our Bodies, Ourselves*, as well as women's numerous other public health initiatives attests to, women did not wait to see whether the international community would meet their demands. They published their own information designed to

[169] Robert Steinbrook, "Optimism, Concern Mark Close of AIDS Conference: Medicine: Progress is reported in vaccine research. But the disease continues unabated in Third World," *Los Angeles Times,* June 22, 1991.
[170] Jamie Penney, "Women & AIDS," July 1992, box 79, fol. 21, BWHBC records, Schlesinger Library.

reach women and educate them on how transmission occurs and how to protect the health of themselves and their partners. Women also used the meetings as an international forum to protest not only the lack of basic HIV and AIDS information available to women but the fact that women continued to suffer and receive inadequate medical care because of under-diagnosis and a limited case definition.[171]

As the end of the decade approached, women had become the fastest growing group of persons with AIDS. In 1989, 10,000 American women had AIDS, or nine percent of adult cases, up from six percent in 1985 and three percent in 1981.[172] But a number of commentators noted that it was unclear exactly how many of the estimated one million HIV-infected individuals in the United States were women as the CDC's routine reports issued on AIDS did not include female mortality and the CDC did not count gynaecological conditions as manifestations of HIV infection until 1993.[173] Women activists from around the world had also travelled to Amsterdam to confront James Curran, AIDS Program Director of the CDC, and demand that he add women-specific manifestations of HIV to the agency's official definition of AIDS in order to give women access to crucial services and benefits denied to many for nearly a decade.

Activists saw the most concrete changes in their demand that the CDC amend its official AIDS definition in the early 1990s. A wide array of organisations and individuals, including state legislatures, AIDS services providers, legal advocates, AIDS researchers, and AIDS activists had for years demanded that the CDC expand their AIDS surveillance definition to

[171] San Francisco International AIDS Conference Tape #2: Women's demonstration 1990 June 00:60:00. AIDS Activist Videotape Collection, NYPL Manuscripts and Archives Division.
[172] Santa Cruz Women's Health Center Newsletter, "AIDS: A Woman's Issue," Number XXXVIII, Summer 1985, 3-4; Dr Rosmarie Erben, "The special threat to women," *World Health Special Issue on Women and AIDS*, November/December 1990, 8, box 139, fol. 13, BWHBC, Schlesinger library.
[173] Anastos and Marte, "Women—The Missing Persons in the AIDS Epidemic," 6.

include clinical symptoms common in women and injection drug users. The tireless campaigning during the epidemic's first decade included hearings held on the AIDS case definition by a congressional subcommittee who pressed the CDC to make additions to the definition until the proposed changes were announced; a class-action lawsuit that activists brought against the SSA and CDC; and the lobbying of the NIH by members of the Women's Caucus to hold a conference on women and AIDS. In December 1992, the CDC conceded and published its "1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults" which reported that the CDC were adding three conditions commonly found in women and intravenous drug users—invasive cervical cancer, pulmonary tuberculosis, and recurrent pneumonia—to its official definition of AIDS.[174] Evidence of the extent to which the earlier iterations of the case definition had resulted in under-diagnosis, the expansion saw a vast increase—from 49,016 in 1992 to 103,500 in 1993—in the total number of AIDS cases reported to the CDC that year.[175]

As the campaign to change the CDC's official AIDS definition showed, different organisations and individuals worked continually to shape and reshape scientific and popular knowledge of AIDS throughout the 1980s: revealing the ongoing processes by which diseases are defined. Women's health activists learned about the new disease in order to inform women at large of their risk of infection while petitioning the federal government for equal access to medical care and treatment. Activists and advocates succeeded in getting the

[174] CDC, "1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults," *MMWR* 41, no. RR-17 (December 18, 1992); Maxine Wolfe, Ph.D., "Submitted as Public Comment for Hearing Re: New Case Surveillance Definition of AIDS, held in Atlanta, Georgia, Sept. 2, 1992," 1-4, in 6/92-12/92 CDC Campaign, box 4, fol. 24, Maxine Wolfe papers, LHA.
[175] Wolfe, "CDC Campaign, 9/92-12/92," box 4, fol. 24, Maxine Wolfe papers, LHA; CDC "Impact of the Expanded AIDS Surveillance Case Definition on AIDS Case Reporting—United States, 1993," *MMWR* 43, no. 9 (March 11, 1994): 160-161, 167-170. For more on the campaign to change the definition, see Bell, "Rethinking the 'Straight State,'" 931-952.

CDC to amend its original definition of AIDS that clearly failed to account for the full reach of the disease in 1987 and again in the early 1990s.

Following numerous direct action protests demanding the inclusion of women, people of colour, and intravenous drug users in drug trials – including those by ACT UP and WHAM! held outside the New York University AIDS Clinical Trial Units on International Women's Day in March 1990, the National Institutes of Health in May, and at the International AIDS Conference in San Francisco in June – women and their political advocates also made gains when in December 1990, Congress passed a bill, sponsored by Senator Barbara A. Mikulski (D-MD) titled the Women's Health Equality Act.[176] The Act, among other things, directed the Secretary of Health and Human Services to establish an Office of Women's Health Research requiring "that women and minority groups are included as research subjects" in clinical trials, to ensure "that research relating to women's health is identified and addressed throughout the research activities conducted and supported by the NIH," and authorising the Secretary of Health and Human Services to "make grants regarding prevention of AIDS and other sexually transmitted diseases in women, including preventative health services, screening, providing treatment, referrals, and follow-up services."[177] In 1993, the US government went one step further, passing the National Institute of Health Revitalization Act that made it illegal not to include women and racial and ethnic minorities in federally funded clinical trials.[178]

[176] To emphasise the extent of women's exclusion from clinical trials, women at the protest held up posters that read: "Mice have a better chance of getting experimental AIDS drugs than women." Zoe Leonard, "HIV-Antibody Testing and Legal Issues for HIV-Positive People," in Banzhaf et al., *Women AIDS Activism*, 68. See also Marea Murray, "An Activist Perspective on the First National Women and HIV Conference," *Gay Community News* 18, no. 24, January 13, 1993, 8-10, Subject file: AIDS, LHA.
[177] S.296—101st Congress: Women's Health Equality Act of 1990, accessed February 2020, https://www.congress.gov/bill/101st-congress/senate-bill/2961
[178] The rules only applied to NIH-funded trials and not the clinical trials of private drug manufacturers. S.1—103rd Congress: National Institutes of Health Revitalization Act of 1993, accessed February 2020, https://www.congress.gov/bill/103rd-congress/senate-bill/1

With the passage of legislation that protected women's right to access clinical trials as women and not just as mothers, and a broadening of diagnostic symptoms pertaining to women, activists had succeeded in shaping a broader, more inclusive public health consensus in the post-1989 period.

Conclusion

After diagnosticians began reporting on cases of immunodeficiency in men and infants at the turn of the 1980s, they were slower to diagnose the unknown "AIDS agent" in women. The discovery that AIDS passed between men and women and from mother-to-child and that transmission was therefore not only about sex, but reproduction, increased the medical urgency to diagnose and treat the disease in women. As doctors were diagnosing increasing numbers of women with HIV and increasing numbers of women were therefore qualifying for clinical trials, activists called for treatments that did not separate reproduction from women's overall health, seeking to ensure that women's autonomy, and the autonomy of their infants, were protected in treatment programmes.

For the women in this chapter, getting public health agencies to see women at all was important, even if as mothers at first. But activists also wanted them to see women as whole people with complex health needs. When public health agencies did see women in terms of their sexual health, their state-wide, voluntary public health initiatives put the onus of prevention both sexually and reproductively on women. In an attempt to remove the burden of prevention, feminists created alternative public health publicity that educated women on how transmission occurred and how to protect the health of themselves and their partners. By

1993, activists had succeeded in gaining the public health recognition that women got AIDS as women and not just as mothers and that they also needed education and protection. Specifically, they secured women's access to clinical trials and the expansion of the CDC's official AIDS definition to include gynaecological conditions pertaining to women, meaning that more women qualified for benefits when they were too ill to work.

Nonetheless, the AIDS epidemic emerged in the United States in an era of conservative politics and converged with an already fraught debate about abortion and women's right to have children when and whether they chose. Chapter two shows how, despite the success of activists in shaping a broader public health consensus by the mid-1990s, the issue of reproductive rights remained dominant within political debate in this period, with the scientific discovery of AIDS in women complicating the existing debate. Before the approval of the use of the AZT drug in pregnancy in 1994, dealing with the issue of abortion became inseparable from dealing with the problem of AIDS, and AIDS became ever more integral to the fight for reproductive justice in the first decade and a half of the epidemic.

***

Chapter Two

Of Childbearing Age:

The Reagan Administration, AIDS, and Reproduction, 1981-1994

Washington, D.C., 23rd March 1987:

"If a woman tested positively for the AIDS virus, would you recommend an abortion?". This was the question one reporter asked Surgeon General Charles Everett Koop as he stood before a crowd of journalists and twenty-two television cameras at the National Press Club, ready to capture his speech for the evening news and next day's papers.[179]

"If you wanted to give her all the possibilities that were available to her, you would have to mention abortion," Koop replied quickly. "It is my understanding that in major obstetrical clinics on the East Coast, where the population has a high incidence of AIDS virus, that women who are pregnant under 13 weeks are being advised to have abortions and about 50 percent of those, I understand, are indeed having abortions."[180]

While Koop later assured reporters that his personal opposition to abortion had not changed, pro-life commentators and members of the Reagan administration viewed his pronouncement that abortion was an option for HIV-positive pregnant women as only the latest "re-thinking" of his former anti-abortion position.[181] Feminist commentators such as Cindy Patton also expressed their surprise on learning that "even long-time abortion foe Surgeon General Koop

[179] Memorandum from Donald A. Clarey to Nancy J. Risque, "Dr. Koop's Speech at the Press Club," March 24, 1987, box 1, fol. 1, Cribb files, RRPL.
[180] Clarey to Risque, "Dr. Koop's Speech at the Press Club."
[181] "Pre-Pregnancy AIDS Test Urged," *AP-NY*, March 25, 1987, box 1, fol. 1, Cribb files; Jack Fowler, "Koop Report to Find No Proof of Abort Damage to Women," *Lifeletter*, no. 4, March 1988, 1, box 14, series II, Risque files, RRPL.

now concedes that women at risk for AIDS might be good candidates for abortion."[182] Later that day, Edwin A. Steane, President of the American Association of Blood Banks, and James Curran, AIDS Program Director of the CDC, supplemented Koop's comments by suggesting instead that all women "of childbearing age" get tested before contemplating pregnancy and delay or prevent pregnancy if the results were positive.[183]

As Koop's speech at the Press Club demonstrated, HIV testing in the 1980s was as much about abortion as it was gay rights. Throughout the decade, the growing recognition of AIDS in women came at a crucial time both in terms of preventing the spread of AIDS and protecting women's bodily autonomy. The discovery of the epidemic among women coupled with the treatment of all women as mothers and potential childbearers raised new questions for the anti-abortion movement, in particular whether the desire to protect the health of the foetus meant endorsing the termination of pregnancies in cases where women tested HIV-positive. At the same time, many women's health advocates mobilised around protecting the reproductive rights and defending against the reproductive abuses of all women in the wake of the epidemic.

Koop's evangelical faith and his personal pro-life sympathies made him an unlikely advocate of people with AIDS and endorser of the need for contraception, sex education, and—in cases where women wanted the procedure—abortion as HIV prevention. However, as the 13th US Surgeon General, guided by a duty to put pragmatic public health before partisan politics, Koop put his faith in science and used the influence of his office to override the Reagan administration's political agenda, reject the calls for taking coercive measures to control

[182] Patton, "Feminists Must Oppose Widespread Testing," 3.
[183] Clarey to Risque, "Dr. Koop's Speech at the Press Club."

AIDS and to discredit, from a medical standpoint, the legitimacy of post-abortion syndrome.[184] His actions embodied the tension between ideological and public health approaches to women's health, and especially the health of women with AIDS, within the federal government, which surprised his supporters as well as his critics. It was not only his endorsement of condoms and sex education in public schools as HIV prevention that Koop upset his once conservative allies, as religious studies Professor Anthony Petro and others have argued.[185] Koop also betrayed the hopes of those who had expected him to use the institution of his office to deliver a practical blow against *Roe v. Wade*. In his study of AIDS and religion, Petro emphasised the conservative nature of Koop's promotion of sexual morality as AIDS prevention. In contrast, I argue that Koop's actions and the alliances he built in dealing with the interconnected issues of AIDS and abortion were more radical for protecting women's reproductive choices.[186] Moreover, a focus on his actions reveals not only what historian Jennifer Brier described as the fragility of the conservative consensus in the 1980s, but the fundamental realignment that took place within both political parties and political factions in this period especially over women's reproductive rights.[187]

In examining the interplay between women's health advocates—in particular Faye Wattleton, the President of Planned Parenthood Federation of America, pro-life members of the Reagan administration, Surgeon General Koop, and Republican women such as First Lady Barbara Bush—who put AIDS and abortion alongside each other during the uncertain first decade and

[184] The term "post-abortion syndrome" refers to the idea that abortion has negative psychological effects on women and that abortion increases women's risk of depression and suicide. For more information, see Jill Wolhandler et al., "Abortion," in *New Our Bodies, Ourselves*, 369-371.
[185] Petro, *After the Wrath of God*, 72. Other scholarship that addresses the surprising nature of Koop's approach to AIDS include William Martin, *With God on Our Side: The Rise of the Religious Right in America* (New York: Broadway Books, 1996), 240-241; William B. Turner, "'Adolph Reagan?' Ronald Reagan, AIDS, and Lesbian/Gay Civil Rights," (July 13, 2009): 15-16, available at SSRN: https://ssrn.com/abstract=1433567; Patterson, *Restless Giant*, 180.
[186] Petro, *After the Wrath of God*, 90.
[187] Brier, *Infectious Ideas*, 82.

a half of the epidemic, this chapter asks how abortion politics informed AIDS and how AIDS in turn informed the wider battles over women's reproductive justice in and beyond the federal government. The first section of the chapter examines the stakes that came with the political and public health recognition of AIDS in women and the desire to curb perinatal transmission for HIV-positive women seeking to protect their reproductive autonomy in situations where they either wanted to prevent or delay pregnancy, or to terminate unwanted pregnancies. In section two, I show how Koop surprised many with his promotion of condoms and sex education as the solutions to prevention. Addressed in section three, Koop's actions became even more surprising when he worked in unlikely alliance with Wattleton and Planned Parenthood and, lacking sufficient statistical evidence, refused to publish a public health report confirming the negative health effects of abortion on women. The chapter concludes in section four, which examines how conservative women such as Barbara Bush offered a solution to the question of what to do with children neither prevented nor aborted but born with AIDS.

Through his endorsement of the need for contraception and sex education as HIV prevention and in offering abortion as a less morally desirable, but medically viable, option for women who wanted to terminate their pregnancies, Koop's two-fold approach to the interconnected problems of AIDS and abortion served to protect women's reproductive choices. Moreover, through their support of AIDS Houses founded to care for sick infants in this period, conservative women such as Barbara Bush took up the challenge of what to do with children who were neither prevented nor aborted but born with AIDS. Before the approval of the use of the AZT drug in pregnancy in 1994, dealing with the problem of abortion became inseparable from the issue of AIDS, and AIDS became ever more integral to the fight for reproductive justice. Driven by compassionate conservatism and pragmatic public health,

Koop's two-fold approach, and Bush's third way, gave women the means to protect their autonomy in the first decade and a half of the epidemic.

Maternal Concerns

On 14th November 1988, 38 year-old Carol Doe, a Haitian woman living in New York, then five months pregnant, visited Jamaica Hospital in New York City for a routine prenatal check-up.[188] During the visit, a nurse encouraged Doe to undergo a test for HIV as part of her prenatal care and later informed her that she had tested positive for the virus. Three days later, Doe met with Dr Maurice Abitbol, chief of obstetrics and gynaecology at Jamaica Hospital. Since learning of her test results, Doe had decided to carry her pregnancy to term. She claimed that when she voiced her intention, a nurse told her that an abortion was desirable, and Dr Abitbol informed her that she could no longer receive prenatal care at Jamaica Hospital's high-risk clinic. Doe was referred to King County Hospital, where three weeks later she had a second-trimester abortion. The following year, Doe filed a suit against Jamaica Hospital, Kings County Hospital, and her individual carers at both institutions, alleging that they breached their duties to provide appropriate care and obtain her informed consent. The New York Supreme Court ruled that Doe provided sufficient evidence to create an issue of fact as to whether Dr Abitbol negligently gave erroneous advice upon which she acted in deciding to have an abortion.[189]

Carol Doe's experience was not unique. Marie from San Francisco was four months pregnant when she tested HIV-positive in 1986.[190] She said that "the doctor strongly suggested I have

[188] Carol Doe's real name was changed in accounts of the incident.
[189] Ellen Bilofsky, "The Coercion of Carol Doe" in *Health/PAC Bulletin*, Spring, 1990, 16-17, box 139, fol. 14, BWHBC records, Schlesinger Library; Bloche, "Beyond Autonomy," 230-238.
[190] Marie's real name was changed in the *Good Housekeeping* article.

an abortion" on receiving her test results, warning her that "the pregnancy could 'wake up' the sleeping virus and I might go from being HIV-positive to having full-blown AIDS. And the baby could be infected. When the doctor said the baby had a 30 to 50 percent chance of being born infected, I took that to mean he had a 70 to 50 percent chance of *not* being infected."[191] Two physicians in women's health explained that "many doctors and other health care providers feel that it is not only their right but their responsibility to counsel and persuade an HIV-infected woman to abort her pregnancy, even in the face of clear statements that she does not want to choose an abortion."[192] HIV-positive women who wanted to continue their pregnancy also came up against the opinions of journalists such as one who in 1988 wrote that any "pregnant woman who has the lethal AIDS virus and doesn't want to risk the 30 percent to 50 percent chance that the new-born would have it too won't find me barring the door to the abortion clinic."[193] Marie was nevertheless able to continue her pregnancy and five months later gave birth to an HIV-negative son.[194] Both Doe and Marie represented the women who early in the epidemic saw the desire on the part of federal agencies to reduce the rates of perinatal transmission as undermining their rights, including the right to become pregnant, to carry a pregnancy to term, or to terminate it.

Politicians and public health officials also argued at length over whether to mandate states to offer AIDS testing to pregnant women in this decade. As with other aspects of AIDS policy

[191] Micki Siegel, "Children with AIDS: The Youngest Victims," *Good Housekeeping*, August 1988, 153, box 148, fol. 42, Koop papers, NLM.
[192] Anastos and Marte, "Women—The Missing Persons in the AIDS Epidemic," 10. As addressed in chapter one, women's health advocates became concerned following official public health recommendations advising HIV-positive women to delay or forgo pregnancy. CDC, "Recommendations for Assisting in the Prevention of Perinatal Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus and Acquired Immunodeficiency Syndrome," *MMWR* 34, no. 48 (December 06, 1985): 721-6, 731-2. In 1987, the ACOG similarly recommended that HIV-positive women be "strongly encouraged not to become pregnant." ACOG, "Prevention of Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome," ACOG Committee Statement, no. 53 (1987) quoted in Bloche, "Beyond Autonomy, 232.
[193] Douglas Pike, "In search of answers on the abortion issue," *Philadelphia Inquirer*, August 8, 1988, box 148, fol. 42, Koop papers, NLM.
[194] Siegel, "Children with AIDS," 153.

making, state health departments differed in their approach to counselling and testing. Florida and Michigan required HIV testing of pregnant women, and Rhode Island allowed testing of new-borns without maternal consent. Other states considered and enacted similar laws. New York State mandated that doctors offered counselling and voluntary testing for HIV to all pregnant women in 1987. The New York State Department of Health also began an anonymous new-born seroprevalence study to track the rates of HIV infection among childbearing women in the state. Under this programme, doctors tested the blood obtained from all infants born between 1987 and 1990 in order to determine whether a woman was HIV-positive. The Washington, D.C., and New Jersey Departments of Health also proposed instituting forms of mandatory prenatal testing in 1988 and 1989.[195] Testing a new-born for antibodies against HIV could only give accurate information about the mother, not the infant. This is because all new-born babies receive antibodies against many infections, including HIV, from women while in the womb. They retain these maternal antibodies for several months after birth. While the babies of HIV-infected women tested "positive," most did not acquire the virus itself and were not infected. Instead, many women first learned of their positive status when doctors found HIV antibodies in the blood of their new-born children.[196] As the stated goal of such laws and testing programmes was usually to find HIV-infected children, women's health advocates criticised the strategy of using a new-born's test results

[195] In 1988, the D.C. government planned to begin mass, anonymous testing for the AIDS virus of 20,000 newborn infants and 10,000 clinic patients as part of a nationwide, federally financed programme to track the spread of the disease. Lawrence Feinberg, "D.C. to Test Newborns, Clinic Patients for AIDS: Blood of 30,000 to be Screened for Virus," *Washington Post*, August 18, 1988. In 1989, New York Dept. of Health considered "unblinding" the ongoing epidemiologic study of HIV infection rates in all new-borns—revealing the identities of babies who tested positive in what had been designed as an anonymous survey of all New York State births. The Department of Health stated that the purpose was for women to learn their own HIV status. See Karen M. Booth, '"Just Testing': Race, Sex, and the Media in New York's 'Baby AIDS' Debate,'" *Gender and Society*, 14, no. 5 (October 2000): 645. In 1989, the New Jersey Department of Health proposed instituting routine prenatal HIV-testing with "right of refusal." Informed consent would not be required, nor would counselling about HIV-testing and AIDS be mandated, as it was in New York. Marte and Anastos, "Women—The Missing Persons in the AIDS Epidemic Part II," *Health/PAC Bulletin*, Spring 1990, 11, box 139 fol. 14, BWHBC records, Schlesinger Library.

[196] Jeffrey L. Reynolds, "Keep Policy on Newborns' HIV Test," *Viewpoints*, July 2, 1994, 105, fol. AIDS, 1992, Women's Action Coalition Records (WAC), NYPL Manuscripts and Archives Division.

as a proxy for the woman's status instead of expanding programmes of counselling and voluntary testing for all pregnant women giving birth.

As with other forms of testing, proposals for perinatal testing were heavily contested. WAN, the United Nations (UN), the WHO, the American Civil Liberties Union (ACLU) and other organisations argued that if testing of pregnant women was not anonymous or confidential, then there was nothing to stop authorities using a positive HIV antibody test against women as in the loss of a job or in the loss of custody as in a child abuse or neglect charge.[197] Others raised concern that routine testing in prenatal clinics might lead to counselling that would encourage women who tested positive to have abortions, and compulsory sterilisation of HIV-positive women.[198]

Since the scientific discovery of AIDS as a communicable disease in the early 1980s, public health activists had argued for voluntary, anonymous, or confidential as opposed to mandatory HIV testing to protect against discrimination in employment, insurance, housing, and medical services.[199] As members of the AIDS service organisation, the Gay Men's Health Crisis (GMHC), noted in 1997, "the key to confidentiality protections has never been

[197] Letter from Grace Lusby to Gary Titus, re: "Guidelines for the Use of HTLV-III Screening," February 7, 1985, box 11, fol. 538, Coyote records; NOW Legal Defense and Education Fund, "Facts on Women and AIDS," June 1988, 2; "Paris Declaration: on women, children and the Acquired Immunodeficiency Syndrome (AIDS), 17, BWHBC records, Schlesinger Library.
[198] Risa Denenberg, "Pregnant Women and HIV," in Banzhaf et al., *Women, AIDS, and Activism*, 159.
[199] The first AIDS discrimination case was brought to court in the US in 1983 on behalf of Dr Sonnabend, in an effort to prevent the eviction of his medical practical specialising in AIDS patients in Manhattan. In 1987, lawyer Geoffrey Bowers filed a complaint with the New York State Division of Human Rights alleging discrimination from his firm, Hyatt Legal Services Inc. who had fired him on learning of his AIDS diagnosis. The 1973 Rehabilitation Act prohibited discrimination on the basis of disability in programmes conducted by federal agencies, for example federal employment or federal financial assistance. In July 1990, the US Congress enacted the Americans with Disabilities Act, prohibiting discrimination against individuals with disabilities, including people living with HIV/AIDS, in all areas of public life, including jobs, housing, transportation, and all public and private places that are open to the general public. Phillip Shenon, "A Move to Evict AIDS Physician Fought by State," *New York Times*, October 1, 1993, Section 1, 31; David Margolick, "At the Bar: A Lawyer with AIDS Wins a Legal Victory, and Gives His Employer Some Unwelcome Publicity," *New York Times*, April 13, 1990.

about not collecting information but rather it is about ensuring information on HIV status is not used or released inappropriately."[200] Women's health advocates supported the principle of voluntary, informed consent for pregnant women who used city-funded services. Moreover, they believed that anonymity or confidentiality would help persuade women worried about the consequences of having health officials record potentially stigmatising information come forward to have their blood tested in light of the discrimination carried out against people living with HIV.[201] The CDC have regularly amended their recommendations for prenatal testing in light of the introduction of new treatments available for HIV infection. In 1995, after the 076 clinical trial had determined that AZT was able to reduce perinatal transmission, the CDC recommended universal, voluntary counselling and HIV testing for all pregnant women to allow timely, prophylactic use of the drug. In 1999, they also recommended giving women the ability to decline screening (the opt-out approach). As these recommendations have evolved, women's health advocates have continued to assess their impact on women's reproductive rights. They have, for example, highlighted that opt-out testing often takes place in antenatal clinics where women face challenges to informed consent, such as language and literacy barriers, and power dynamics.[202]

Two days after the National Press Club incident, Assistant to the President Gary L. Bauer told Marlin Fitzwater, Assistant to the President for Press Relations, that if anyone asked, "Did Surgeon General Koop advocate abortion for women whose unborn children test positive for AIDS?" to reply:

[200] He also noted that "Over the last decade, the legal protections have been adopted to prevent HIV discrimination in housing, employment, and medical care." Memorandum from Darryl Ng and Derek Link to GMHC Board of Directors, "HIV Surveillance/Names Reporting: A Summary of Issues," September 2, 1997, 1, box 400, fol. 1, series xv, GMHC records, NYPL Manuscripts and Archives Division.
[201] NOW Legal Defense and Education Fund, "Facts on Women and AIDS," June 1988.
[202] Aziza Ahmed, "HIV and Women: Incongruent Policies, Criminal Consequences," *Yale Journal of International Affairs* 6, no. 1 (Winter 2011): 35.

> Dr. Koop answered a hypothetical question about the availability of information on abortion in our society. As you know, this Administration is opposed to abortion on demand. Dr. Koop has a distinguished record as an advocate for the right to life of all unborn children. We simply do not believe that the way to fight this disease is by killing the patient.[203]

Bauer's comments exemplified the political discourse that had come to frame the ongoing contests over abortion, reproductive rights, and AIDS by 1987. The 1976 Hyde Amendment prohibited Medicaid funding for abortion unless a woman's life was in danger and the Supreme Court decision to refuse federal funding for "nontherapeutic" abortion was upheld one year later in *Poelker v. Doe*, *Beal v. Doe*, and *Maher v. Roe*.[204] Following the federal government, many states stopped funding "medically unnecessary" abortions, framed by opponents as "abortion on demand."[205] In addition, in remarking on "the right to life of all unborn children" and identifying a foetus as a "child" separate from a woman, Bauer also drew on the rhetoric surrounding debates over foetal life, foetal personhood, and foetal rights that developed in the post-Roe years. During this time, the pro-life movement appropriated the language of the women's healthcare movement in arguing that women frequently suffered severe and lasting psychological damage after having an abortion in a phenomenon otherwise known as post-abortion syndrome. In *Ourselves Unborn: A History of the Fetus in Modern America*, historian Sara Dubow adeptly showed how the political culture of the 1980s and 1990s increasingly saw the interests and rights of pregnant women as distinct from the

[203] Memorandum from Gary L. Bauer to Marlin Fitzwater, "Dr. Koop and AIDS Question," March 25, 1987, box 1, fol. 1, Cribb files, RRPL.
[204] Ziegler, *After Roe*, 66-68.
[205] For a breakdown of state funding of abortion under Medicaid, see Guttmacher Institute, "State Funding of Abortion Under Medicaid," last updated December 1, 2019, accessed February 2020, https://www.guttmacher.org/state-policy/explore/state-funding-abortion-under-medicaid

interests and rights of the foetus.[206] Dubow's history of abortion in the United States did not, however, examine how the emergence of the AIDS epidemic impacted the contemporaneous debates over abortion and women's reproductive rights to address how in this case the "patient" became the "unborn" instead of the woman. Surgeon General Koop's efforts reveal the unexpected interactions between AIDS and abortion in the 1980s, and the importance of adding the history of AIDS to the battle over reproductive justice.

Dr Koop and the AIDS Question

The remit of the US Surgeon General is to deal with the cause of diseases and their control and to inform the public about prevention techniques. In April 1989, journalist Margaret Carlson published a profile on Koop in *TIME* magazine explaining how "Koop was expected to be a figurehead like most Surgeon Generals, with little authority and few staff or duties."[207] Nominated by the sitting president, the position of US Surgeon General is by its nature a partisan role. During his heated confirmation battles, NOW, the American Public Health Association (APHA), and a number of other rights-based organisations and medical professionals argued that Koop's personal beliefs, in particular his rigid opposition to abortion, made him unsuitable to serve as the chief public health official of the country.[208] According to the regulations, Koop was also seven months too old to become Surgeon General. Nonetheless, Republican congressmen worked hard and even bent the rules to get Koop into office, so sure were they that he would forward the religious right's health agenda.

[206] Dubow, *Ourselves Unborn*, 66.
[207] Margaret Carlson, "A Doctor Prescribes Hard Truth: C. Everett Koop, America's Surgeon General, has an opinion on everything healthful, but he nonetheless enjoys meat and martinis," *Time Magazine*, April 24, 1989, 82, box 148, fol. 43, Koop papers, NLM.
[208] Articles in the United States Congress. Senate. Committee on Labor and Human Resources, "Nomination: hearing before the Committee on Labor and Human Resources, United States Senate, Ninety-seventh Congress, first session, on C. Everett Koop, of Pennsylvania, to be medical director in regular corps and to be surgeon general of the Public," October 1, 1981, 134-137, 176-185, LC, accessed February 2020, available at: http://hdl.handle.net/2027/pur1.32754076791106

Congress voted to lift the age restriction and confirmed Koop as the 13th Surgeon General by a vote of 68-24 in November 1981.[209] Despite his commitment to take the responsibilities of his office seriously, Koop was side-lined for his first term in office.[210] When he was able to adopt a more active role, he acted in unexpected ways, and, according to Carlson, "quickly shook things up."[211] He put partisan politics aside and wrote reports denouncing smoking and criticising the tobacco industry, called on Americans to lower their cholesterol, and condemned domestic violence while working to secure disability rights for children. He applied the same scientific pragmatism that drove his approach to smoking and other health risks to tackling one of the greatest public health crises in US history.

Koop described AIDS as a disease "made for a Surgeon General."[212] Despite his enthusiasm to educate the public on the growing epidemic, for the first four years in office, Koop's immediate boss, the Assistant Secretary of Health Dr Edward Brandt, who led the DHHS' response to AIDS side-lined him. In June 1983, when Brandt created an Executive Task Force on AIDS, a high-level group drawn from the PHS to deal with the many facets of the growing epidemic, he did not ask Koop to join.[213] It was not until Ed Brandt resigned as Assistant Secretary for Health in 1984 and was replaced by James O. Mason, the acting assistant secretary for health, that Koop was asked to join the AIDS Task Force and for the first time assumed a public facing role in addressing the American people about the epidemic.[214] His first major opportunity to speak publicly about AIDS came in February 1986, when, mid-way through his second term in office and five years after the CDC reported

[209] "Senate Confirms Koop, 68-24," *New York Times*, November 17, 1981, A14.
[210] Andrew Hartman, *A War for the Soul of America: A History of the Culture Wars* (Chicago: University of Chicago Press, 2015), 159.
[211] Carlson, "A Doctor Prescribes Hard Truth," 82.
[212] C. Everett Koop, "Introduction to the AIDS Archive," 1, box 148, fol. 32, Koop papers, NLM.
[213] C. Everett Koop, *The Memoirs of America's Family Doctor* (Grand Rapids, Michigan: Zondervan Publishing House, 1992), 248-9.
[214] Phil Gailey, "G.O.P. Aides Organize on Homosexual Issues," *New York Times*, May 16, 1984.

the first cases of AIDS-related diseases, President Reagan instructed the Surgeon General to "prepare a report on AIDS for the people of the United States."[215] In his role as Surgeon General, Koop would denounce the coercive proposals of some in the political and religious right as not only devoid of the compassion that he drew from his Christian faith but of medical necessity. In doing so, he broke with social conservatives in the administration and combined compassionate conservatism with pragmatic public health.

Koop believed that he could not educate the public about preventative techniques without consulting national organisations leading the early AIDS response. Over the next several months, after getting assurances from Dr Otis Bowen, the new secretary for the DHHS, that he would be the sole author of the report, Koop invited twenty-seven groups representing AIDS advocacy, business, education, health, labour, public officials, and religion, to his office at the NIH and carried out meetings that proved fundamental to shaping his perspective on AIDS prevention and education. In addition to consulting Government experts like immunologist Dr Anthony Fauci from the NIH, Koop and his small team met with groups ranging from the National Haemophilia Foundation, the American Council on Life Insurance, the American Red Cross, the Christian Life Council of the Southern Baptist Convention, the National Education Association, the National Coalition of Black Lesbians and Gays, and National Minority AIDS Council. The information that these diverse organisations provided on the behaviours of different groups while infected with HIV proved critical to shaping Koop's perspective on methods of transmission and prevention. In particular, a number of studies confirmed that AIDS was not spread by non-sexual casual contact, and that the strident calls to quarantine people with AIDS or deny them housing, employment, or public schooling were misinformed and wrong. The meetings also greatly influenced the report's

[215] Koop, "Introduction to the AIDS Archive," 2, box 148, fol. 32, Koop papers, NLM.

candour, which emphasised in explicit terms the possibility that the HIV virus is spread through blood and semen as opposed to the vague references to "exchanging bodily fluids" that Koop believed slowed down the public's understanding of HIV transmission.[216]

In October 1986, after seventeen drafts, Koop was ready to reveal his report. The plan was to print it as a thirty-six-page brochure. Worried that when he first presented the report to the White House Domestic Policy Council (DPC), some Cabinet members would ask him to make changes to "soften" the language, Koop ordered two million copies of the document on the cheap paper that the government usually used for such reports. As he felt that specific language was essential to his objective, Koop ordered an additional 1,000 copies of the document printed on glossy paper. He presented each of the Cabinet with the more expensive report, bound with a cover in the PHS' royal blue colour, and imprinted with the title, *The Surgeon General's Report on Acquired Immune Deficiency Syndrome*, and the seal of the PHS in silver. He hoped that the Cabinet would assume the report was so expensive that they would not suggest scrapping the money spent on the thousand that had already been printed, in order to make a few edits. To this end, Koop's plan worked, and no changes were made.[217] Koop also numbered the copies and collected them all in after the meeting in order to avoid Cabinet members leaking information to the press. He presented the report to the public at a press conference the following morning, on the 22nd October 1986.

AIDS organisations and advocacy groups as well as politicians and the press waited anxiously as Koop released the first major public health report addressing AIDS. Koop began the report by correcting the "rumors and misinformation" that he argued had become as

[216] Koop, "Introduction to the AIDS Archive," 3-4, box 148, fol. 32, Koop papers, NLM.
[217] Koop, "Introduction to the AIDS Archive," 5-6, box 148, fol. 32, Koop papers, NLM.

difficult to combat as the disease itself, such as the belief that the virus is spread by casual, non-sexual contact.[218] He then noted that many people, especially youth and minority populations, were not receiving information that was vital to their health and well-being because of reticence in dealing with the subjects of sex, sexual practices, and homosexuality. Imploring that "this silence must end," Koop proposed three solutions. First, he called for frank, open discussions about sexual practices, both homosexual and heterosexual, and suggested that sex education in school should begin as early as third grade "so that children can grow up knowing the behaviors to avoid to protect themselves from exposure to the AIDS virus."[219] Second, he stated that the best protection against infection from sex at that time, aside from abstinence and monogamy, was use of a condom.[220] Finally, he advised against the quarantining of persons with AIDS and mandatory blood testing. He explained that quarantining was inappropriate because HIV is not transmitted through casual contact and, as had been the case with other diseases such as syphilis, that mass blood testing was unnecessary, unfeasible, and cost prohibitive. The PHS distributed twenty-two million copies of the report to the public through newspapers, members of Congress, public health organisations, and Parent-Teacher associations, breaking the near-total silence that had characterised the White House response to the epidemic thus far.[221]

While other members of the Reagan administration had agreed with Koop over the importance of education, noting that "in the absence of a vaccine…education is the only means available to prevent the spread of AIDS," his recommendation for the use of condoms as well as his explicit descriptions of the disease and its transmissions offended conservative

[218] "Statement by C. Everett Koop, M.D. Surgeon General U.S. Public Health Service," October 22, 1986, Washington D.C., 2, box 1, fol. AIDS Education—Koop Statement, Davis files, RRPL.
[219] "Statement by C. Everett Koop," 3.
[220] "Statement by C. Everett Koop," 5.
[221] "Statement by C. Everett Koop," 6.

advisors to the president, in particular White House aides Bob Sweet, Carl Anderson, Becky Dunlap, and Gary Bauer, as well as Secretary of Education William Bennett, who Koop believed put prejudiced ideas before statistics and science.[222] Central to this divergence of opinion was a disagreement over what role the federal government should play in sexual education as education in general took place primarily at a local level. Whereas Koop wanted to distribute education for the entire country, Bauer, Bennett, and others in the administration believed that it was for state and local school boards, families, and parent groups "to determine how best to disseminate this information in the most effective fashion, with consideration of their own values and concerns, to achieve the goal of preventing AIDS among our youth."[223] Their championing of local control clashed with Koop's recommendation that all sexual education should begin in the earliest grade possible. White House communications manager Stephanie Lee-Miller assured the press that while Koop did say that third grade was when children began asking questions that might be answered with information including mention of AIDS, "he did not recommend third grade per se as the right time to begin in such education."[224] Right-wing activist Phyllis Schlafly said that the report "looks and reads like it was edited by the Gay Task Force" and that Koop advocated teaching "safe sodomy" to third-graders.[225] In addition to criticising Koop by mail and through her newsletter, "The Eagle Forum," Schlafly organised a boycott of a dinner in honour of Koop, "Salute to the Surgeon," held the following Spring.[226] By this time, many on

[222] Deborah Steelman, "Memorandum to the Director, DPC Meeting on AIDS Education—Background," January 13, 1987, 1, box 11, fol. DPC Meeting re: AIDS Education, Sprinkel files; Edwin Meese III, "Memorandum for the Domestic Policy Council. Subject: AIDS Education," February 11, 1987, box 5, fol. 1, Klenk files, RRPL; Koop, *The Memoirs of America's Family Doctor*, 279-283.
[223] US Department of Health and Human Services, "Information/Education Plan to Prevent and Control AIDS in the United States," January 1, 1987, 18, box 1, fol. AIDS—II, Davis files, RRPL.
[224] Emphasis in the original. Stephanie Lee-Miller, note to Tom Burke, December 2, 1986, box 1, fol. AIDS Education—Koop Statement, Davis files, RRPL
[225] Carlson, "A Doctor Prescribes Hard Truth," 83.
[226] Deborah Steelman, "Memorandum for the Director: January 13, 1987 DPC Meeting on AIDS Education—Background," January 12, 1987, box 11, fol. DPC Meeting re: AIDS Education, Sprinkel files, RRPL; Koop, *The Memoirs of America's Family Doctor*, 277.

the political right felt betrayed by Koop's unwillingness to solely endorse abstinence, fidelity, and heterosexual marriage as AIDS prevention.

Unlike the opposition Koop faced in the White House and in wider conservative circles, the groups he had originally met with to prepare the report were largely pleased with its recommendations. Gil Gerald, Executive director of the National Coalition of Black Lesbians and Gays, wrote that the Surgeon General's statements had "exceeded [his] expectations," and commended Koop for addressing "the issue of AIDS in Black and Brown communities."[227] Gary B. MacDonald, Executive Director of the AIDS Action Council similarly wrote to "congratulate and commend" Koop "on the excellent report to the nation on AIDS that you released today [which] will do much to combat fear and hysteria, and, we hope, to encourage rational, scientifically-based responses to this crisis."[228] Koop received numerous letters echoing these from members of the medical community as well as the general public thanking him for his "forthright leadership on AIDS."[229] Much of the news coverage similarly praised the report for urging "Americans to put aside prejudices they may have against homosexuals and intravenous drug users, to help victims of this epidemic and to stop talking nonsense about quarantines, universal blood tests and tattoos for those who test positive," and for setting a "standard for other government officials—federal, state and local—in dealing with AIDS and its victims."[230] While some other AIDS advocates such as Priscilla Alexander, co-founder of the National Task Force on Prostitution still worried that the Surgeon General's recommendations did not go far enough to halt the passage of

[227] Letter from Gil Gerald, National Coalition of Black Lesbians and Gays to C. Everett Koop, October 24, 1986, box 149, Koop papers, NLM.
[228] Letter from Gary B. MacDonald, AIDS Action Council to C. Everett Koop, October 22, 1986, box 149, Koop papers, NLM.
[229] Letter from Craig B. Leman, M.D. to C. Everett Koop, April 17, 1987. Other, numerous letters of support can be found in the AIDS folder, Koop papers, box 149, NLM.
[230] Letter to the Editor, "A Doctor's Good Advice," *Washington Post*, October 24, 1986, Section A.

quarantine bills, many praised what they saw as an objective and "honest" report, absent of the moralistic judgements typical of the political right's response to the epidemic.[231]

In sum, when Reagan first nominated Koop to the position of Surgeon General in early 1981, many activists, politicians, and members of the medical community saw the appointment in terms of the larger threat the Reagan administration posed to legal abortion.[232] Their concerns came from Koop's involvement in a provocative anti-abortion project, *Whatever Happened to the Human Race?* that he narrated and produced with theologian Dr Francis Schaeffer. But after six years in the job, Koop had surprised his supporters as well as his critics. Democrats and organisations who had originally fought Koop's confirmation six years earlier now supported him while his former Republican backers denounced him. Most infuriating to Koop's former conservative allies and most pleasing to his new supporters was his call for a larger government role in fighting AIDS and endorsement of condoms, sex education, and clean needles for the prevention of HIV.[233] In the year following the publication of his AIDS report, conservatives in the administration felt betrayed again after Koop refused to condemn abortion as psychologically harmful to women. In this context, Koop's new detractors criticised his response to AIDS for not only being morally offensive to a great majority of Americans, but for taking vital resources away from what they perceived as the more pressing issue of post-abortion syndrome.

[231] Priscilla Alexander commented that "the fact that the Surgeon general of the United States addressed a special and almost unique joint session of the State Legislature and urged them not to adopt mandatory testing as a strategy means nothing," in "The A(IDS) Word," AIDS 0787.3, undated, box. 1, fol. 34, Coyote records, Schlesinger Library; "Flying the Koop," *Washington Times,* October 27, 1986.
[232] Remarks of Chairman Henry A. Waxman Before Planned Parenthood, May 29, 1981, 5, box 2, fol. Planned Parenthood Federation of America, Inc., Mary Elizabeth Quint files, RRPL.
[233] Sandra G. Boodman, "How C. Everett Koop shook up his former allies on the right and surprised his new friends on the left," *Washington Post*, November 15, 1987.

The Anti-Abortionist Surgeon General, and the Bureaucrat

The 1980s was a decade of uncertainty over women's reproductive autonomy, and the AIDS epidemic raised the stakes of the conflict. The politics of abortion was not as partisan in the 1980s as it is in our contemporary moment. A number of Republican women supported Planned Parenthood and abortion and did so because of AIDS. Others in the Republican party, such as Robert "Bob" Sweet, a senior member of the Office of Policy Development and the DPC and a former Chemistry teacher from Maine, were part of a bigger push toward a more coercive approach to reproductive healthcare that came with the rise of the right-to-life movement. Whereas pro-life conservatives like Sweet felt that Koop owed the pro-life faction and administration a report damming abortion as payment for his AIDS report, women's health advocates such as Faye Wattleton of Planned Parenthood also worried about the implications of a report claiming the medical efficacy of post-abortion syndrome for women's reproductive autonomy. For two years working as a nurse at the Miami Valley Hospital School of Nursing in Dayton, Ohio, and serving as president of their local Planned Parenthood chapter, Wattleton worked to resist the government's rollback on its support for family planning and reproductive health services. Wattleton became an ally in the AIDS fight in her role as President of Planned Parenthood, continuing to defend American women's right to determine on what terms they might have children.[234] As a pro-life Republican committed to public health, Koop was caught in the middle of this broader divide within the Republican party over abortion, and none of the stakeholders knew how the Surgeon General would approach writing a public health report on the subject.

[234] Pamela Smith, "Planned Parenthood President: Faye Wattleton: A Woman with a Calling," *Philadelphia Tribune,* February 23, 1982; Faye Wattleton, "Planned Parenthood Fights Back," *National Now Times* 11, no. 8, July 1987, 12.

In January 1987, three months after Koop published *The Surgeon General's Report on Acquired Immune Deficiency Syndrome*, President Reagan invited a group of right-to-life leaders to the White House and informed them of his plan to direct "the Surgeon General to issue a comprehensive medical report on the health effects, physical and emotional, of abortion on women."[235] In doing so, Reagan sought to create:

> A solid body of public health information on the effects of abortion on women. Growing numbers of women who've had abortions now say that they have been misled by inaccurate information. Making accurate data on maternal morbidity available to women before an abortion is performed is an essential element of informed consent.[236]

Koop's efforts frustrated anti-abortionists who viewed his actions, in particular his completion of Reagan's instruction to prepare a "report to the American people on AIDS" in 1986 and refusal to complete Reagan's instruction one year later to publish a medical report on the health effects, physical or emotional, of abortion on women as a missed opportunity to strike a practical blow against *Roe v. Wade*.

Koop followed the same initial path as he did with AIDS, but once again public health trumped his personal beliefs. Just as Koop had argued that AIDS was a public health and not a moral issue, he believed that abortion was an issue of morals and not of public health and that it therefore lay outside the responsibilities of his office. However, since *Roe*, the anti-abortion movement had advanced the idea that abortion was a dangerous procedure that had

[235] Memorandum from Robert W. Sweet, Jr. to Ralph C. Bledsoe, "Surgeon General's Report on Abortion," March 25, 1988, box 14, fol. Dr. Koop (Abortion & AIDS), Risque Papers, RRPL.
[236] Sweet, Jr. to Bledsoe, "Surgeon General's Report on Abortion."

negative psychological effects on women in a phenomena otherwise known as "post-abortion syndrome" or "post-abortion trauma."[237] Reagan's call for an abortion report tapped into these same "woman-centred" anti-abortion arguments that centred around the idea that if a woman had an abortion without full knowledge of what the procedure involved, she was often left suffering long-term psychological damage. In making calls for "informed consent," Reagan also lifted the language used by women's health activists at the same time who sought to ensure pregnant women had full knowledge of the possible risks and benefits of HIV testing. Evidence of the disconnect between rhetoric and policy, while women's health activists argued for increased funding to improve the medical and social services available to pregnant women and women considering pregnancy, the Reagan administration instead cut funding to the very services that gave women sexual and reproductive health and rights information, and the social programmes that provided nutrition, maternal medical care, childcare, and education that advanced women's health and well-being.[238]

The Republican party was itself divided on abortion, often along gendered lines, although not entirely. A number of Republican women supported Wattleton's efforts to protect a woman's right to choose against the backdrop of the rising right-to-life movement. Republican women who supported abortion complicate the historical portrayal of such actors in the 1980s as mostly anti-feminist and anti-abortion—typified by the right-wing activism of women like Phyllis Schlafly.[239] Instead, conservative women such as Margaret J. Atwood, a "life-long

[237] Jill Wolhandler et al., "Abortion," in *New Our Bodies, Ourselves*, 369-370; Dubow, *Ourselves Unborn*, 162-163.
[238] Domestic programmes that saw cuts during the Reagan years included Food Stamps, Medicaid, Aid to Families with Dependent Children, Comprehensive Employment and Training Act, federal guaranteed loan programmes for higher education, and Legal Assistance. John O'Connor, "Us Social Welfare Policy: The Reagan Record and Legacy," *Journal of Social Policy* 7 no.1 (1998): 40. Davies, "Reagan and Welfare," 211-212, 225-227.
[239] For more on the conservatism of Phyllis Schlafly, see Berman, *America's right turn*, 9, 19, 79; Critchlow, *Phyllis Schlafly and Grassroots Conservatism*; Lisa McGirr, *Suburban Warriors: The Origins of the New American Right*, 233-234; Laura Kalman, *Right Star Rising*, 72.

Republican" from Connecticut, told the President that she would "never vote again for any person who is against abortion" as "no man should legislate against Women's rights."[240] In May 1987, Pandora M. Cooke from Alabama signed a petition from Wattleton to the White House concurring that Reagan's "efforts to make medically safe abortions illegal will cause untold suffering for millions of women." In an accompanying letter, Cooke told the President that:

> As a thirty-five-year-old mother of one, wife, career woman, and Christian, the moral rights and responsibilities of each of us must be upheld. However, the disservice that would be done in deleting the freedom of choice would be as criminal as unnecessary abortion. You cannot regulate how a woman feels about her body and an unwanted or unhealthy pregnancy, anymore than you can regulate free commerce and trade…Rethink your position, President Reagan. In this case, even fence-sitting would be better.[241]

The 1980 election of Ronald Reagan to president energised anti-abortion activists who saw Reagan as an opportunity to move from a more libertarian to coercive reproductive politics.[242] From the outset, anti-abortion advocates within the federal government worked to "separate the Federal government from the performance of and referral for abortion."[243] Efforts to amend the nation's abortion laws and policies with the aim to undermine *Roe v. Wade* included the 1976 Hyde Amendment, the 1981 Family Protection Act, the 1981

[240] Letter from Margaret J. Atwood to President Reagan, undated, box 9, fol. 6, Sweet files, RRPL.
[241] Emphasis in the original. Letter from Pandora M. Cooke to President Reagan, May 18, 1987, box 9, fol. 6, Sweet files, RRPL.
[242] Critchlow, "Mobilizing Women: The 'Social' Issues," in *The Reagan Presidency*, ed. Brownlee and Graham, 301-302; Lawrence J. McAndrews, *What They Wished For: American Catholics and American Presidents, 1960-2004* (Athens, Georgia: University of Georgia Press, 2014), 230-231.
[243] Memorandum, "Actions on the Anniversary of Roe v. Wade," January 23, 1987, box 1, fol. Abortion Memo 01/23/1987, Davis files, RRPL. Emphasis in the original.

Adolescent Family Life Act, numerous proposals under the Human Life Amendment, and proposals to amend Title X of the PHS Act, the federal programme that paid for reproductive health services for low income women.[244] The Title X amendment would have barred any organisations from receiving federal family planning funds if they did not separate their Title X prevention services from their abortion procedures, abortion referrals, or abortion counselling that were funded from other sources. This amendment was—and still is—known as the "domestic gag-rule." The Supreme Court upheld the rule in 1991 but Bill Clinton rescinded it when he came to office.[245] The proposal to amend federal Title X funding proved additionally controversial when in January 1987 the DHHS dismissed Jo Ann Gasper, a pro-life appointee and the Deputy Assistant Secretary for Population Affairs, for refusing to pay Planned Parenthood their training grants.[246]

The incident with Gasper angered members of the pro-life movement who believed her firing involved a pro-abortion bias within the DHHS. Koop suspected that Reagan called for the abortion report in order to placate their concerns, motivated by "a silly idea touted by one of the neophyte right-wingers on the White House staff that the evidence of adverse health effects (presumably mental) of abortion on women that the Surgeon General could pull together would be sufficient to overturn *Roe v. Wade*."[247] Koop also wondered whether the abortion report was Reagan's last attempt to challenge *Roe* with the end of his presidency in sight, as well as to "distract me from my blunt and realistic approach to AIDS."[248] Despite

[244] For more on the amendments seeking to undermine *Roe v. Wade* in this period, see McAndrews, *What They Wished For*, 231-237.
[245] Jo Ann Gasper Memorandum to Koop, "Ensure that Programs Under Title X Separate Family Planning from Abortion," January 24, 1984, 1-3, box 149, fol. 50, Koop papers, NLM.
[246] Nancy Risque to Will Ball, "Joanne Gasper," March 10, 1987, box 1, fol. Abortion, Davis files, RRPL.
[247] Koop, *The Memoirs of America's Family Doctor*, 274.
[248] Koop, *The Memoirs of America's Family Doctor*, 274-275. As Charlie Jeffries and a number of other historians have noted, Reagan's seeming prioritisation of economic and foreign policy issues over socio-moral issues such as abortion frustrated members of the Religious Right. See Jeffries, "Adolescent Women and Antiabortion Politics in the Reagan Administration," 194, esp. footnote 4. See also Patterson, *Restless Giant*, 177; Gil Troy, *Morning in America: How Ronald Reagan Invented the 1980s* (Princeton, NJ: Princeton

their efforts to restrict funding of birth control and family planning services and the access to these services for women dependent on publicly funded health care, over the course of two terms in office, the Reagan administration had ultimately failed to decisively overturn legal abortion.[249] Whatever Reagan's motive, Koop accepted the directive with assurances from Dr Otis Bowen that he may assume the same control of the abortion report as he had done with AIDS and, though he believed that the question of abortion and its health effects on women could not draw on the kind of "unassailable" scientific data and interpretation that the AIDS report had, he got to work.[250]

In the Spring of 1988, Koop and his team began collecting information on the subject of post-abortion syndrome by inviting bipartisan national organisations involved on both sides of the abortion debate to his office. As with the AIDS report, Koop planned to synthesise a number of different perspectives in coming up with his recommendation. While these bipartisan consultations might seem neutral, the strong connections and mutual respect Koop had built from the AIDS report meant that Planned Parenthood and women's health activists had Koop's ear. Koop met first with a delegation from Planned Parenthood and other pro-choice groups who gave presentations that provided extensive information on the alleged connection between abortion and mental and physical disturbances.[251] Dr Jacqueline Forrest, vice president for research at the Alan Guttmacher Institute, argued that American women needed access to effective methods of contraception in order to reduce the rates of abortion and that, in the event of a woman deciding to obtain an abortion, she should not have to "walk through a gauntlet of protestors screaming that she's a murderer, waving placards in her face and

University Press, 2007), 17; Robert Mason, *The Republican Party and American Politics from Hoover to Reagan* (Cambridge: Cambridge University Press, 2011), 259-261; Neil J. Young, *We Gather Together: The Religious Right and the Problem of Interfatih Politics* (New York: Oxford University Press, 2016), 241.
[249] Jeffries, "Adolescent Women and Antiabortion Politics in the Reagan Administration," 193-194.
[250] Koop, *The Memoirs of America's Family Doctor*, 275.
[251] Faye Wattleton, *Life on the Line* (New York: Ballantine Books, 1996), 354.

copying down her license plate number when she enters the clinic."[252] Dr Nancy Adler of the American Psychological Association agreed that data from before-and-after studies suggested that the time of greatest distress for women was prior to the abortion and that abortion could contribute to "a positive resolution of an extremely unfortunate and stressful event, the occurrence of an unwanted pregnancy."[253] The meeting concluded with Wattleton describing her experiences working as a nurse in Harlem, New York, where in one year 6,500 women entered Harlem Hospital suffering from the complications of incomplete abortion.[254] Koop and his team also met with representatives from the National Right to Life Committee, state health officers, the American Nursing Association, the Religious Coalition on Abortion Rights, the American Council on Science and Health, NOW, the American Public Health Association, and the American Psychiatric Association.

As with many of his other former critics, Wattleton's opinion of Koop changed as a result of his work on AIDS. Wattleton had herself assumed a leading role in educating the public about HIV/AIDS in the 1980s and praised Koop's failure to back down on his position that condoms should be widely distributed. For Wattleton, in his pursuit of educating the American public on the nature of HIV/AIDS, including its modes of transmission, risk factors for contracting the disease, and ways for people to protect themselves, Koop had become a remarkable ally of women doctors and public health professionals who had worried that he might forsake real health issues for ideological views.

---

[252] Testimony of Jacqueline Darroch Forrest PhD, Vice President for Research, the Alan Guttmacher Institute, in "Medical and Psychological Impact of Abortion: Hearing Before the Human Resources and Intergovernmental Relations Subcommittee of the Committee on Government Operations, House of Representatives, One Hundred First Congress, First Session," Vol. 4, March 16, 1989, 6, accessed February 2020, http://hdl.handle.net/2027/pur1.32754076877616

[253] Testimony of Nancy E. Adler PhD, Department of Health Psychology, University of California, San Francisco on behalf of The American Psychological Association in "Medical and Psychological Impact of Abortion," 131.

[254] D.P. Swartz, M.D., and M.K. Pananjpe, M.D., "Abortion: Medical Aspects in a Municipal Hospital," *Bulletin of the New York Academy of Medicine* 47, no. 8, August 1971, 846, quoted in Wattleton, *Life on the Line*, 94.

Planned Parenthood's support of the Surgeon General extended beyond its president. In May 1987, Christy Burton and Lee Lopez of the Planned Parenthood Association of Cameron & Willacy Counties in Brownsville, Texas, wrote to Koop to tell him that:

> As Family Life Educators in one of the most poverty-stricken areas in our country, we want you to know how much we appreciate your recommendations supporting earlier and better sexuality education and increased protective health care measures against AIDS. Being so close to the issue we are painfully aware that the complications of early and uninformed sexual activity (unplanned pregnancies and AIDS) are frightful both emotionally and economically.[255]

That same year, the South Texas branch of Planned Parenthood added screening services for HIV and treatment for chlamydia as part of the wider efforts to connect AIDS prevention with family planning services and reproductive health care. Commenting on the unexpected alliance that developed between Koop and Planned Parenthood at this time, a journalist writing for the *Washington Post* observed that:

> It isn't often that Planned Parenthood and the Reagan administration see eye to eye, but a national crisis has brought them together on at least one subject: AIDS. A report issued earlier this week by Surgeon General C. Everett Koop drew praise from the family-planning group specifically because it urges sex education in schools at the earliest possible grade.[256]

[255] Letter from Christy Burton and Lee Lopez to C. Everett Koop, May 18, 1987, box 149, fol. AIDS, Koop papers, NLM.
[256] Letter to the Editor, "A Doctor's Good Advice," *Washington Post,* October 24, 1986, Section A.

Expecting that Koop would further their conservative health agenda, the political right instead felt betrayed that he had sided with public health.

Just over one year into the planning of the Surgeon General's report on abortion, Koop was struggling with his current presidential assignment and coming under increasing pressure from the administration over his alliances and actions. Most of the information he and his team had gathered from the hundreds of people they had met with was anecdotal, consisting of both the stories of women who were in deep depression because of the remorse they felt after an abortion, or women who said that their abortion had saved their marriage. But anecdotes, Koop explained, did not make statistics.[257] While anecdotes had long provided women with a powerful tool to assert credible knowledge about their bodies and lives, in this case statistics worked more in women's favour. In addition to the lack of empirical medical evidence on the psychological effects of abortion on women, Koop also believed that the limited number of scientific papers that did exist on the subject were invalidated by each author's own clear sociological or moral bias.[258]

Members of Reagan's DPC, such as Bob Sweet, Deputy Executive Secretary of the Council, grew increasingly frustrated as Koop explained that no current studies could reach a defensible conclusion on the health effects of abortion on women, as there was as much evidence of positive effects of abortion as negative and, whereas the DHHS had set aside $200,000 from other projects for the abortion report, that a proper study of the issue would cost between $10 and $100 million. For Sweet, the proactive steps Koop had taken to respond

[257] Jack Fowler, "Koop Report to Find No Proof of Abort Damage to Women," *Lifeletter*, no. 4, March 1, 1988, box 14, fol. Dr. Koop (Abortion & AIDS), Risque files, RRPL; Warren E. Leary, "Koop Says Abortion Report Couldn't Survive Challenge," *New York Times*, March 17, 1989.
[258] Koop, *The Memoirs of America's Family Doctor*, 275, 278, 279.

to AIDS exposed how little institutional weight he was willing to put behind proving the medical efficacy of post-abortion syndrome in comparison. Koop suggested that he could either meet with the president to explain the problem or put it in a letter. Bauer replied that Koop should continue with his report, remarking that the president never changed his mind.[259]

Bob Sweet told Nancy Risque—Deputy Assistant to the President and Cabinet Secretary—that "after listening to Dr. Koop last Wednesday I had the clear impression that he was not interested in doing research on post abortion syndrome, felt it couldn't be done or would cost $1 billion…abortion is the most frequent surgical procedure used in medicine today. Yet we spend virtually nothing to research the impact of this traumatic event on women, physicians and nurses to say nothing of the baby."[260] He complained that "AIDS on the other hand is a recent phenomenon with a total estimated infected US population of less than four tenths of one percent and we are spending nearly $1.5 billion on AIDS in 1988 alone…What in God's name is wrong with us? Where are our priorities? Have we lost our moral compass? The blood of our children crys [*sic*] out to us from the ground. Will no one listen?"[261] Risque was already backpedalling on nearly every public message Koop gave on AIDS. In February 1988, for example, the *Associated Press* quoted Koop recommending that clinics provide free needles if doing so curbed the spread of HIV. Risque asked Arsht Leslye, Deputy Press Secretary, to "please be careful" with the quote as "IV is an issue that I know would further divide Koop and DPC talks."[262] Two months later, Risque wrote to Koop to tell him that she

[259] Koop, *The Memoirs of America's Family Doctor*, 276; Memorandum from Sweet Jr. to Risque, "Washington Post Article— 'The Ex-Abortionists'/Koop Report," April 1, 1988, box 14, fol. Dr. Koop (Abortion & AIDS), Risque files, RRPL.
[260] Sweet, Jr. to Risque, "Washington Post Article."
[261] Sweet, Jr. to Risque, "Washington Post Article."
[262] Memorandum from Risque to Arsht Leslye, February 2, 1988; Memorandum from Hanns Kuttner to Risque, February 2, 1988, box 14, fol. Dr. Koop (Abortion & AIDS), Risque files, RRPL.

was concerned that he had given "the impression that there hasn't been Presidential leadership on AIDS" besides advocating sexual abstinence.[263] Koop retorted that he had consistently defended the president and his leadership on the question of AIDS in front of the press yet had not received a word of approval or thanks in doing so.[264]

Bob Sweet's belief that Koop cared more about AIDS than abortion was reinforced when, in May 1988, in one of his last acts as Surgeon General, Koop, together with the CDC, sent an eight-page, condensed version of his AIDS report, costing $17 million to all 107 million households in the United States, a mailing unprecedented in its size and for its sexual content. The brochure explained that "you can become infected by having sex—oral, anal or vaginal—with someone who is infected with the AIDS virus." Nancy Risque circled the words "vagina" "penis" "rectum" and "anal intercourse" on her copy of the brochure, along with the note, "Is this appropriate for children? Won't parents be offended?"[265] Koop again invited the input of Wattleton and a delegation of Planned Parenthood to help develop the AIDS brochure, *Understanding AIDS: America Responds to AIDS*, evidence of Wattleton's continued influence on shaping the Surgeon General's approach to the epidemic.[266]

As had been the case with nearly every other issue involving AIDS, sexual education, and public health, Koop and the Cabinet clashed over the contents of the brochure. In December 1987, Congress had ruled that the director of CDC should distribute, "without clearance of the content by any official, organization or office," an AIDS mailer to every American

[263] Letter from Risque to Koop, April 19, 1988, box 14, fol. Dr. Koop (Abortion & AIDS), Risque files, RRPL.
[264] Letter from Koop to Risque, April 25, 1988, box 14, fol. Dr. Koop (Abortion & AIDS), Risque files, RRPL.
[265] Risque's annotated copy of DHHS, *Understanding AIDS: A Message from the Surgeon General*, 1988, 2, in box 5, fol. 1, Klenk files, RRPL.
[266] Wattleton, *Life on the Line*, 355.

household by 30th June 1988.[267] Congress' decision to not involve the White House upset members of the DPC who believed that, because the brochure "promotes condoms" and "assumes widespread sexual promiscuity among young people," it "could embarrass the President and set back the fight against AIDS if it goes out without a thorough rewrite."[268] Nancy Risque suggested that Director of the DHHS, Dr Bowen, amend "potential discrepancies between this and previous PHS publications," in particular the 1987 guidelines that emphasised "responsible sexual behaviour—based on fidelity, commitment, and maturity, placing sexuality within the context of marriage."[269] The section "AIDS and Babies" on page six informed readers that an infected woman could transmit HIV to her foetus during pregnancy or childbirth, and advised women considering having a baby to receive counselling and get tested.[270] After a number of heated exchanges between the DPC and the CDC, Koop made no changes to the brochure. It was published in English and reprinted in Spanish and was aimed at people with a seventh-grade education. On 5th May 1988, Dr Bowen released the "frank and explicit" document to favourable press coverage that praised its facilitation of a public discussion of sexuality.[271] Gary Bauer and William Bennett, who had long opposed Koop's endorsement of explicit sexual education, declined to comment.[272]

Members of the administration including Sweet became particularly frustrated with what they perceived to be the "unsolicited" amount of money spent on AIDS as opposed to the dearth

[267] Memorandum for the Domestic Policy Council, "National AIDS Mailing," 1, March 25, 1988, box 5, fol. 1, Klenk files, RRPL.
[268] "Analysis of CDC's Proposed Mailer," undated, 1988, 1, box 5, fol. 1, Klenk files; Memorandum for the Domestic Policy Council, "National AIDS Mailing," 1, 2, March 25, 1988, Klenk files, RRPL.
[269] Memorandum from Risque to Otis R. Bowen, April 25, 1988, 2, box 5, fol. 1, Klenk files, RRPL.
[270] DHHS, *Understanding AIDS*, 6, 1988, box 5, fol. 1, Klenk files, RRPL.
[271] Sandra G. Boodman, "HHS AIDS Brochure: Frank, Explicit and Ready to be mailed," *Washington Post,* May 5, 1988; "U.S. takes war on AIDS to the public," *Chicago Tribune,* May 5, 1988; "U.S. to Mail AIDS Advisory to All Households," *New York Times,* May 5, 1988; Peter Johnson, "AIDS booklet 'spells out' facts, fiction," *USA Today*, May 5, 1988, box 5, fol. 1, Klenk files, RRPL.
[272] Boodman, "HHS AIDS Brochure," *Washington Post,* May 5, 1988.

of resources spent on the more pressing issue of abortion. Sweet thought that the Surgeon General's report on abortion should get the same resources for circulation as his report on AIDS. He argued that it "should be mass-mailed, with a great deal of publicity along the lines of the Surgeon General's report on AIDS" and, in line with the anti-abortion movement's tactic of using audio and visual materials as evidence of foetal pain in this period, that it "should be accompanied by a high-quality, colourful booklet that is simply and clearly written describing foetal development at different stages, including the baby's capacity for pain; a description of the different abortion procedures and their effect on the baby; their possible effects on the mother; and, services for women seeking alternatives to abortion."[273] Koop therefore angered pro-life members of the administration such as Sweet for seemingly misdirecting federal resources towards AIDS and away from the more pressing issue of post-abortion syndrome.

On 9th January 1989, two years after Reagan ordered Koop to prepare a report on abortion, Koop wrote the president a letter explaining that there was no decisive scientific research on the effects of abortion on women's health that could serve as the basis for a Surgeon General's report on the issue.[274] In refusing to adopt the pro-life position, Bob Sweet condemned Koop as somebody who had missed their opportunity to "educate the American people and put our priorities back in order."[275] After Koop delivered the letter to White House staffers, the DPC continued its fight to secure the abortion report for the president before he left office. The group recommended that Koop direct the DHHS to proceed immediately with the design of a survey to produce "reliable raw data" upon which a study

[273] Memorandum from Sweet, Jr. to Bledsoe, "Surgeon General's Report on Abortion."
[274] Koop to President Ronald Reagan, January 9, 1989, reprinted in "Medical and Psychological Impact of Abortion," 68-71.
[275] Sweet, Jr. to Bledsoe, "Surgeon General's Report on Abortion."

on the health effects of abortion could be based. The department never began work on the study and the opportunity passed with George H. W. Bush's incoming administration.[276]

Given the polarisation of positions around the question of legal abortion in the 1980s, it is not surprising that much media attention surrounded Koop as press outlets announced that the Surgeon General had issued a report confirming that abortion produced no evidence of negative health effects on women. The following morning, on 10th January, Koop appeared on *Good Morning America* to reiterate that legal abortions are medically safe and clarify that he had not wavered in his personal pro-life stance. He said that as Surgeon General, he had always attempted to put science before his personal views, and that in the case of the psychological impact of abortion on women, the science was simply not conclusive either way.[277] Whereas *Washington Post* journalist Michael Specter had wondered whether "the abortion report would present Koop with an opportunity to even the score" after alienating his former conservative supporters over AIDS, pro-life and religious leaders widely condemned Koop and accused him of burying the pro-life movement.[278]

At the same time, some pro-choice members of Congress, led by Representative Ted Weiss (D-NY), also criticised Koop and his staff for not publishing a full report of their research review and accused them of ignoring the overwhelming medical evidence that abortion is safer than pregnancy and childbirth, and in 1989 Weiss launched a Congressional investigation into the preparation of the abortion letter.[279]

---

[276] Memorandum from Risque to the President, "Surgeon General's Update on Health Effects of Abortion Study," January 9, 1989, box 14, fol. Dr. Koop (Abortion & AIDS), Risque files, RRPL.
[277] Koop, *Memoir of America's Family Doctor*, 277-278.
[278] Michael Specter, "Koop Won't Issue Report on Abortion: Studies of Effects Called Inconclusive," *Washington Post*, January 10, 1989.
[279] Marlene Cimons, "House Panel Accuses Koop of Ignoring Medical Evidence on Safety of Abortion," *Los Angeles Times,* December 11, 1989.

In the end, the Weiss hearing came to nothing, and Koop left office in October 1989. A few months earlier, in July, the Supreme Court handed down the decision granting states the ability to deny women access to abortion in all publicly funded facilities in the case *Webster v. Reproductive Health Services*. In April, when *Webster* was being argued, NOW and Planned Parenthood organised a March for Women's Lives in Washington, D.C., with the hope of showing the Supreme Court and Congress that most Americans supported legal abortion. During the march, Wattleton took to the podium and in an impassioned speech, told the crowd of 600,000 protesters—a crowd whose size had not been seen in Washington since the anti-Vietnam war protests of 1969 and 1971—that "as a woman, I know that the power of the government to control women's reproduction is more frightening than any other tyranny, more binding than any other prison."[280] The March for Women's Lives did not have Wattleton's desired effect, as the Court announced its five-to-four decision upholding a Missouri law that prohibited the use of state funds, facilities, and employees in performing, assisting with, or counselling on abortions and required physicians to test for viability in July. *Webster* did, however, inspire the formation of new grassroots organisations, including African American Women for Reproductive Freedom and WHAM! both of which continued to fight to protect legalised abortion that would increasingly take place at the state level in the next decades.

The Reagan era ended with stalemate at multiple levels for multiple people. The pro-life movement did not get their abortion report and the *Webster* decision stymied Planned Parenthood and Faye Wattleton. The period also concluded with the development of new

[280] Speech by Wattleton, President, Planned Parenthood Federation of America, Washington, D.C., April 9, 1989, quoted in Wattelton, *Life on the Line*, 362.

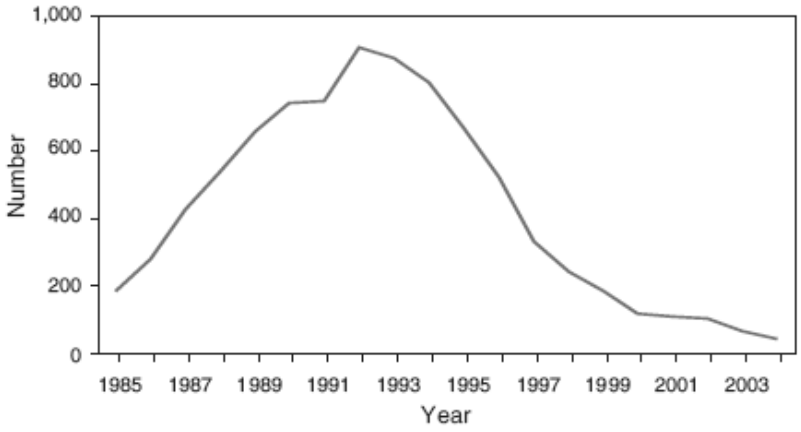
factions that represented a fundamental realignment within the Republican party between the rising political right and right-to-life movement and the traditional libertarian and caregiving strands of the party who were still more committed to expertise and coalition building. One of these new, short-lived factions included Republican women who took on the issue of caring for infants with AIDS.

Boarder Babies with AIDS

Whether women with HIV chose, were coerced, or forced into having children, for an approximately ten-year period between discovering perinatal transmission in 1985 and the approval of AZT for pregnant women in 1994 the question of what to do with babies born with AIDS was a key political and public health issue. While the literature on young people with AIDS has tended to focus on school-aged children, the graph at figure 3 shows that the growing number of infants born with AIDS throughout the 1980s was also a problem that needed attention.[281]

[281] Particular attention is typically given to the case of Ryan White, a teenager from Indiana who contracted HIV in the early 1980s and whose name is attached to the largest federally funded programme for persons with HIV and AIDS. See Edelman, *No Future*, 19; Patterson, *Restless Giant*, 181; Petro, *After the Wrath of God*, 65-66; France, *How to Survive a Plague*, 311-312.

FIGURE. Estimated number of cases of perinatally acquired AIDS,* by year of diagnosis — United States, 1985–2004†



* Acquired immunodeficiency syndrome.
† Data adjusted for reporting delays and for estimated proportional redistribution of cases in persons reported without an identified risk factor.

Figure 3. Data on cases of perinatal AIDS in the United States, June 2006.[282]

Throughout the decade, women's health activists frequently articulated the need to protect the rights of HIV-positive women to decide whether or not to have children on their own terms. Carola Marte and Kathryn Anastos, two physicians in women's health, persistently critiqued the advice given to a woman with HIV-infection to postpone pregnancy on the grounds that it was essentially advising her to prevent conception or, if pregnant, to elect abortion— "in other words, to give up the possibility of having a child."[283] According to Marte and Anastos, policies aimed at discouraging women from having children took on a special significance in light of the anti-abortion politics of the Reagan era, as the conflict between attempting to outlaw abortion on the one hand and the official goal of preventing the birth of new-borns who might carry HIV infection on the other could only be achieved if HIV-positive women never had children.[284]

[282] CDC, "Achievements in Public Health: Reduction in Perinatal Transmission of HIV Infection—United States, 1985-2005," *MMWR* 55, no. 21 (June 2, 2006): 592-597.
[283] Marte and Anastos, "Women—The Missing Persons in the AIDS Epidemic Part II," 16.
[284] Marte and Anastos, "Women—The Missing Persons in the AIDS Epidemic Part II," 14.

At the same time that women's health advocates protested the policy of advising women living with HIV to abort, delay, or forego pregnancy, they also wanted to protect a woman's right to choose to terminate a pregnancy. According to the authors of the *New Our Bodies, Ourselves*, an HIV-positive woman who wanted to terminate her pregnancy may have found that the option of abortion was unavailable, highlighting the irony that women "may face the untenable situation of being counselled to have an abortion yet being unable to find one—another serious restriction of your reproductive choices."[285] The Hyde Amendment, enacted in 1977, had already denied women who received Medicaid access to federal funds for abortion services. As philosophy professor Marlene Gerber Fried wrote in 1998, since the passage of *Roe v. Wade* in 1973, the anti-abortion movement has worked to decrease abortion access with the long-term goal of recriminalisation. Through decreases in federal and state funding, in available services and providers, the pervasive violence and harassment of women seeking abortions and abortion providers, and by state legislative restrictions such as parental consent laws and mandatory waiting periods, abortion in the United States was by Gerber's estimation "legal but inaccessible."[286] By the 1990s, Medicaid plans covered abortion only in twelve states.[287] Since many low-income women obtained medical services only through Medicaid—or, if ineligible for Medicaid, not at all—they did not have the option to terminate a pregnancy.[288]

While abortion remained a prevention option for some, women such as Barbara Bush recognised the need to put structures in place to care for children and infants born with AIDS. Although Bush fashioned herself stylistically as traditional, she presented AIDS Houses as a

[285] BWHBC, *New Our Bodies, Our Selves*, 336.
[286] Marlene Gerber Fried, "Abortion in the United States—Legal but Inaccessible," in *Abortion Wars*, 201-211.
[287] Chavkin, "Preventing AIDS, Targeting Women," 20.
[288] Dennenberg, "Pregnant Women and HIV," in Banzhaf et al., *Women, AIDS, and Activism*, 162.

third way for conservatives to address the reality of paediatric AIDS without contradicting their pro-life worldview. Realising that if conservatives were not going to support abortion, society was going to have to deal with the problem of children born with AIDS, Bush supported AIDS Houses and helped to shift public attention away from the actions of HIV-positive pregnant women and toward the need to care for sick children, hence this "third way" approach.

Other Republican women, often in their role as mothers, joined the growing chorus of individuals protesting the president's silence on children with AIDS. During protests at the site of the Republican convention in New Orleans in June 1988, two women stood in front of the crowd of demonstrators and told how both of their sons had recently died of AIDS-related causes. Sue Caves and Barbara Cleaver, both Californian Republicans, read statements that they intended to deliver to President Reagan on the opening day of the convention. In their letter, they told the president that "these deaths are not just numbers, but some parents' children as dear to them as our sons, Michael and Scot, were to us."[289] Caves and Cleaver called on Reagan to support expanded access to experimental drugs to help combat the disease as the government stalled on renewing a federal subsidy programme that helped thousands of people throughout the country purchase the drug AZT, which in 1988 cost patients $8,000 a year.[290]

By the middle of the 1980s, as recorded cases of paediatric AIDS rose, journalists began reporting on a new phenomenon that members of the medical community called "boarder babies with AIDS" that referred to infants born with HIV who were healthy enough to leave

[289] Michael Johnson "Two mothers who lost sons issue plea to President Reagan," *Boston Globe*, August 16, 1988.
[290] Lou Chibbaro Jr. "States unprepared for end of AZT subsidies," *Washington Blade*, September 2, 1988.

hospitals but stayed there because they had nowhere else to go. Journalists reported that these children often waited on foster home placement in cases where their parents died or proved unable to care for them while financially crippling the medical system in the process. In 1988, Dr James D. Hegarty of Harlem Hospital Center in New York published a study reporting that the lifetime cost of hospital care for children with AIDS averaged $90,347 per child, more than three times the cost for adults with AIDS.[291] Dr Kathi Kemper led a concurrent study at the Yale-New Haven Hospital in Connecticut that similarly found that HIV-positive children "are in the hospital not because they're sick with AIDS or with anything else. But because they test positive, nobody wants to take care of them at home or in foster care, and so there's no place else for them to go."[292] Medical professionals explained that an acute fear of contagion surrounding HIV-positive children inhibited foster care placement.[293]

Fear of contagion often manifested through the exclusion of school-age children with HIV from public schooling. In 1984, teachers and parents famously barred 16-year-old Ryan White—a haemophiliac who contracted HIV from a blood transfusion and whose name Congress attached to the biggest piece of AIDS legislation in 1990—from attending school in his hometown of Kokomo, Indiana. In August 1982, Rosa Martinez from Tampa, Florida, had responded to a radio message asking for someone to house a child who lived in a hospital. By 1985, Martinez had adopted the girl, Eliana, as her daughter.[294] US District

[291] "Cost for Child with AIDS: $90,347," *Richmond Times-Dispatch*, October 7, 1988.
[292] "High Costs Cited for AIDS 'Boarder Babies," *New York Times*, October 9, 1998.
[293] Stephen W. Nicholas and Elaine J. Abrams, "Boarder Babies with AIDS in Harlem: Lessons in Applied Public Health," *American Journal of Public Health* 92, no. 2 (February 2002): 163, accessed February 2020, available at: https://dx.doi.org/10.2105%2Fajph.92.2.163
[294] Kit Lively, "For 6-year-old girl with AIDS, school is an 8-by-10-foot booth," *Philadelphia Inquirer*, August 18, 1988. Local opponents to the Eldredge's proposal included John Edkin, a 67-year-old retiree who expressed fear that a home for children with AIDS might reduce property values in Estella, while others expressed concern that the house might not have the proper regulations to care for and protect the children. Edkin and other Elkland Township residents and officials who opposed the house thought that something should be done to address severe and far-reaching epidemics, just "not in my back-yard." 45-year-old Peggy Marengo who lived

Judge Elizabeth A. Kovachevich ruled that Eliana Martinez could only attend school if she stayed in an 8-by-10-foot glass booth that separated her from her teachers and the other students. After each testing positive for HIV in 1986, the DeSoto County school system in Arcadia, Florida, also banned three brothers, Ricky, Robert, and Ray Clifford, as public health hazards. In August 1987, after a federal judge ordered that the school reinstate the brothers, a fire that authorities suspected was arson destroyed their home, forcing the family to relocate to Sarasota, Florida. Malcolm and Kim Eldredge lived with their three children, including a foster son with AIDS, in Elkland Township in Philadelphia, Pennsylvania. In 1988, the Eldredge's sought permission to run a nearby 12-bedroom farmhouse for a group of infants and young children with AIDS from the Philadelphia-area while they found permanent housing.[295]

In addition to the families who fostered and adopted HIV-positive children, some public health professionals proposed establishing more permanent institutional housing for children in a similar vein to the Foundling Hospitals that philanthropists had set up in metropolitan areas in the eighteenth and nineteenth centuries.[296] At the April 1987 workshop that Koop had organised on "Children with HIV Infection and Their Families" at the Children's Hospital of Philadelphia, Dr Stephen Nicholas and Dr Elaine Abrams of Harlem Hospital raised the issue of boarder babies with AIDS and proposed the creation of community-based homes for HIV-positive children in New York City and Newark, New Jersey.[297] Their

near Boston, Massachusetts, adopted three HIV-positive daughters from the Children's Hospital in Boston and in Chicago, Illinois, John and Susan Smith adopted two-year-old HIV-positive Billy. Siegel, "Children with AIDS," 153.

[295] George Esper, "Shelter for AIDS children is fought," *Philadelphia Inquirer*, August 31, 1988.

[296] For more information on the New York Foundling Hospital, see Martin Gottleib, *The Foundling: The Story of the New York Foundling Hospital* (New York: Lantern Books, 2002).

[297] Address by C. Everett Koop, MD, ScD Surgeon General of the U.S. Public Health Service and Deputy Assistant Secretary of Health, US Department of Health and Human Services. Presented to the Surgeon General's Workshop on Children with Human Immunodeficiency Virus and Their Families, Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, April 6, 1987, 1, box 148, fol. Introduction to AIDS Speeches, Koop papers, NLM; Nicholas and Abrams, "Boarder Babies with AIDS in Harlem," 163.

recommendations to institutionalise AIDS houses drew upon similar rhetoric of the Foundling Hospitals over the need to care for forgotten children. The proposed AIDS houses, like Foundling Hospitals, would function both for the sake of children's well-being but also as a way to ease the financial strain they placed on the services of a city. Nicholas and Abrams' suggestions were met with strong opposition from some within child welfare circles, who denounced the idea as Dickensian, retrogressive, and likened it to warehousing.[298]

Despite these reservations, in 1988, Congress enacted the Abandoned Infants Assistance (AIA) Act, which authorised the DHHS to award grants to public and private organisations to carry out residential care programmes that addressed the needs of abandoned infants, especially those with AIDS.[299] In addition, the paediatricians of Harlem Hospital Center managed to organise a coalition of collaborators—doctors, nurses, priests, social workers, and government officials—to help develop plans for New York City's first group residence and nursing facility for children with HIV. The group obtained the support of mayor of New York, Ed Koch, and long-time anti-abortion advocate, the cardinal of the Catholic Archdiocese of New York, John O'Connor, and lobbied local churches, service organisations, police precinct councils, and community boards for support. City and state health and social services agencies approved the group's plans and granted them funding. In 1988, a 4-story red brick former convent in the Bronx was converted into a residence for twenty-four HIV-positive children and became New York's Incarnation Children's Center (ICC). In February 1989, Diana, Princess of Wales visited Harlem Hospital Center and opened the ICC. In the following years, the centre cared for over 700 HIV-positive children, providing nutritional and medical services.[300]

[298] Nicholas and Abrams, "Boarder Babies with AIDS in Harlem," 163.
[299] Children's Bureau, "The Abandoned Infants Assistance Initiative 1988-2017," August 2018, 1, accessed February 2020, https://www.childwelfare.gov/pubPDFs/aia_summary.pdf
[300] J Zamgba Browne, "Di's Harlem Hosp visit hailed," *New York Amsterdam News*, February 11, 1989.

The opening of New York's ICC coincided with the opening of Grandma's House, a residence for HIV-positive children near Logan Circle in the North West quadrant of Washington, D.C. Similar to the medics at Harlem Hospital, sisters Joan McCarley and Reverend Debbie Tate had founded the residential programme for children after becoming aware of the growing number of babies with HIV and AIDS residing in nearby hospitals. The sisters secured funding through contracts with the District of Columbia government and from private donations, and the home opened to take in children from new-born to age twelve.

In March 1989, in one of her first outings in her tenure as first lady, Barbara Bush visited Grandma's House and embodied the maternal role women have often assumed in social movements for rights and justice.[301] Dressed in a smart red suit with her signature pearls and grey permed hair, photographers captured images of the First Lady cradling a five-month-old baby on her shoulder, kissing a toddler, and playing with three little girls.

Photographer Brian Weil noted that pictures of children with AIDS risked giving the impression that these were the "innocent victims" of the epidemic.[302] The art activist collective Gran Fury similarly critiqued the optics of Bush's visit for perpetuating this binary of "guilty" woman versus "innocent" child. They argued against pitting the well-being of the

[301] For example, in 2013, a group of women whose children had been killed by police and gun violence founded "Mothers of the Movement," an organisation that uses various media platforms to raise awareness of police brutality and advocate for political change. The artist Beyoncé included several members of the group in her 2016 visual album *Lemonade*. In the 1980s and 1990s, groups of women founded similar mother support groups in response to AIDS, including the PWA Mother's Support Group and the Mother's Love Support Group who held regular "Mother's March Against AIDS" events in New York. Ephemera in box. 5, fol. 15, WAC records, NYPL Manuscripts and Archives Division. Activists also established the "Mother Cares Foundation" to provide promotional and fund-raising support to other AIDS groups, and through their spokes-character, an elderly woman wearing an apron and holding a wooden spoon, Zelda "Mother" Rubenstein, the organisation brought public and media attention to various AIDS causes with their motto, "AIDS is a Family Matter, and Mother Cares." box. 15, fol. 769, Coyote papers, Schlesinger Library.

[302] Brian Weil, *Every Seventeen Seconds: A Global Perspective on the AIDS Crisis* (Aperture: New York, 1992), 37.

child against its mother in their 1989 poster "Control," (shown in figure 4 below) which pictured Bush cradling an African American baby next to the caption:

> This is one of the thousands of HIV-positive babies living with AIDS in America. These babies have been photographed in the arms of princesses and presidents' wives, are the object of media attention and public sympathy, and have access to health care and drug trials often denied their parents. These 'most innocent victims of AIDS' are symbolically useful as repositories of sentiment to reflect the values of those in control. And their mothers?[303]

[303] Gran Fury, "Control [Barbara Bush] (Black and white)," *The New York Public Library Digital Collections*, 1989, NYPL Manuscripts and Archives Division, accessed February 2020, http://digitalcollections.nypl.org/items/510d47e3-5330-a3d9-e040-e00a18064a99



Figure 4. Gran Fury "Control [Barbara Bush]," 1989.[304]

The criticism that the right-to-life movement was hypocritical for claiming to care about black foetuses while at the same time undermining the rights of black adults was one that different groups had levelled against the anti-abortion movement for years.[305] Writing on policies that criminalised drug use during pregnancy, historian Dorothy E. Roberts succinctly noted that "We must question such a policy's true concern for the dignity of the foetus, just as we question the motives of the slave owner who protected the unborn slave child while whipping her pregnant mother."[306] In 1989, Gran Fury similarly criticised Bush's visit to

[304] Gran Fury, "Control [Barbara Bush] (Black and white)," *The New York Public Library Digital Collections*, 1989, NYPL Manuscripts and Archives Division, accessed February 2020, http://digitalcollections.nypl.org/items/510d47e3-5330-a3d9-e040-e00a18064a99. Used with permission of the NYPL Manuscripts and Archives Division.
[305] Dubow, *Ourselves Unborn*, 104.
[306] Dorothy E. Roberts, "Punishing Drug Addicts Who Have Babies: Women of Color, Equality, and the Right to Privacy," in *Abortion Wars*, 149.

Grandma's house as shifting the conversation about AIDS away from the health and social concerns of HIV-positive women and toward the needs of HIV-positive infants and toddlers. Although in her memoir Bush noted that she had privately supported the pro-choice position in the early 1990s, she presented a third way to those who did not accept abortion as a means for women to control their reproduction without contradicting their ideological worldview.[307] She also embodied the acceptable role women played in response to the AIDS crisis as the mothers and carers of children and men.

The emergence of AIDS Houses in the late 1980s and early 1990s coincided with the results of the ACTG 076 trial which had proven the effectiveness of the drug AZT to block perinatal transmission. In 1994, the US PHS recommended that pregnant women be given the antiretroviral drug AZT to reduce the risk of perinatal transmission of HIV.[308] The use of AZT during pregnancy led to a sharp drop-off in paediatric AIDS cases from the mid-1990s onwards that helped to ease fears of mother-to-child transmission.[309] Despite this breakthrough, the introduction of combination therapies in 1996 would again raise new and complex ethical questions about administering AZT to pregnant women, as women reported being taken off combination therapies by their doctors because they did not yet know the effects of the new drugs on the foetus.[310] Nonetheless, the FDA's approval of AZT in 1994 at least gave women the possibility of reducing the risk of perinatal transmission without threatening their right to choose when and whether to have children. Whereas health

[307] Barbara Bush, *Barbara Bush: A Memoir* (New York: Simon & Schuster, 1994), 154.
[308] CDC, "Recommendations of the Public Health Service Task Force on use of zidovudine to reduce perinatal transmission of human immunodeficiency virus," *MMWR* 43, no. RR-11 (August 5, 1994): 1-20.
[309] According to the CDC, estimates of the number of perinatal HIV infections peaked in 1991 at 1,650 and declined to an estimated range of 144-236 in 2002, attributing this reducing to routine screening of pregnant women; use of antiretroviral drugs for treatment and prevention; avoidance of breastfeeding; and use of elective caesarean delivery. CDC "Achievements in Public Health: Reduction in Perinatal Transmission of HIV Infection—United States, 1985-2005," *MMWR* 55, no. 21 (June 2, 2006): 592-597.
[310] Lauren Shapiro and Derek Link, "Access to State of the Art AIDS Therapy for Women," *LAP Notes*, Issue no. 6 (Summer 1997): 16, BWHBC records, Schlesinger Library.

advocates Carola Marte and Kathryn Anastos had in 1990 worried that "eliminating congenital HIV infection can be achieved only if HIV-positive women never have children," the FDA's approval of AZT in 1994 largely resolved the problem of perinatal transmission.[311]

Conclusion

When Reagan nominated Koop to the position of Surgeon General in early 1981, no one had expected that Koop's two-fold response to AIDS and abortion would protect women's reproductive choices in the wake of the AIDS epidemic. But, along with Barbara Bush's call for treatment for infants born with AIDS, his endorsement of contraception and sex education for prevention on the one hand and abortion as a less desirable, though medically viable, option in cases where women wanted to terminate their pregnancies on the other provided women with ways to protect their autonomy in the uncertain first decade and a half of the epidemic.

Koop's refusal to publish the Surgeon General's report on the health effects of abortion on women also meant that the anti-abortion movement could not deploy it in their persistent campaign against legal abortion. As a result, women activists like Faye Wattleton, who had worried that the federal government might use HIV to claim greater ownership of the rights of the foetus and therefore the bodies of women in the wake of the political ascendency of Ronald Reagan and the emboldened right-to-life movement that supported him, found an unlikely ally in Koop. While Koop continued to personally disagree with abortion and believed that the best way to prevent the transmission of HIV was through abstinence or

[311] Marte and Anastos, "Women—The Missing Persons in the AIDS Epidemic Part II," 14.

monogamy with an HIV-negative person, he had used the institution of Surgeon General to advance a position that was grounded in compassionate conservatism and pragmatic public health as opposed to conservative ideology. Doing so, Koop's efforts offer an example of the unexpected consequences of a particular person acting in a particular time.

The Reagan era was a period of transition that gave rise to the culture wars of the 1990s, during which the right-wing faction of the Republican party continued to gain prominence. Chapter three explores how the debate over women and AIDS shifted to lesbian women in the 1990s, partly as a consequence of the beginning of the culture wars and partly as a result of the sharp drop-off in cases of perinatal HIV following the approval of the use of the AZT drug in pregnancy in 1994. Although lesbian women had largely evaded political attention while the problem of women and AIDS revolved around prevention, abortion, and motherhood, they became central figures in the ensuing battle over what sex education looked like. The political attacks against their safer sex materials brought unprecedented focus to the lives of queer women who had, for the most part, evaded the punitive measures targeted at gay men for the sake of symbolically protecting America's children throughout much of the twentieth century. As shown in the next chapter, this hostility ushered in a new wave of organising among lesbian women across the United States.

***

Chapter Three

Women's Fight for Safer Sex in the Culture Wars, 1989-1995

At 3 a.m. on Sunday 27th September 1992, four young, white supremacist men tossed a Molotov cocktail into the basement apartment of Hattie Mae Cohens, a twenty-nine-year-old black lesbian, and her 45-year-old white gay disabled friend, Brian H. Mock in Salem, Oregon, killing them both.[312] Two months later, on 3rd November, Oregon citizens turned out to vote on Ballot Measure 9, a referendum proposed by the conservative group, Oregon Citizens Alliance (OCA), on whether the state should amend its constitution to classify homosexuality as "unnatural and perverse" and in need of being "discouraged and avoided."[313] Using the slogan "no special rights," the initiative sought to amend the Oregon constitution to prevent local or state governments from adopting laws protecting gay men and lesbians from discrimination. Many viewed the referendum campaign as the backdrop to the Salem attack motivated by racial and homophobic hate.[314] As the murders of Cohen and Mock attest to, the contentious battles of the culture wars played out not only in debate, but in violence and sometimes death.

That summer, on the other side of the country, six well-established members of the New York gay and lesbian activist scene—Ana Maria Simo, Sarah Schulman, Maxine Wolfe, Anne-Christine D'Adesky, Marie Honan, and Anne Maguire—came together to form a direct-action group. Dedicated to raising lesbian women's visibility and to fight the current

[312] Lesbian Avengers Recruitment Poster: "Don't Let Them Rest in Peace. Avenge the Oregon Martyrs," box 7, fol. 10, WAC records, NYPL Manuscripts and Archives Division.
[313] Initiative Petition submitted by the OCA, Oregon History Society Research Library, accessed February 2020, https://oregonencyclopedia.org/articles/oregon_citizens_alliance/#.WnQ5HFPFKqA
[314] Anna Quindlen, "Public & Private: Putting Hatred to a Vote in Oregon," *New York Times,* October 28, 1992; Bettina Boxall, "Battle Lines Drawn Over Oregon's Anti-Gay Measure," *Los Angeles Times*, October 22, 1992.

wave of state-wide anti-gay initiatives, they called themselves the Lesbian Avengers.[315] The murders of Cohens and Mock inspired the group to choose fire eating as their trademark. Homophobic attacks had often come in the form of firebombing queer spaces.[316] The Lesbian Avengers' appropriation of arson took the Salem attack as a particular incidence that crystalized anger and made it part of the symbolic response to the culture wars on the side of queer people. In October 1992, the Avengers built a shrine for Cohens and Mock in the West Village and, during a memorial held on Halloween, they ate fire, chanting, "The fire does not consume us. We will take it and make it our own."[317] The following April, these burgeoning lesbian networks demonstrated the women's remarkable mobilising capabilities when the group organized their first "Dyke March" in Washington, D.C., which saw more than 20,000 people join the Avengers as they ate fire outside of the White House. In April 1993, when Dee DeBerry made plans to join the Lesbian Avengers for the first Dyke March in D.C., her neighbours threatened to firebomb her house. Ignoring this threat, DeBerry travelled to D.C. from her home in Tampa, Florida, only to return home to find her house torched and destroyed. In June, the New York Avengers travelled to Tampa and held a vigil at the site of her home.[318] The group reclaimed fire as a queer symbol of resistance, and their emphasis on humour, anger, and sex positivity inspired the formation in the early 1990s of more than sixty locally-run chapters across the United States, an active branch in London and in other parts of the world, and with them the creation of a vast network of women committed to advancing lesbian autonomy, survival, and visibility.[319]

---

[315] The founding members of the Lesbian Avengers were already involved in AIDS work. Maxine Wolfe and Sarah Schulman were particularly active as a founding member of the ACT UP/NY Women's Caucus.
[316] The attack on the New Orleans gay bar, Upstairs Lounge, that killed thirty-two people in June 1973, the bombing of the Atlanta lesbian nightclub, Otherside Lounge in February 1997, and the attack on Backstreet Café, a gay bar in Roanoke, Virginia, that killed Danny Overstreet and injured many others in September 2000 are just a few examples.
[317] Kelly Cogswell, *Eating Fire: My Life as a Lesbian Avenger* (Minneapolis: University of Minnesota Press, 2014), 23.
[318] Lesbian Avengers, *Communiqué: From the Frontline. New York: Lesbian Avengers*, no. 3 (June 1993): 1, BWHBC records, Schlesinger Library.
[319] For a list of chapters, accessed February 2020, see http://www.lesbianavengers.com/about/chapters.shtml

The murders of Cohens and Mock, the Oregon referendum, and the founding of the Lesbian Avengers did not happen in isolation. Instead, they represented both the increase in violence that accompanied local and national efforts to undermine advances in gay and lesbian liberation that became a part of what historians have come to term the "culture wars," and the resulting surge in lesbian women's organising in this period.[320] While the homophobic attacks of the political right rendered gay women and men like Cohens and Mock hypervisible and therefore vulnerable, the emergence of the AIDS epidemic in the early 1980s simultaneously raised the stakes of women's organising as securing lesbian women's recognition for treatment became a matter of life and death.

Since the beginning of the epidemic, lesbian women living with HIV had struggled for recognition, especially within public health agencies and their own communities. During the 1980s, at the same time that activists and advocates worked to get the CDC to expand its official AIDS definitions to include gynaecological conditions pertaining to women, queer women also worked to challenge the CDC's exclusion of women who have sex with women in their surveillance, research, and treatment protocols. Lesbian AIDS activists coined the phrase "the myth of lesbian immunity" to describe what some believed was the inability for women to transmit HIV sexually to each other or through other behaviours that put them at risk of infection.[321] Public health agencies' slowness to recognise or track lesbian behaviours perpetuated this myth, but it also resulted from the debates over what constituted lesbian

[320] Local efforts to roll-back advances in gay rights began in 1978 with the Briggs initiative, also known as California Proposition 6, that sought to prohibit gay and lesbian teachers from working in public schools. In the early 1990s, a series of state-wide and local anti-gay measures similarly sought to repeal lesbian and gay anti-discrimination laws across the country, from Colorado and Idaho to Maine and Massachusetts. Hate crimes were also increasing in cities like Los Angeles. Somni Sengupta, "Hate Crimes Hit Record High in 1992," *Los Angeles Times*, March 23, 1993. See also McKay, *Patient Zero*, 23-24.
[321] Laurie Fitzpatrick, "Lesbians and AIDS," *A&U: America's AIDS Magazine* 30, March/April 1997, 22-24, box 47, fol. 3, Meredith papers, Schlesinger Library.

identity that had driven the lesbian separatist movement of the 1970s. In the wake of AIDS, lesbian activists wanted to emphasise that risk of HIV infection was not about how people identified but about what people did, and so they argued for an expanded understanding of their sexual identities that acknowledged that many women who had sex with other women also had sex with men, used drugs, received blood transfusions, and underwent artificial insemination, all of which put them at risk of infection. In 1990, after a decade of AIDS activism, Amber Hollibaugh founded the Lesbian AIDS Project (LAP) at the Gay Men's Health Crisis (GMHC) for the sake of centring the needs of lesbian women in the response to HIV and AIDS. In 1993, she commissioned filmmaker and visual artist Cynthia Madansky and performance artist Julie Tolentino Wood to design a safer sex handbook for the lesbian community.

The LAP produced their brochure against the backdrop of heightened homophobia and within the context of fear that such hostility evoked. Similar to Koop's efforts to distribute accurate information on AIDS to the public at large in the previous decade, the LAP created the brochure, albeit with an intentionally radically different tone, in order to overcome the lack of thorough and accessible medical information available to lesbian women about HIV and AIDS and to simultaneously intervene in the ongoing debates in the lesbian community over the meaning of lesbian identity as it related to sexual practice. Their efforts to equip lesbian women with detailed safer sex information was co-opted by the political right who, not viewing queer women's bodies as a threat to HIV in children, instead framed their attempts as dangerous homosexual propaganda in need of censorship for the sake of symbolically protecting America's children.

This chapter traces the journey of the safer sex handbook for lesbians to explore the intersection of lesbian identity, HIV, and the coalescing of the new political right in the culture wars of the 1990s. Section one examines the efforts of lesbian activists to overcome the "myth of lesbian immunity" that pervaded their own communities and public health circles. They did so partly by publishing intentionally explicit safer sex materials, such as the LAP's *Safer Sex Handbook for Lesbians*—the subject of section two. Section three then explores the political backlash that came with the distribution of the handbook, as factions of the political right became threatened by what widely available, sex-positive, non-patriarchal sex education might look like.

Existing histories of the origins and evolution of the culture wars have typically tied the political right's response to AIDS to a homophobic backlash against gay men in particular, and their simultaneous attacks on women-specific issues such as abortion and the ERA to a backlash against feminism. As a result, they do not put the political responses to AIDS and women alongside one another to show how AIDS brought new political focus to the lives of lesbian women fighting for recognition and autonomy as women living with HIV in the 1990s.[322] The journey of the *Safer Sex Handbook for Lesbians* —first distributed in lesbian communities and eventually debated on the floor of Congress and censored by the New York Board of Education—reveals how the AIDS epidemic shaped conceptions of lesbian identity at the end of the twentieth century and how such conceptions were tied to politics, medicine, and sexual practice. The fact that members of the political and religious right co-opted and

[322] For studies that largely treat the issues of feminism and AIDS in the culture wars separately, see Critchlow, "Mobilizing Women" in *The Reagan Presidency*, ed. Brownlee and Graham, 293-326; Michael Schaller, *Right Turn: American Life in the Reagan-Bush Era, 1980-1992* (New York: Oxford University Press, 2007), 40-42, 163-165; Robert Collins, *Transforming America: Politics and Culture in the Reagan Years* (New York: Columbia University Press, 2009), 171-192; Matthew Avery Sutton, "Reagan, Religion and the Culture Wars of the 1980s," in Johns, ed., *A Companion to Ronald Reagan*, 204-220; Hartman, *A War for the Soul of America*, 134-170.

framed women's safer sex materials as dangerous homosexual propaganda reveals not only the centrality of the symbol of the child to LGBT rights battles, but also the centrality of lesbian women to the 1990s culture wars.

Challenging the "Myth of Immunity"

Early in 1988, Alice Terson decided to take an HIV test. She already suspected she was positive because of all the behaviours she had engaged in: "I drank and used drugs for most of my adolescent and adult life. Repeatedly sharing needles and practicing unsafe sex, I was at risk many years before anyone in this country even knew that HIV existed." Writing for the inaugural LAP newsletter, *LAP Notes*, in April 1993, Terson noted that thirteen years into the epidemic, society still did not take woman-to-woman transmission seriously. Her biggest fear came from what she saw as the universal belief that lesbians did not get HIV or AIDS. She argued that lesbians "often forgot that our behaviours vary," and that many self-identified lesbians had sex, often unsafe sex, with men, had unprotected sex with other women, shared injection drugs, and engaged in other behaviours that put them at risk. Terson wanted to take the risk of being "out" as an HIV-positive lesbian in order to challenge the denial among lesbians, the public health system, and society at large about the risks and realities of women who had sex with women. Lesbians were not immune simply because of their sexual identity, explained Terson.[323] Or, as Amber Hollibaugh of the LAP put it, "Lesbianism is not a condom."[324]

[323] Alice Terson, "Positively Lesbian," *LAP Notes*, Issue no. 1 (April 1993): 3, BWHBC records, Schlesinger Library.
[324] Amber Hollibaugh, "Lesbianism is Not a Condom: Facing Our Risks for HIV In The Middle Of An Epidemic" (1993/94), 3, Subject file: AIDS, LHA.

As Terson's article attests, the onset of AIDS caused a reckoning within the lesbian community over what it meant to be a lesbian woman especially as it related to sexual practice. Historians of sexuality have long examined the converging forces acting on the conceptions of lesbian identities throughout the twentieth century and the changing terminology used to signify lesbian life. Shifts in what society understood as female homosexuality ranged from the "romantic friendships" of women who felt passion for other women in the early twentieth century, to the butch-femme categories prominent in the working-class lesbian bar culture of the 1940s, 1950s, and 1960s.[325] In the 1970s, a group of lesbian feminists who felt frustrated at their marginalized position within the broader women's liberation movement called for a movement for lesbian separatism that worked to detach sexual practice from lesbian identities.[326] Proponents argued that institutionalised heterosexuality was detrimental to women's freedom, and that lesbian women should disengage personally and politically with all heterosexual and homosexual men as well as heterosexual women.[327] Not everyone in the lesbian movement agreed with the separatist position. Some, particularly women of colour, including twin sisters Barbara and Beverly Smith, co-authors of the Combahee River Collective Statement, criticised the ideology as the class and racial privilege of women who, unlike those who needed to build alliances with men of colour, could afford to remove themselves from all family, community, and institutional affiliations.[328] Despite these criticisms, prominent members of the lesbian-feminist movement continued to advance the argument that women should be willing to consider other women as life as well as sexual partners in order to overcome sexual and

[325] Faderman, *Surpassing the Love of Men*; Kennedy and Davis, *Books of Leather, Slippers of Gold*.
[326] Evans, *Tidal Wave*, 102-104.
[327] Echols, *Daring to be Bad*, 238; Faderman, *Odd Girls and Twilight Lovers*, 218; Rousseau, "Wages Due Lesbians," 364-374.
[328] Barbara Smith, "Response to Adrienne Rich's 'Notes from Magazine: What does Separatism Mean?'" in *Sinister Wisdom* 20 (1982): 100-103, LC Periodical PS 508 W7 S54; Barbara Smith and Beverly Smith, "Across the Kitchen Table: A Sister-to-Sister Dialogue," in Cherríe Moraga and Gloria Anzaldúa, *This Bridge Called My Back: Writings by Radical Women of Color* (Albany: SUNY, c.1981, 2015), 118-121.

gender oppression. This understanding of lesbian identity necessitated neither the need to have sexual relations with nor sexual attraction to other women—the choice to partner and sleep with other women as opposed to men was as much a political as a personal act.[329]

By the 1980s, lesbian women were struggling to raise awareness of the varied behaviours that put women who had a sexual history with other women at risk from HIV in part because of the disputes that had erupted in the lesbian-feminist, pro-sex, and anti-pornography movements of earlier decades. Specifically, pro-sex members of the lesbian-feminist movement such as activist Amber Hollibaugh argued that with the onset of the AIDS epidemic, the focus on prescriptive ideas about what it meant to be a lesbian woman, as opposed to a focus on explicit sexual practice and behaviour, lent a false sense of security to women whose membership in the lesbian community led them to believe that they were at low risk for transmission, regardless of their actions.[330] Women such as Hollibaugh therefore wanted to broaden the definition of the term "lesbian" to recognise not only women who self-identified as lesbian, but those who engaged in sexual activities with both women and men; who asserted a sexual desire for women but did not self-identify as lesbians; and those who may have had a sexual experience with another woman. Speaking of the variety of lesbian self-identification, Hollibaugh wrote that "we call ourselves by many names or none at all, and our needs are complex and varied." Artist and Assistant to the Director at the LAP Cynthia Madansky similarly challenged the "false sense of security that 'it can't happen to us,'" arguing that "the perpetual myth in the lesbian community that we are not at risk

[329] Radical Lesbians, "The Woman Identified Woman Manifesto," 1970 https://www.historyisaweapon.com/defcon1/radicalesbianswoman.html; Jill Johnston, *Lesbian Nation: The Feminist Solution* (New York: Bantam, 1973); Adrienne Rich, "Compulsory Heterosexuality and Lesbian Existence," *Signs* 5, no. 4 (Summer, 1980): 631-660; Sarah Lucia Hoagland, "Lesbian Separatism: An Empowering Reality," *Sinister Wisdom* 34 (Spring 1988): 23-33, LC Periodical PS 508 W7 S54; Rosen, *The World Split Open*, 167-170, 171, 172-174.

[330] For more on the ruptures within the feminist movement over lifestyles and identities, see Rosen, *The World Split Open*, 172, 194; Gerhard, *Desiring Revolution*, 183-196; Evans, *Tidal Wave*, 121-123.

contributes to the silence, invisibility, and isolation of those among us who have HIV/AIDS."[331] Safer sex educator Catherine Saalfield agreed that "we tell ourselves that we don't have to worry since HIV-positive lesbians don't exist. It's a lame justification, based on our fantasies and enforced by our own silence."[332] The women's argument for the fluidity and malleability of lesbian identities aligned with the emerging queer politics of the 1990s that rejected the view of sexual identity as fixed, natural, or inherent.[333]

Amber Hollibaugh, a self-described "lesbian sex radical, ex-hooker, incest survivor, Gypsy child, poor-white trash, high femme dyke," grew up in a working-class family near Bakersfield, California. Beginning with the Freedom Summer in 1964, she spent her life as a full-time activist involved in New Left, feminist, and queer movement politics. In the 1980s, her desire to do explicit work around sexuality and to represent women whose class, race, and sexual desire lay outside the boundaries of middle-class lesbian-feminism drove her to AIDS activism. In her belief that these women and their children would comprise the next group that AIDS would greatly impact, she focused her energies on communicating how an often invisible community of lesbians were at risk.

In the early 1980s, Hollibaugh began working as an HIV pre- and post-test counsellor and hotline worker in New York before joining the AIDS Discrimination Unit of the New York City Commission on Human Rights. Beginning work at the Gay Men's Health Crisis (GMHC) in New York City, she also helped the organisation to expand its services beyond white gay men to reflect the growing diversity of people living with AIDS and HIV. In 1990,

[331] Amber Hollibaugh, "Notes from LAP" and Cynthia S. Madansky, "In the Beginning," *LAP Notes*, Issue no. 1 (April 1993): 1, 2, BWHBC records, Schlesinger Library.
[332] Catherine Saalfield, "Coming to Safer Sex," *LAP Notes*, Issue no. 2 (Spring 1994): 13, BWHBC, Schlesinger Library.
[333] Hobson, *Lavender and Red*, 191.

she launched and became director of the Lesbian AIDS Project (LAP) at GMHC, the first organisation that fought exclusively for the needs of lesbians with HIV and AIDS. Just as documentary photographer Ann P. Meredith had described women as the "hidden population" in the AIDS epidemic, Hollibaugh described lesbians with HIV as "the disappeared" population in lesbian communities. She therefore launched LAP for the sake of reaching out to isolated lesbian women who were living with HIV.[334]

As director of LAP, Hollibaugh worked with a growing number of lesbian women who were either HIV positive, had AIDS, or who had questions about risk. She later recalled that:

> I kept finding lesbians with HIV. You know, nobody would say that they had anything to do with the epidemic and nobody would say that lesbians were at risk…I knew that lesbians were at risk and I knew that this was about class and race and I felt like all that I had believed in, and all I had been trying to say in the ways that I was a feminist would be at its best use, because I would be creating a project that would be built on the class and race and gender of women around HIV who were queer.[335]

In order to challenge what some in the lesbian community called the "myth of lesbian immunity" that implied that sex between women did not easily transmit HIV and that queer women did not engage in other behaviours that put them at risk for infection, Hollibaugh and other activists worked to make visible the lives of women who had sex with other women and who also injected drugs, or who had sex with men for work but who turned to other women

[334] Amber L. Hollibaugh, "Lesbian Denial and Lesbian Leadership in the AIDS Epidemic: Bravery and Fear in the Construction of a Lesbian Geography of Risk," in *My Dangerous Desires: A Queer Girl Dreaming Her Way Home* (Durham: Duke University Press, 2000), 209.
[335] Amber Hollibaugh, interview by Kelly Anderson, transcript of video recording, January 20, 2004, 155, Voices of Feminism Oral History Project, Sophia Smith Collection, Smith College, Northampton, MA.

for sex, love, and intimacy.[336] In 1991, ACT UP Book Group member and family nurse practitioner at Bronx Lebanon Hospital Risa Denenberg similarly challenged the invisibility of lesbians who injected drugs when writing for the queer magazine *Out/Look*:

> Just as lesbians are often invisible in the straight world, injection drug users who have sex with women aren't always visible in the lesbian world. All lesbians struggle with issues related to visibility, yet those of us who call ourselves lesbians often attempt to create a homogenized portrayal of who we are and what we do. It's a picture that hardly includes all women who struggle in the bedroom with other women.[337]

Denenberg went on to question why "lesbian AIDS activists have readily tackled the safer-sex issues for lesbians" but "not the drug risk." Hollibaugh was one such activist who used her past experiences with drug use to clarify the confusion between visibility, identity, and behaviour. Denenberg also argued that "lesbians who contracted HIV through sex with men are not considered to be 'authentic' enough to claim the lesbian identity."[338] Doing so, she worked to challenge prescriptive ideas about what it meant to be a lesbian woman in the wake of AIDS and emphasise that risk was not about how a woman identified but what they did.[339]

In addition to acknowledging that drug use put lesbian women at risk of infection, lesbian AIDS activists also sought to expand the perception of AIDS as not just a gay male problem

[336] Fitzpatrick, "Lesbians and AIDS," 22-24.
[337] Risa Denenberg, "We shoot drugs, and we are your sisters," *Out/Look*, No. 11 (Summer 1991): 32, LC Periodical HQ 76 .3. U5099.
[338] Risa Denenberg, "Lesbians and HIV: Is IDU the Missing Link?" *LAP Notes*, Issue no. 1 (April 1993): 10, BWHBC, Schlesinger Library.
[339] Hollibaugh, "Lesbian Denial and Lesbian Leadership in the AIDS Epidemic: Bravery and Fear in the Construction of a Lesbian Geography of Risk," in *My Dangerous Desires*, 203.

and integrate the responses to it with efforts to tackle other women-related issues, such as rape, domestic violence, and poverty that affected queer women too. Doing so, they faced criticism from other prominent women in the lesbian community such as Naja Sorella, Jackie Winnow, and June Jordan who expressed frustration at suffering from other diseases, most commonly breast cancer, "while Lesbians put their physical, emotional and financial energy into AIDS."[340] Lesbians with HIV worked hard to challenge the misconception that lesbian women only occupied the role of the carers of men in the epidemic instead of acting on behalf of their own illness, and to show that AIDS, like breast cancer, was also a woman's health issue.[341]

Evidence of the changing understanding of AIDS as a disease of behaviours and not rigid identities, lesbian activists pointed to a number of informal studies conducted in the United States and in other parts of the world that showed that women who had sexual history with other women were at a greater risk of HIV infection than women who did not.[342] Data gathered from studies at the Bronx-Lebanon Hospital and Montefiore Hospital showed that more than 40 percent of HIV-positive women had had a same-sex partner. Unpublished data from Seattle found that the infection rate for women who engaged in same-sex behaviours was five times higher than it was for women partnering exclusively with men. Studies in California reported that one-fifth of a sample of female intravenous drug users were either

[340] Naja Sorella, "A/part of the Community," and Jackie Winnow, "Lesbians Evolving Health Care: Our Lives Depend on It," in *Sinister Wisdom* 39 (Winter 1989-90): 104-107, 53-63, LC Periodical PS 508 W7 S54; June Jordan, "I am Seeking an Attitude," in June Jordan, *Some of Us Did Not Die: New and Selected Essays* (New York: Basic Books, 2002), 96.
[341] Historian Katie Batza has noted the struggle lesbian women faced in putting lesbian-specific health concerns on the 1970s gay and women's health agendas. Katie Batza, *Before AIDS: Gay Health Politics in the 1970s* (Philadelphia: University of Pennsylvania Press, 2018), 5.
[342] As Dr. Roy Widdus, director of the "Confronting AIDS" report, stated when testifying for the Presidential Commission on the HIV Epidemic, "AIDS is a disease of behaviour. That has been said over and over." 00:34:02. November 24, 1987, accessed February 2020, https://www.c-span.org/video/?389-1/aids

bisexual or lesbian, while Australian researchers put the figure closer to one-third.[343] In October 1993, the San Francisco Department of Public Health published a "Women's Survey" based on 498 randomly chosen women which showed that lesbian and bisexual women had an HIV infection rate three times higher than that of the general population of women.[344] The report also pointed to the direct connection between violence and HIV infection, whereby 32.1 percent of lesbian and bisexual women surveyed reported non-consensual sex with men, and 5.8 percent reported non-consensual sex with women.[345] Each study concluded that despite their increased risk, women who had sex with women frequently fell beyond the reach of traditional HIV programmes.

These studies further angered activists already outraged at the CDC's refusal to track HIV risk among lesbian women. The death of twenty-six-year-old Joan Baker from AIDS-related complications on 3rd September 1993 became a further rallying cry for members of the San Francisco Lesbian Avengers. Thirteen years since the emergence of the AIDS epidemic in the United States, Baker's death symbolised the long overdue need to recognise that lesbians, bisexual women, transgender lesbians, and all women who had a sexual history with other women were at risk. Baker had spent the six years since Ann P. Meredith had first taken her photograph in 1987 campaigning alongside groups like the Lesbian Avengers for recognition and services on behalf of other women living with the virus. Baker was one of many women activists in the Bay Area who, through direct action protests, speeches, and various forms of documentary media, educated others about the risk of infection in women. "It doesn't matter

[343] GMHC HIV Counseling, Testing & Prevention Initiative, 6-7, box 400, fol. xv, GMHC records, NYPL Manuscripts and Archives Division.
[344] AIDS: News and Information. City and County of San Francisco Department of Public Health, "Two New Surveys Show that Lesbians and Bisexual Women are at Risk for HIV Infection," October 19, 1993, box 1, fol. Centers for Disease Control/Lesbians Get AIDS Protest, August 1994, Lesbian Avenger Records, Gay Lesbian Bisexual Transgender (GLBT) Historical Society Archives & Special Collections, San Francisco. Hereafter: GLBT Archives.
[345] Terry A. Maroney, "Lesbians, HIV & Violence," *LAP Notes*, Issue no. 2 (Spring 1994): 10, BWHBC records, Schlesinger Library.

how I got it," Baker would explain. "It's the fact that I have been diagnosed and I am coming out as a woman with AIDS, because a lot of lesbians still don't think that they can get AIDS, and I am here to say that it can happen."[346] One month after her death, on 23rd October, members of the Lesbian Avengers, ACT UP San Francisco and ACT UP Golden Gate, the San Francisco Women's Action Coalition (WAC), and the Lyon-Martin's Health Services held a political funeral for Baker which saw hundreds of women and men march from Dolores Park into the Castro playing drums and holding signs (seen in figure 5 below) that featured Baker and read: "We Are Women Living with AIDS," "It's Time to Stop the Denial," and "Wake up Call. Get the Facts: Women Who Fuck Women Can Contract HIV/AIDS."[347] Joan's death and her funeral reinforced that lesbians living and dying with HIV were not statistics but integral members of their communities.

[346] See various leaflets, posters, and other miscellaneous ephemera in box 2, fol. Political Funeral for Joan Baker, October 23, 1993, Lesbian Avengers Records, GLBT Archives.
[347] See various leaflets, posters, and other miscellaneous ephemera in box 2, fol. Political Funeral for Joan Baker, October 23, 1993, Lesbian Avengers Records, GLBT Archives.



Figure 5. Political Funeral for Joan Baker, October 1993.[348]

The concurrent publication of the San Francisco Health Department's "Women's Survey" and the death of their friend Joan Baker led the San Francisco Lesbian Avengers to create a number of leaflets and posters highlighting the CDC's failure to collect statistics on HIV among lesbians including "Lesbians Get AIDS Just Like Joan Baker," "Dykes Get AIDS. How? The Center for Disease Control doesn't have a clue," and "We Demand a Definitive Study of Woman-to-Woman Transmission of HIV!"[349] The chapter organised a demonstration targeting the CDC's policies as part of a larger campaign criticising the federal government for "its complete failure to address the issues surrounding dykes and AIDS." The San Francisco Avengers made three demands. First, that the CDC conduct thorough studies

[348] Photograph in box 3, fol. Political Funeral for Joan Baker, October 23, 1993, Lesbian Avengers Records, GLBT Archives. Used with permission of the GLBT Archives.
[349] Ephemera in box 2, fol. Centers for Disease Control/Lesbians Get AIDS protest, August 1994, Lesbian Avenger records, GLBT Archives.

of the possibility of woman-to-woman transmission, second, that it fund outreach efforts directed at lesbian and bisexual women and, finally, that the agency revise its definition of "lesbian" so that it more accurately reflected the lesbian population.[350] With these objectives in mind, on 13th August 1994, twenty-two Lesbian Avengers demonstrated outside the CDC's Bay Area office, covertly located at the San Francisco International Airport. As some women wrapped other women's pelvises in saran wrap, others unfurled a 20-foot-long banner which read, "Dykes demand the CDC study woman-to-woman AIDS transmission."[351] During the following months, the women bombarded the CDC with faxes to its headquarters and phone calls inundated its AIDS information hotline.

As the protests demonstrated, lesbian AIDS activists worked not only to make visible the varied behaviours that put lesbian women at risk for transmission, but for the official inclusion of women who have sex with women in the CDC's surveillance, research, and treatment protocols. In response to AIDS, the CDC began using the term "men who have sex with men" (MSM) as a way to mark men's sexual behaviours without their having to identify themselves as gay, homosexual, or bisexual. The CDC's development of a medical category that transcended rigid identity categories reflected the urgent need to respond to the initial prevalence of HIV among men who either did or did not self-identify as gay, but who described having had a same-sex experience at some point in their past. The CDC did not develop an equivalent term for women who had sex with other women but who may not have identified as lesbian, bisexual, or gay. Their failure to introduce a medical category that similarly reflected women's sexual subjectivities spoke to the broader difficulties many lesbian women faced in accessing the health care system in general; women who were on the

[350] Press Release, "Lesbian Avengers Target the CDC's AIDS Policies," August 1994, box 2, fol. Centers for Disease Control/Lesbians Get AIDS protest, August 1994, Lesbian Avenger records, GLBT Archives.
[351] Press Release, "Lesbian Avengers Target the CDC's AIDS Policies."

whole medically under-insured and who often chose not to disclose their sexuality to health care providers, fearing sanction or discrimination.[352]

In 1990, the percentage of "no identified risk" for women was double that of men.[353] The CDC compiled its data from the reports of physicians across the country and, unlike with men, the agency did not require physicians to collect sexual orientation data from any HIV-positive women nor ask women about same-sex practices, and researchers did not classify woman-to-woman transmission as a possible exposure category.[354] If physicians reported cases of woman-to-woman transmission, such cases were counted as "no identified risk." The CDC categorised women like Lynette Hubbard, also known as "Cookie," who was diagnosed with HIV in 1989 and died in June 1993, in one of those opaque "other" transmission categories, even though she had been a lesbian all her life.[355] Beginning in the early 1980s, the CDC had separated reported AIDS cases into groups based on four "risk factors": male homosexuality, intravenous drug use, Haitian origin, and haemophilia A. The risk group concept roughly identified people whose membership in a group practicing certain behaviours was likely to bring them into contact with the virus. As the reported cases of HIV grew and diversified, the CDC expanded which populations they marked as "at risk." It added risk factors for women in 1985 after researchers confirmed that women could also contract HIV.

[352] GMHC HIV Counseling, Testing & Prevention Initiative, 6-7, box 400, fol. xv, GMHC records, Manuscripts and Archives Division.
[353] Rebecca Cole and Sally Cooper, "Lesbian Exclusion from HIV/AIDS Education: Ten Years of Low-Risk Identity and High-Risk Behavior," *SIECUS Report* (December 1990/January 1991): 18, Subject file: AIDS, LHA.
[354] Cynthia S. Madansky, "In the Beginning," *LAP Notes*, Issue no. 1 (April 1993): 2, BWHBC records, Schlesinger Library.
[355] Lisa Winters, "In Memory of Cookie, 9/19/60-6/25/93," *LAP Notes*, Issue no. 2 (Spring 1994): 9, BWHBC records, Schlesinger Library.

The CDC used a hierarchy of exposure categories to assign one HIV transmission category for each reported case of AIDS, and if a woman had more than one possible exposure, she would be categorised as the highest risk only. The hierarchy for infection in women was: 1) intravenous drug use, 2) receipt of blood products, 3) heterosexual contact with an HIV-positive man, and 4) no identified risk. If a man had more than one possible exposure, for example from drug use and sexual contact, he would be listed in an exposure category such as: IV drug use (heterosexual) or male homosexual/bisexual contact and IV drug use. Researchers did not apply the same layering of categories of risk to women. As ACT UP Book Group member Zoe Leonard explained, if a lesbian woman was raped, she did not stop being a lesbian, but if she developed AIDS, she was not counted as a lesbian with AIDS.[356] The data collection methods and the lack of official medical studies on the possibility of women to transmit HIV sexually to each other sustained the notion held by some public health professionals and, by extension, many in the lesbian community, that women who had sex with women were a "low-risk" group.

As major areas regarding HIV infection in all women went under-researched and women in the lesbian community continued to contract HIV and die, lesbian health activists and advocates argued for the need for official studies on lesbian practices and information about HIV in menstrual blood, vaginal and cervical secretions, and other discharges. In *Women, AIDS, and Activism*, Leonard observed that:

> Since transmission through oral sex and other sexual activities between women cannot be ruled out, all educational materials and safer-sex guidelines must include information pertinent to lesbians. We must learn from the history of the AIDS

[356] Zoe Leonard, "Lesbians in the AIDS Crisis," in Marion Banzhaf et al., *Women, AIDS, and Activism*, 114.

> epidemic, and recognize the need for prevention in the lesbian community, rather than rely on flawed "low-risk group" analysis.[357]

Hollibaugh agreed that "until women's (heterosexual, bisexual, and lesbian) sexuality becomes part of the public discourse on HIV prevention, all women are being neglected."[358] Not acknowledging and discussing sex toys, multiple and unprotected sex partners, sex during menstruation, and female ejaculation as risks left women who partner with women isolated from life-saving education and prevention.[359] The lost or hidden sexual aspects of lesbian identity throughout the twentieth century culminated in the sentiment, as articulated by Dr Charles Schable who conducted HIV transmission studies for the CDC, that it wasn't necessary to include the risks for gay women because "lesbians don't have much sex."[360] In 1992, at the Eighth International Conference on AIDS in Amsterdam, as women activists pressurised the CDC to amend its official AIDS definition and women's health advocates such as Jamie Penney of the BWHBC called on the international AIDS community to take seriously the threat AIDS posed to women's reproductive rights, a group of lesbians, bisexual women, and transgender lesbians also put together a list of seventeen demands directed at the AIDS establishment, including increasing funding for research on woman-to-woman transmission of HIV.[361]

In the absence of full institutional recognition and support and, similar to the educational initiatives of other activists, LAP filled the gap in knowledge about HIV and lesbian women.

---

[357] Leonard, "Lesbians in the AIDS Crisis," in Marion Banzhaf et al., *Women, AIDS, and Activism*, 116.
[358] Hollibaugh, "Lesbian AIDS Project Curriculum and Education Training Guide," August 3, 1994, 7, GMHC records, box 401, fol. 16, NYPL Manuscripts and Archives Division.
[359] Hollibaugh, "Transmission, Transmission, Where's the Transmission?" in *My Dangerous Desires*, 193.
[360] Quoted in Leonard, "Lesbians in the AIDS Crisis," in Marion Banzhaf et al., *Women, AIDS, and Activism*, 113.
[361] Catherine Saalfield, "Coming to Safer Sex Part II," *LAP Notes*, Issue no. 3 (Summer 1995): 14, BWHBC records, Schlesinger Library.

Hollibaugh believed that the lack of sexual communication between lesbians caused both lesbian women and policymakers to form a monolithic "non-risky" picture of lesbian sexuality. LAP ran a series of sexual and empowerment workshops with titles such as "Feeling Good All Over" and "Living Examples: Lesbians and HIV in Three Acts," to teach lesbian and bisexual women as well as service providers ways to negotiate safer sex, address drug use, and connect with women concerned about HIV.[362] LAP preserved these ephemeral workshops, publishing the curriculum complete with training guides.[363] Their efforts, culminating in the publication of their *Safer Sex Handbook for Lesbians* in 1993, were part of a larger movement to increase public discussion about the relationship between lesbian sexual practices and risk with the aim to save lives in the wake of the epidemic.

During the 1980s, many public health agencies and condom manufacturers had directed their safer sex campaigns at heterosexual women for the sake of preventing mother-to-child transmission of HIV. In the 1990s, lesbian activists published their own safer sex educational materials that centred sexual acts between women in order to raise awareness of the reality of risk of HIV in lesbian women and challenge the "myth of lesbian immunity" within lesbian communities and public health agencies. Their efforts to break the silences around lesbian sexuality made them an easier target for political attack. The heteronormative political response to the tone and imagery of the safer sex information revealed women's broader struggle to protect their right to sexual self-determination in the public sphere. As the political right did not view queer women's bodies as a threat of HIV in children, they instead

[362] For the ephemera of the workshops, see Workshop Facilitator: Marianela Virella, Negotiating Safer Sex Workshop, Safer Sex Workshops, and Feeling Good All Over Workshop, and various other guides, box 401, fol. 8, 9, 15, GMHC records, NYPL Manuscripts and Archives Division.
[363] Hollibaugh, LAP/Curriculum and Education Training Guide, August 3, 1994, GMHC records, box 401, fol. 16, NYPL Manuscripts and Archives Division.

judged their safer sex publicity as obscene homosexual propaganda in need of censorship for the sake of symbolically protecting America's children.

The Safer Sex Handbook for Lesbians

The women who the LAP wrote the *Safer Sex Handbook* for were not children and were not, for the most part, shocked or offended by the literature. They already engaged in sex and wanted to know how to do it more safely. Similar to other prevention materials, the handbook told them how and sought to save lives. However, unlike sex education projects that were more family-orientated, such as Koop's *Understanding AIDS* booklet published five years earlier, the tone of the brochure was intentionally radical. Coming from the pro-sex faction of the feminist movement, Hollibaugh sought to counter clinical, sterile, and condescending sex education. Instead, she wanted to explore lesbian erotics and sexual health and do so in a way that was explicit but safe and without shame. The tone and visuals of the brochure were therefore purposefully explicit—wanting lesbian women to practice safer sex because it was fun and raunchy. It came out of a specific need for pro-sex lesbian erotics that even differed from the sexual education offered in feminist anthologies such as *Our Bodies, Ourselves*. Its success shocked people, as it highlighted that the need for sex education applied not only to school-age children, but to women exploring what a pro-sex, lesbian future free from sexual violence by men might look like.

Prior to the publication of the *Safer Sex Handbook*, much of the fight over what constituted lesbian sexuality had stayed within the lesbian community.[364] Now that lesbian activists were trying to reach the broadest number of women, they attracted the attention of the political

[364] Rosen, *The World Split Open*, 172-175.

right who were threatened by what sex-positive, non-patriarchal sex education might look like. As was the case for women seeking treatment following the outbreak of AIDS in the 1980s, lesbian women's need for recognition for treatment was loaded with prescriptiveness and risk.

AIDS brought unprecedented attention to the lives of lesbian women who had, for the most part, evaded the more punitive government measures targeted at gay men throughout the twentieth century. In 1991, Julia Creet commented on how her experiences living as a lesbian woman in society compared to the experiences of gay men:

> I was never in danger of being thrown in jail for practicing sodomy…This is not to say that lesbians weren't arrested and harassed by the police for being lesbian and there were no severe repercussions for such "gender treachery." But there never were any laws specifically forbidding lesbian sexual practices; the only lesbian case ever charged in Canada fell instead under the code forbidding "gross indecency," and this did not occur until 1981.[365]

Although Creet wrote from a Canadian perspective, her comments applied to the United States.[366] Throughout much of the twentieth century, the federal government paid relatively little attention to regulating same-sex relationships between women in comparison to their efforts to regulate those between men. As historian Margot Canaday has noted, in the first half of the twentieth century, federal officials were comparatively slow to regulate

[365] Julia Creet, "Lesbian Sex/Gay Sex: What's the Difference?" *Out/Look*, No. 11 (Winter 1991): 29, LC Periodical HQ 76 .3. U5099.
[366] The 1986 Supreme Court ruling in *Bowers v. Hardwick* criminalised oral and anal sex in private between consenting adults, with respect to homosexual sodomy. Chauncey, "What Gay Studies Taught the Court," 516-519.

homosexuality among women because male citizens—and therefore male "perverts"—mattered more to the state than women did.[367] While Canaday and Creet referred more to the policing of actual sexual acts, the *Safer Sex Handbook* was more closely tied to sex education and lesbian erotics that, for public health reasons, had to become more visible in the 1990s.

In 1993, Hollibaugh commissioned artists Cynthia Madansky and Julie Tolentino Wood to write a safer sex handbook for the lesbian community that would counter the widespread lack of accurate information on HIV and lesbian women and be sex positive, sexually explicit, and "informative yet erotic."[368] The resulting twenty-sided-brochure, entitled *The Safer Sex Handbook for Lesbians*, encouraged women to control their sexual experiences and name their desires. Similar to other lesbian-specific safer sex brochures produced at the time, such as The Galaei Project's 1995 *Let's Talk AIDS* leaflet advising use of latex dental dams, rubber gloves, or condoms for vaginal, oral, or anal sex, the *Safer Sex Handbook* contained explicit guidance on learning "erotic and comfortable techniques for practicing safer sex," detailing how women could integrate gloves, plastic wrap, latex barriers, clean sextoys, and implements into fantasies and fetishes. Acknowledging that these practices also put women at risk of infection, the handbook also contained information on drug use and sex with men.[369] It opened asserting that:

> It is impossible to describe all the ways women have sex with each other. The one thing we know about ourselves is that we love to connect, meet and sleep (fuck, make love, do it, have sex) with other women. As diverse as our sexual practices, there are

[367] Canaday, *The Straight State*, 12-13.
[368] Cynthia Madansky, "fierce fists," in *Gendered Epidemic: Representations of Women in the Age of AIDS*, ed. Nancy L. Roth and Katie Hogan (New York: Routledge, 1998), 83.
[369] The Galaei Project, *Let's Talk AIDS*, 1995, box 401, fol.1, GMHC records, NYPL Manuscripts and Archives Division. For examples of other lesbian safer sex posters, see Stoller, *Lessons from the Damned*, 56.

> as many ways to eroticize safer sex. Welcome to the first lesbian safer sex handbook produced by the Lesbian AIDS Project.[370]

Similar to other lesbian AIDS activists, Madansky and Tolentino Wood believed that lesbian women would struggle to protect themselves in the epidemic if they could not say who they were or describe what they did. They produced the handbook for women who frequented lesbian bars and clubs and who, for the most part, participated in a wide range of sexual activities. The premise of the handbook was that no matter how women identified (as lesbian, bisexual, or homosexual), if they slept with other women there was some basic medical information which they needed to know about transmission of STDs and HIV during sexual activity. Most important was to address a variety of sexual activities between women that might involve transmission of HIV in some detail and to do so without censorship or judgment.[371]

Within a year, GMHC had printed 67,000 copies of the *Safer Sex Handbook*, most of which they gave out for free while selling some copies to organisations. The majority of the handbook's distribution was through word of mouth. LAP received phone requests from individuals and organisations who had seen or heard about the brochure or from people searching for safer sex materials for lesbians. LAP distributed the brochure internationally to AIDS organisations, prisons, physicians, as well as at New York's Gay Pride in 1993, the New York Clit Club, the Community Health project, the Lesbian and Gay Community Centre, and through the mail from GMHC when requested.

[370] Cynthia Madansky and Julie Tolentino Wood for LAP, *The Safer Sex Handbook for Lesbians*, 1993, Subject file: AIDS, LHA.
[371] Madansky, "fierce fists," in *Gendered Epidemic*, 83.

In 1994, one year after the *Safer Sex Handbook* had appeared on this cultural landscape, the Evaluation Research Department at GMHC held four focus groups composed of a total of thirty-two Black, Latina, Caucasian, and Asian women to evaluate the effectiveness of the handbook among the diverse lesbian communities for whom it was designed. Topics covered in the focus groups ranged from the handbook's distribution, layout and design, the language used, and the content. In the meetings, participants said that they appreciated the direct and sex-positive tone of the brochure and its inclusion of less common sexual activities not usually discussed in safer sex brochures. One woman mentioned that the section on less common sexual activities was important because it presented a diverse view of lesbian lifestyle. Others agreed that the brochure personalized safer sex and made it erotic: "all other things I've read says to do this [practice safer sex] 'cause there's an epidemic… [but this brochure]…makes lesbian [safer] sex sound good."[372] They also praised the explicit nature of the photography, particularly the cover, suggesting that the images helped create a positive feeling about lesbian sex (figure 6).[373]

[372] Jennifer L. Kaplan, "Focus Group Evaluation of the *Safer Sex Handbook for Lesbians*," Department of Evaluation Research at the Gay Men's Health Crisis, Inc. August 11, 1994, 9, box 400, fol. 6, GMHC records, NYPL Manuscripts and Archives Division.
[373] Kaplan, "Focus Group Evaluation of the *Safer Sex Handbook for Lesbians*," 5-6.



Figure 6. The Safer Sex Handbook for Lesbians, 1993.[374]

The women who participated in the GMHC's focus groups voiced their relief over the availability of a pamphlet that addressed their desire to practice safer sex. While not all of the women liked the handbook—some thought that the language and imagery was too harsh and explicit—it was the response it received outside the lesbian community that proved the most

[374] Madansky and Tolentino Wood for LAP, *The Safer Sex Handbook for Lesbians*, 1993, 1, Subject file: AIDS, LHA. Used with permission of the LHA.

controversial. The political right's anti-gay and anti-woman agenda as seen throughout the HIV epidemic's first decade coalesced to impede lesbian activists' efforts to curb its spread and effects. What made the political debates of the early 1990s distinct from those of the previous decade was that the performance of specific sexual acts between women, including HIV-positive lesbians, were now at their centre, in what marked a turning point in bringing lesbian sexualities and lives to the mainstream political landscape.

Do You Know Where Your Daughters Are?

The *Safer Sex Handbook* was not written for young people. Yet less than a year after its publication, the political right had co-opted the brochure and weaponised it as evidence of the need to symbolically protect America's children from the alleged threat of gay recruitment. As queer theorist Lee Edelman argued in his book, *No Future*, the political right's attack on gay and lesbian liberation has historically hinged on their pitting the child, as the epitome of innocence in need of protection, against the queer, as the embodiment of antisocial narcissism.[375] The "protect the children" arguments gained traction in the post-1960s period as a way to undermine the increasingly visible movement for gay and lesbian rights. In 1977, actress Anita Bryant, under the banner "Save Our Children," launched a campaign to repeal a Florida ordinance which prohibited discrimination on the basis of sexual orientation.[376] The following year, Senator John Briggs sponsored Proposition 6, a state-wide initiative attempting to prohibit gay individuals or those who supported gay rights from working in public schools in the state of California.[377] The same protect the children argument also drove

[375] Edelman, *No Future*, 19.
[376] Mary Otto, "Rallying Cry is a Perceived Gay Threat to Kids: Religious Right Flexing its Might," *San Jose Mercury News*, September 9, 1994.
[377] Clendinen and Nagourney, *Out for Good*, 299-311; Rimmerman, *From Identity to Politics:* 129-131; Fred Fejes, *Gay Rights and Moral Panic*, 110-112; Frank, *Out in the Union*, 86-87.

the British Parliament to ban local authorities in England, Wales, and Scotland from "promoting homosexuality" in 1988, and Russia's 2013 ban on "homosexual propaganda" similarly drew on the alleged threat of paedophilia and homosexual recruitment.[378] In the United States, as in other parts of the world, the political right's weaponization of children to attack the LGBTQ community erased the efforts of lesbian and gay men to secure the legal right to adopt and raise children of their own, as well as those who lost custody of their children because of their sexual orientation.[379] As Lisa Winters, a social worker and AIDS activist at Bronx-Lebanon Hospital put it, "homophobia prevents love where bonds are thicker than blood."[380]

LAP created the safer sex handbook within the context of heightened moral panic over the gay recruitment of children that had gained momentum in the 1970s and intensified with the onset of AIDS in the 1980s. The 1995 film *Kids*, which sees the protagonist, Jennie, have unprotected sex and contract HIV from her friend Telly encapsulated the conservative fears over the association between AIDS and sex and the corrupting influences of drugs, sex, and alcohol on youth culture.[381]

LAP also created the brochure as the federal government was implementing a number of policies detrimental to the advancement of gay rights. In 1993, President Bill Clinton signed the "Don't Ask, Don't Tell" policy on military service by gay, bisexual, and lesbian

[378] Known as Section 28, the ban was repealed in 2003. A week after the 2013, propaganda ban, Russia passed a law banning same-sex couples from adopting children.
[379] Carlos A. Ball, *The Right to Be Parents: LGBT Families and the Transformation of Parenthood* (New York: New York University Press, 2012), 4.
[380] In 1993, after coming out as a lesbian, Sharon Bottoms' mother, Kay Bottoms, sued her daughter for custody of her son, Tyler Doustou. On 5th April, Judge Burford Parsons ruled that Sharon Bottoms was an unfit parent and Kay awarded Bottoms custody of her grandson. The Lesbian Avengers, *International Comminiqué* 1, Issue 1 (May 1994): 8-9, box 1, fol. Internal Records, Lesbian Avenger records, GLBT Archives; Lisa Winters, "In Memory of Cookie, 9/19/60-6/25/93," *LAP Notes*, Issue no. 2 (Spring 1994): 9, BWHBC records, Schlesinger Library.
[381] Ben Detrick, "'Kids,' Then and Now," *New York Times*, July 21, 2015.

Americans. Three years later, in 1996, he signed the Defence of Marriage Act that defined marriage for federal purposes as the union of one man and one woman thereby denying same-sex couples the same access to marriage and its associated legal rights and benefits as couples of opposite sexes.[382] At the same time, Congress continued to debate the LGBT communities' relationship to wider society, particularly to children and schooling. It was within this context that the political and religious right used the *Safer Sex Handbook* as evidence of the need to remove any references to gay and lesbian life from public schools.

In 1989, a group of teachers in New York City began designing a curriculum to teach children in the first grade to respect the city's myriad racial and ethnic groups. The 443-page "Children of the Rainbow" curriculum offered teachers games, songs, and other lessons to teach racial harmony to their students. While the curriculum focused on celebrating racial and ethnic diversity, it also dedicated three pages to discussing lesbian and gay lives. The curriculum's recognition of gay parents was its most controversial aspect. In particular, the inclusion of Michael Willhoite's children's book *Daddy's Roommate* and Lesléa Newman's *Heather has Two Mommies* sparked city-wide protests that involved prominent individuals such as the Roman Catholic Bishop of Brooklyn and Queens, Thomas V. Daily. In Congress, politicians cited the two books as evidence of the need for an anti-gay amendment that prohibited federal funds to "promote or encourage sexual activity, whether homosexual or heterosexual"; "to distribute…legally obscene materials to minors on school grounds"; to provide condoms, or for sex education that does not include "the health benefits of

[382] H.R. 3396—104th Congress: Defense of Marriage Act of 1996, accessed February 2020, https://www.govtrack.us/congress/bills/104/hr3396

abstinence" to the Improving America's Schools Act of 1994 that reauthorised the Elementary and Secondary Education Act of 1965.[383]

Mary A. Cummins, a local grandmother and president of the school board in District 24 in Queens led the protests and called *Daddy's Roommate* and *Heather has Two Mommies* "dangerously misleading lesbian/homosexual propaganda" and argued that schools should not teach homosexuality as a "morally valid alternative lifestyle."[384] "When the homosexuals are hitting on kids like this," she noted, "it becomes my business."[385] Cummins refused to adopt the curriculum and, as a result, in the fall of 1992, three years after it was first developed, Schools Chancellor Joseph A. Fernandez suspended the entire school board in District 24. Fernandez had already come under fire for endorsing AIDS education in elementary schools and condom distribution in high schools. "Make no mistake," he said as he suspended the school board, "there will be no changing the requirement that, at some time in the elementary grades, diverse family structures be recognized and acknowledged as loving, caring households."[386] Fernandez's commitment to diversity was not enough to overcome the fears that many parents expressed in bringing gay and lesbian lives into the classroom. In February 1993, after months of heated political debates over the future of the city's public-school system, the New York City Board of Education forced Fernandez to reinstate District 24's school board and voted not to renew his contract as Schools Chancellor.[387]

---

[383] Steven Lee Myers, "How a 'Rainbow Curriculum' Turned into Fighting Words," *New York Times*, December 13, 1992; Robert D. McFadden, "Bishop Assails School Leaders Over Lessons on Homosexuals," *New York Times*, December 28, 1992.
[384] Lally Weymouth, "Mrs. Cummins's Triumph," *Washington Post*, January 8, 1993.
[385] Congressional Record 140, no. 103 (August 1, 1994), accessed February 2020, https://www.gpo.gov/fdsys/pkg/CREC-1994-08-01/html/CREC-1994-08-01-pt1-PgS11.htm
[386] Steven Lee Myers, "Few Using Curriculum in Dispute: 'Children of the Rainbow' Is Staying on the Shelf," *New York Times*, December 6, 1992, 49.
[387] Sam Dillon, "Board Removes Fernandez as New York Schools Chief After Stormy 3-Year Term," *New York Times*, February 11, 1993.

The first New York Lesbian Avenger action was in support of the Rainbow Curriculum and took place on 9th September 1992, the first day of school in New York City. Dressed in knee socks and plaid skirts of Catholic school uniforms and tee-shirts that read "I was a lesbian child," sixty women played brass drums, handed out purple balloons and held banners that read "Ask About Lesbian Lives" and "Teach About Lesbian Lives" and marched down Metropolitan Avenue to P.S. 87, an elementary school that was at the heart of District 24 in Queens.[388] One month later, the Lesbian Avengers held a similar protest outside of the Board of Education in Brooklyn. In February 1993, the group prepared a collection of lesbian love songs that they performed in front of the home of Mary Cummins. Like the public service announcement that asked, "Do you know where your kids are?", they asked, "Do you know where your daughters are? (At the Lesbian Avengers' back-to-school-party!)" With their slogans, "We recruit" and "I was a lesbian child," the group appropriated the scare tactics that the political right deployed against them and offered the message that they had all been, with varying degrees of awareness, gay children with a large stake in other children being taught about diversity in the classroom.[389]

The debates over the Rainbow Curriculum fit into a larger national conversation about the types of sex education schools should make available to young people in the wake of the AIDS epidemic and the rising rates of teenage pregnancy. In New York City, Cardinal John O'Connor, member of Reagan's 1987 HIV/AIDS commission and a friend of Mary Cummins, regularly used his platform to speak out against the use of condoms, clean needles, abortion, and gay rights while counselling abstinence only sex education in public schools in

[388] Cogswell, *Eating Fire*, 14.
[389] For Lesbian Avenger ephemera, see box 10, fol. 7, WAC records, NYPL Manuscripts and Archives Division.

the city. In December 1989, his outspoken position led to the notorious 4,500-strong "Stop the Church" protest at St. Patrick's cathedral organised by ACT UP and WHAM![390] In states throughout the country, school board members similarly debated whether sex education should acknowledge homosexuality, discuss sex education beyond reproduction, emphasise abstinence only, or reference to anal sex, and questioned how young was too young to start introducing these subjects. In October 1986, Surgeon General Koop had called for sexual education to begin at home and in school "at the lowest grade possible" so that "children can grow up knowing the behaviours to avoid to protect themselves from exposure to the AIDS virus."[391] In December 1994, President Clinton asked his Surgeon General, Jocelyn Elders, to resign amid controversy over her comments that teaching children about masturbation should be part of sex education.[392] During the 1990s, while most states mandated some form of sex education and did so because of AIDS, the question of what that education should look like continued to be deeply divisive.[393]

On Saturday 12th February 1994, New York University held a Conference of Peer Education organised by and for youth HIV educators between the ages of fourteen and twenty-four. Nineteen organisations sponsored the event, including the Chemical Bank, New York Board of Education's High School HIV/AIDS Resource Centre, the New York City Department of Youth, the AIDS Institute of New York State, The Manhattan Borough's Presidents' Office, and the Department of Paediatrics at New York University Medical Centre, the Unitarian Church/All Souls AIDS Task Force, and GMHC.

---

[390] Jason Deparle, "111 Held in St. Patrick's AIDS Protest," *New York Times*, December 11, 1989. See also Adrienne E. Christiansen and Jeremy J. Hanson, "Comedy as Cure for Tragedy: ACT UP and the Rhetoric of AIDS," *Quarterly Journal of Speech* 82, no. 2 (1996): 157; Caroll, *Mobilizing New York*, 20-21.
[391] Christine Russell, "AIDS Report Calls for Sex Education: Surgeon General Urges End to 'Silence,' Opposes Compulsory Testing," *Washington Post*, October 23, 1986, A1.
[392] Janice M. Irvine, *Talk About Sex: The Battles Over Sex Education in the United States* (Berkeley: University of California Press, 2002), 1.
[393] For more on the battle over education in public schools, see Jonathan Zimmerman, *Whose America? Culture Wars in the Public Schools* (Cambridge, Mass.: Harvard University Press, 2002)

Only young people were allowed to attend the conference bar a select number of adult speakers. John Hartigan, an attorney from Hands Off Our Kids (HOOK), an organisation that opposed what they saw as the extreme liberalisation of sex education, two members of the HIV Advisory Council from the Board of Education, and members of Parents for the Restoration of Values in Education (PROVE) tried unsuccessfully to register for the conference. Harold Hurwitz, the head of the New York Family Defence Council, who viewed the conference as evidence that the gay community were "perhaps the greatest menace to morality in the United States," filed a complaint with the Commission on Human Rights claiming age discrimination. When their complaint fell through, they recruited and sent a 14-year-old boy to the conference on their behalf to collect materials, attend the workshops being offered, and write up a report.[394]

GMHC volunteers set up a table outside the conference and put out copies of some of their leaflets and brochures for peer educators. These included *Listen Up!*, a pamphlet aimed at gay black teenagers that advocated the use of condoms, as well as *The Safer Sex Handbook* that someone had put out by accident. The 14-year-old boy collected both pamphlets and brought them back to base.

A few days later, with their new evidence in hand, HOOK's Jon Hartigan, with the support of *New York Post* journalists Mona Charen and Ray Kerrison, sent two letters of complaint to Ramon C. Cortines, the new Schools Chancellor of the New York Board of Education, demanding that he eliminate the High School HIV/AIDS Resource Center and that he blacklist GMHC from entering schools. Cortines complied with their demands two days later,

[394] Otto, "Rallying Cry is a Perceived Gay Threat to Kids."

also relocating the Resource Centre to a Board of Education building in Brooklyn in order to ensure closer surveillance.

The New York press picked up and sensationalised the story through coverage that fuelled the political right's campaign to discredit the *Safer Sex Handbook*. Mona Charen told readers of the *New York Post* that "at a 'peer educators' conference organised by a coalition of New York City public-high-school students, and sponsored in part by the Gay Men's Health Crisis, the GMHC used the occasion to engage in homosexual propaganda…Bleach and soap, condoms and dental dams this is the stuff that masquerades as fighting AIDS."[395] Lynda Richardson of the *New York Times* similarly reported that the handbook included "vulgar words and phrases many considered shocking and unsuitable for children."[396] It was, according to *New York Post* journalist Ray Kerrison, just another example of the "Disgusting ways gays brainwash our School kids; Mixing porn with suicidal sex advice." Kerrison warned that the sexual practices described—in particular fisting—were "masochistic" and could result in death by internal injuries.[397] According to Madansky, the two pages on "fisting" was the most frequently cited reason put forward to censor the *Safer Sex Handbook*, framed not as an act of pleasure but as a lewd pornographic act (figure 7). Mandansky also claimed that a well-known conservative physician had provided support material to the vocal opponents of the handbook by referencing a case where a young woman was raped and killed by a man who tortured her through the act of fisting. Yet the physician omitted the relevant details—the rape and the man—from his presentation.[398] The focus on death revealed the

[395] Quoted in Madansky, "fierce fists," in *Gendered Epidemic*, 89.
[396] Lynda Richardson, "Cortines, Upset, Moves Student AIDS Center," *New York Times*, March 23, 1994.
[397] "Lesbian Safer Sex Handbook Under Attack," *LAP Notes*, Issue no. 2 (Spring 1994): 13; John Hartigan from HOOK said that "The indisputable medical fact is that fisting is so brutally sadistic that it often causes internal injuries that require major corrective surgery and can result in death." Quoted in Madansky, "fierce fists," in *Gendered Epidemic*, 89.
[398] Madansky, "fierce fists," in *Gendered Epidemic*, 85.

extent of the political right's distortion of the handbook's aims, given that its purpose was to provide women basic safer sex information with the aim to save lives.



Figure 7. The Safer Sex Handbook for Lesbians, 1993.[399]

On the heels of this media frenzy, the New York Board of Education decided to censure the handbook in 1994. Their censorship coincided with, and publicly legitimised, the attempts on the part of various Republicans in the Senate to censor the *Safer Sex Handbook* and knowledge of lesbian sexual activity itself.

[399] Madansky and Tolentino Wood for LAP, *The Safer Sex Handbook for Lesbians*, 1993, 6-7, Subject file: AIDS, LHA. Used with permission of the LHA.

Like John Hartigan of HOOK and others, Reverend Louis P. Sheldon, a Presbyterian minister from Washington, D.C., and head of the Traditional Values Coalition representing 31,000 churches across the United States believed that the *Safer Sex Handbook* would validate people's fears about homosexual recruitment in schools. Mary Cummins from Queens had sent Sheldon the handbook and on 28th March 1994, he joined Duffy, the talk-show host of the radio programme "Live in LA" to discuss it. Duffy began describing the handbook for the audience, "a book that's about three inches by five inches." The conversation that unfolded served to belittle the handbook, with Duffy telling listeners that "what you can see is a nude woman. I'm assuming this is a woman…this person has latex gloves on. There's no polite way to say this, friends, on her left breast there is a ring that has been pierced through the nipple. There is in her belly button a pierced ring that goes through her belly button." Both men agreed that while they were "not homophobic" they did not want "to affirm a lifestyle of vaginal fisting" either.[400] Sheldon explained that:

> The bottom line to this, uh, Duffy, is that they're telling these young children how they can counsel lesbians not to get HIV virus infection…And they say this about themselves: that lesbians are now into vaginal fisting. I've heard of homosexuals, gays, into rectal fisting, but this is vaginal fisting. And I want to tell you that a woman can die—the vaginal, the vagina is not made to have a fist placed in it for such purposes as this booklet is trying to say. And what their purpose in this booklet is to say to young children, you must wear a latex glove. As you do vaginal fisting, wear a latex glove. Then it goes on to tell you all these other things.

[400] Exchange in Amber Hollibaugh, "Seducing Women into a 'Lifestyle of Vaginal Fisting,'" in *Policing Public Sex: Queer Politics and the Future of AIDS Activism*, ed. Ephen Glenn Colter (Boston: South End Press, 1996), 321-323.

> And as we showed this on the floor of the Congress, as men and women were coming into the floor of the Congress, we went there with fear and timidity and I tell you we prayed before we went, 'cause I've never given out pornography. I don't participate in any kind of pornography. But when these were sent to me by dear Mary Cummins, a 74-year-old grandmother, president of School District 24 in Queens, New York, she said "Lou, you've got to tell the Congressman." I gave it to Congressman Mel Hancock; Mel Hancock said, "I will instruct the sergeant-at-arms not to touch you. You may give this out on the street, at the foot of the steps of the House side of the U.S. Capitol as they come in to vote." And we did that.[401]

As he explained to radio listeners, Sheldon took the brochure to Capitol Hill where he visited Representative Mel Hancock (R-MO). In March 1994, as the House of Representatives began debating Clinton's reauthorisation of the Elementary and Secondary School Act, which provided $12.5 billion to the nation's public schools, Hancock introduced an amendment that would cut off federal funding to any school district that "affirms a homosexual lifestyle" in any of its instruction, counselling, or student referral programmes. The House didn't vote on the amendment, approving instead a less severe substitute.

Undeterred, Sheldon took his amendment to the Senate, where Senator Bob Smith (R-NH) took up the cause. On 1st August 1994, with the help of Senator Jesse Helms (R-NC), Senators heard Smith's amendment "to prohibit any school system receiving funds under the Elementary and Secondary Education Act from implementing any school programme that encourages homosexuality."[402] Echoing the anti-abortion argument that taxpayers should not

[401] Exchange in Hollibaugh, "Seducing Women into a 'Lifestyle of Vaginal Fisting,'" in *Policing Public Sex*, 321-323.
[402] Congressional Record 140, no. 103 (August 1, 1994).

fund abortion, Smith argued that "it is imperative that we understand and take a good look at where our dollars, as the taxpayers provide them to us, are being spent." He told his colleagues that "there are some materials here that are so obscene that I cannot show them to the public. I cannot display them here and I cannot hold them up. I cannot quote from them, because to put them on the airwaves in any way, shape, or form would be considered obscene." He instead invited his colleagues to look at the materials that he had at his desk, including the *Safer Sex Handbook*, *Listen Up!*, *Heather Has Two Mommies*, *Daddy's Roommate*, and a series of other books and pamphlets. The Smith amendment passed 63-36.[403] Shortly afterwards, Senator Edward Kennedy (D-MA) offered a measure intended to blunt the homophobic angle of the Smith-Helms amendment. Kennedy's alternative proposal, approved 99-0, cut federal money to schools that encouraged any sexual activity, homosexual or, crucially, heterosexual.

In the wake of the backlash, the LAP continued to petition the government for equal medical care. A breakthrough in their efforts came in 1994, around the same time that conservative members of Congress were working to censor their safer sex materials, when Dr Mary Guinan chaired the first CDC internal working group on woman-to-woman HIV transmission. A few months later, in April 1995, the CDC organised the first government official's meeting to address HIV issues pertaining specifically to lesbian women.[404] The CDC called the two day meeting in Decatur, Georgia, which brought together CDC staff, including its AIDS director, James Curran, and eighteen community-based women activists including Hollibaugh and representatives of WAN, the Office of Gay and Lesbian Health Concerns, and the National Gay and Lesbian Health Association. Participants offered their

[403] Katharine Q. Seelye, "Senate Backs Cuts for Schools that Endorse Homosexuality," *New York Times*, August 2, 1994.
[404] Eileen Hansen, "Woman-To-Woman HIV Transmission Finally Acknowledged," *LAP Notes*, Issue no. 3 (Summer 1995): 20, BWHBC records, Schlesinger Library.

varying perspectives on the HIV prevention needs of women who had sex with women to CDC staff. The conference also drew attention to the concerns of community health activists and advocates, as well as the dearth of information available to people who planned prevention programmes for women who have sex with women. Fifteen years into the epidemic, the meeting marked the first time that the agency had formally acknowledged that woman-to-woman HIV transmission occurred. Crucially, it also recognised the need for health care professionals to better understand the behavioural risk factors such as substance abuse, sex with men (including gay and bisexual men), and artificial insemination that put women who have sex with women at risk. The meeting culminated in the publication of an article on woman-to-woman transmission, written by staff members of the CDC and reviewed and edited by attendees in the *Journal of the American Medical Women's Association*.[405]

The historic 1995 meeting was the outcome of lesbian activists' indefatigable efforts to press the CDC to recognise lesbian women and take seriously lesbian health issues. Despite this breakthrough, concerns over the federal effort to silence women's sexuality persisted. Women were particularly worried about the attempts to pass legislation that would cripple funding programmes for lesbian health services and for research through the DHHS, in particular a bill that Representative Robert Dornan (R-CA) proposed in 1995 that would "prohibit the use of Federal funds to promote, condone, accept or celebrate" homosexuality, lesbianism, or bisexuality.[406] As concerns with ongoing federal efforts to undermine lesbian

[405] "CDC Finally Meets," *Lesbian Health Issues Newsletter* 2, no. 3 (Summer/Fall 1995): 3, San Francisco, CA: National Center for Lesbian Rights. Periodicals, Schlesinger Library; Division of HIV/AIDS Prevention, "Report on Lesbian HIV Issues Meeting Hosted by the Centers for Disease Control and Prevention National Center for HIV, STD, and TB Prevention Division of HIV/AIDS Prevention April 20-21 1995," March 6, 1996, box 400, folder xv, GMHC records, NYPL Manuscripts and Archives Division.
[406] "Stop Homophobia Now!" *Lesbian Health Issues Newsletter* 2, no. 3 (Summer/Fall 1995): 1. Periodicals, Schlesinger Library.

women's health and autonomy persisted, lesbian women also turned their attention to dealing with the rising carceral state, as prisons and jails were sites where HIV prevalence reached and sometimes exceeded that of men.[407]

Conclusion

In the early 1990s, the LAP wanted to reach as many women as possible in order to overcome the "the myth of lesbian immunity" that implied that women who had relationships with other women were not at risk of infection. Public health agencies' slowness to recognise or track lesbian behaviours perpetuated this myth, but it also resulted from the debates over what constituted lesbian identity that had driven the lesbian separatist movement of the 1970s. In the life and death context of AIDS, lesbian activists such as Amber Hollibaugh wanted to emphasise that risk of HIV infection was not about how people identified but about what people did, and so they argued for an expanded understanding of their sexual identities that acknowledged that many women who engaged in other activities that put them at risk.

The popularity of the LAP's initiatives, particularly their *Safer Sex Handbook for Lesbians*, drew unwanted attention from the political right who became threatened by what popular, pro-sex, anti-patriarchal sex education looked like. Reflecting on the consequences of the political campaign led by individuals such as Mary Cummins and Hel Hancock to censor the handbook, both Madansky and Hollibaugh noted that one outcome was the silencing of a frank discussion of lesbian sexuality. In 1996, Madansky wrote that she "read this move toward censoring the handbook as symptomatic of a desire to silence the articulation of

[407] Akilah Wise, "In Prison, Women are 9 Times More Likely to be HIV-Positive," *The Nation*, November 24, 2017, accessed February 2020, https://www.thenation.com/article/in-prison-women-are-9-times-more-likely-to-be-hiv-positive/

lesbian sexuality."[408] In her article published the same year, "Seducing Women into a 'Lifestyle of Vaginal Fisting,'" Hollibaugh explained that when the political right mounted its attack, the lesbian community was itself still divided about lesbian risk of HIV infection. As the right had largely excluded lesbians from debates around HIV and safer sex information during the first fifteen years of the epidemic, she wrote that lesbian women were now silenced in their defence of lesbian sexuality and their attempts to provide thorough, accurate information on the risk AIDS posed to lesbian women.[409] The campaign ultimately showed that, for lesbian women, in the politically-charged atmosphere of the 1990s, and with the rise of the political right, simply getting recognition for treatment still remained key.

In 1996, the FDA approved combinations of three antiretroviral agents, including one protease inhibitor, which dramatically improved the health of many people living with HIV and AIDS. Despite this breakthrough, the medicines were only as effective as a person's ability to access them.

From the mid-1990s onwards, lesbian women, including members of activist groups such as the San Francisco Lesbian Avengers continued to fight for HIV-positive women living in institutions cut off from networks of support to access treatment in the 1990s and early 2000s. In 1994 and 1995, the Avengers travelled 150 miles southeast of the Bay Area to join large demonstrations that the California Coalition for Women Prisoners had organised to protest the medical neglect of women prisoners with HIV and AIDS at the Central California Women's Facility (CCWF) in Chowchilla, California.[410] Since CCWF opened its doors in

[408] Madansky, "fierce fists," in *Gendered Epidemic*, 85.
[409] Hollibaugh, "Seducing Women into a 'Lifestyle of Vaginal Fisting,'" in *Policing Public Sex*, 334.
[410] The Lesbian Avengers, "Prison Officials Called to Task for Medical Neglect: Demonstrations at Chowchilla Bear Witness to Suffering of Women Prisoners," July 1995, box 2, fol. Chowchilla Demonstration for medical care for women prisoners, July 8, 1995, Lesbian Avengers records, GLBT Archives.

1990 to become the largest correctional facility and the only death row for women in the United States, inmates with chronic illnesses had advocated for treatment and the compassionate release of women who deserved not to die in prison. Women in prison faced numerous obstacles to accessing and adhering to medication, in part because the ramped-up carceral state of the 1990s was not adequately prepared to deal with reproductive and chronic illnesses that are common in women. As the culture wars of the 1990s coincided with the rise of the carceral state that saw the United States imprison a larger proportion of women than any other country in the world, many women already mobilised in outside progressive organisations directed their energies toward connecting with HIV-positive women inside, in what marked the next evolution in women's fight against AIDS. The next chapter explores how women responded to this situation and attempted to achieve structural reform, drawing on the consciousness raising tradition of the feminist health care movement and culminating in the 1995 *Shumate v. Wilson* court case.

***

Chapter Four

The Fire Inside:

Women Protesting in Prison, 1990-2005

In 1984, Katrina Haslip, a black Muslim woman from Niagara Falls, New York, received a five-and-a-half-year sentence for pickpocketing. Authorities originally placed Haslip in the New York Albion Correctional Facility and later moved her 300 miles away to the Bedford Hills Correctional Facility in Westchester County in New York.[411] Prior to incarceration, Haslip had long suffered from repeated vaginal yeast infections—infections thought to be AIDS-related, but not included in the CDC's definition of AIDS at that time. But in 1987, doctors at Bedford Hills found antibodies to the virus in her blood that confirmed she was HIV-positive. After learning of her status, prison guards isolated Haslip along with other women known to have HIV at the facility. Her experience was not unique. Prison staff across the country frequently segregated women prisoners found to have HIV.[412] Her response to mistreatment was not unique either. Similar to other women, the shock and horror of inhumane prison conditions led her to protest in prison and beyond. As a black Muslim woman, her efforts to connect with other women inside continued a long history of Muslim advocacy work in prison, just as her efforts to educate other women contributed to a new

[411] Mireya Navarro, "An AIDS Activist Who Helped Women Get Help Earlier: Her advocacy for women infected with the virus began in prison, and led to the Government's expanded definition of the disease," *New York Times*, November 15, 1992, E9.

[412] When Carmen Harris tested HIV-positive at the Julia Tutwiler Prison for Women in Alabama, prison guards sent her to solitary confinement and several days later moved her to death row to emphasise the fatality of her condition. Prison staff also forced Harris and other HIV-positive inmates to wear a surgical mask when outside their isolation cells. See Sandra G. Boodman, "HIV in Prison: Is Isolation Cruel or Prudent? Alabama Sued Over Testing, Segregating Those with AIDS Virus," *Washington Post*, April 29, 1989. In 1986, Dee Farmer, a 19-year-old transgender woman who tested HIV-positive at the male Baltimore County Detention Center, was similarly isolated in a cell where she suffered discrimination and abuse. Declaration of Dee Deidre Farmer, In the United States District Court for the District of Maryland, Dee Deidre Farmer, Petitioner v. United States of America, Respondent, 4, box 5, fol. 162, Judy Greenspan papers, The Lesbian, Gay, Bisexual & Transgender Community Center Archive, Manhattan, New York. Hereafter: LGBT Community Center Archive.

movement among Muslim women to fight AIDS.[413] This initiative included women like Waheedah Shabazz-El, a black Muslim woman who similarly learned of her HIV-positive status while incarcerated in the Philadelphia Prison System in 2003 and who shared Haslip's journey in becoming an AIDS educator for other women.[414]

As the shared experiences of Haslip and many other women attest to, HIV was prevalent in women's prisons from the 1980s onwards, but the political and public health response to AIDS inside largely mirrored the public response to the epidemic in society at large in that it focused predominantly on male as opposed to female inmates. As in other arenas of the US epidemic, prison officials and public health agencies often ignored women's specific healthcare needs, leaving inmates to fill the gap left by a lack of institutional recognition and support. Women in prison did not riot against existing prison conditions in the ways more commonly associated with male prisoners. It would have been difficult for many of them to do so given their health complications. Instead, they started small prison support groups at their facilities with the aim of providing critical education about HIV and AIDS. Whereas historian Sara Evans has noted that by the 1980s the traditional consciousness raising meetings of the 1960s and 1970s had largely ended, women's prison support groups continued the feminist practice of women educating and supporting one another, prominent in the earlier decades of the feminist movement.[415] The support group that the women of Bedford Hills started in 1987 was replicated in other institutions across the country, often marking the beginning of women's collective action inside.

[413] Dawn-Marie Gibson, *The Nation of Islam, Louis Farrakhan, and the Men Who Follow Him* (New York: Springer, 2016), 50-54.
[414] Laura McTighe, "Refusing to Vanish: Muslim Women's AIDS Activism," *the revealer*, December 1 2017, accessed January 2020, https://therevealer.org/refusing-to-vanish-muslim-womens-aids-activism/
[415] Evans, *Tidal Wave*, 188.

About 2,500 miles west of Bedford Hills, in the Central California Women's Facility (CCWF) in Chowchilla, California, the largest correctional facility for women in the country, a small group of women living with HIV similarly led the efforts to educate one another about the disease. Prison authorities frequently denied women at CCWF adequate medical treatment, prompting the women to seek outside support for their efforts to reform the healthcare system at the facility. As women who, by virtue of their incarceration, had already violated societal gender norms, the mostly male prison guards came down particularly hard on women who agitated for change. Despite prison officials' attempts to restrict the women's communication with outside organisations, the women at CCWF eventually succeeded in connecting with external activists, lawyers, and advocates. As politicians, the public at large, and the media largely ignored women in prison and because women still struggled to gain recognition in the epidemic, these women were well-placed to make a difference. Their efforts shifted the focus of existing progressive organisations toward confronting the dire prison conditions in their facilities and informed the increasing calls to reform the entire penal system throughout the 1990s and into the 2000s. The action the women took to improve the conditions of their confinement culminated in a lawsuit against the state of California in 1995. The court case, *Shumate v. Wilson*, marked a turning point in legal advocates using the medical mistreatment of women prisoners with HIV and AIDS to call into question the inhumanity of the entire prison system especially toward women at the end of the twentieth and beginning of the twenty-first century.

The extent of the women's activism inside prison is surprising given the restrictions placed on their ability to organise, not to mention that many of them were seriously ill and living in institutions cut off from networks of support. That the women at CCWF could nevertheless effectively mobilise outside support in order to mount a lawsuit against the state of California

was an achievement in and of itself. In 1997, in what the coalition to support women at CCWF originally celebrated as a "win" for the women prisoners in their newsletter, *The Fire Inside*, the legal representatives acting on behalf of the plaintiffs got the California Department of Corrections and Rehabilitation (CDCR) to agree to a court ordered settlement that saw an initial improvement in the provision of care at the facility.[416] Despite the court ordered settlement and securing the compassionate release of a few inmates, a series of scandals in 2000, including incidents of retaliation and the deaths of several more women, called these improvements into question. While women prisoners continued to make allegations of abuse and medical neglect, their complaints, along with the court case, were ultimately dismissed, and medical abuse persisted at CCWF.

The women's ability to mobilise outside support and launch the lawsuit was a testament to the power of ordinary women working individually and collectively to take on entrenched authority. Much of what they achieved in mounting the lawsuit came from their ability to build supportive alliances with other women in prison and, crucially, with external advocates. In contrast, their inability to secure the structural reform they sought reflected the stark power imbalance that existed between sick women in prison and the massively expanding correctional system of the state of California during this period. As one prisoner rights advocacy group put it, this fight was a "modern day David v. Goliath."[417]

This chapter follows the journey of women's AIDS activism in prison, which began inside prison walls and went all the way up to the state. The first section of the chapter goes inside

[416] Karen Shain, "'Women Prisoners Win Shumate Case!' Demonstration for Rights of Women Prisoners Set for October 4th," *The Fire Inside*, Issue no. 5 (September 1997), California Coalition for Women Prisoners, Fire Inside Archive, accessed February 2020, https://www.womenprisoners.org/fire/000474.html
[417] Legal Services for Prisoners with Children, "Protecting Basic Human Rights," Vol. No. III, Spring 1997, 1, box 2, fol. flyers, Nancy E. Stoller papers, University of California San Francisco Archives, San Francisco, California. Hereafter: UCSF.

the prison in order to show how women suffered as a result of navigating a scaled-up prison system that was built for men. Similar to other arenas of the AIDS epidemic, the medical neglect women experienced in prison was a consequence of what feminist theorist Perez argued happens when different arenas of society fail to address the specific needs of women.[418] Many prisons took a healthy young male, and not a woman with reproductive and chronic illnesses, as its model prisoner, and implemented a healthcare system in which inmates only received care when they requested it.[419] This system cost less than providing continuous, and not only emergency, care for long-term, chronic conditions. Section two then examines women's attempts to connect with outside support and shift the focus of outside organising to helping their cause. Their efforts, which revealed the strength and extent of their courage, community-building, and friendship, culminated in the *Shumate v. Wilson* lawsuit of 1995—the subject of section three.

Women's fight for basic treatment in prison complicated the medical progress taking place outside. They faced a number of obstacles to accessing available medicine following the ground-breaking introduction of protease inhibitors in 1996 that helped people diagnosed with HIV to live longer.[420] As a result, women in prison continued to fight for care within a changed treatment situation. As women in prison struggled against medical neglect, as well as the restrictions placed on their ability to obtain information about HIV/AIDS, and the threat of reprisal in attempting to seek outside help, their experiences revealed the stakes of what happened when the system failed. Women inside, like those outside, did not passively

[418] Perez, *Invisible Women*, 32.
[419] Nina Siegal, "Dying Behind Bars: Women in California Prisons are Facing Death Sentences for Lack of Basic Health Care. A Special Investigation by Nina Siegal," *S.F. Guardian*, February 5, 1997, 17, box 8, fol. Shumate files, Stoller papers, UCSF.
[420] Following the introduction of highly active antiretroviral therapy, AIDS diagnoses and deaths declined substantially from 1995 to 1998 and remained stable from 1999 to 2008, at an average of 38,279 AIDS diagnoses and 17,489 deaths per year, respectively. CDC, "HIV Surveillance—United States, 1981-2008," *MMWR* 60, no. 21 (June 3, 2011): 689.

accept their circumstances either, but attempted to improve the situation they found themselves in using the resources and means at their disposal.

Inside Prison Walls

Since the beginning of the epidemic, rates of HIV among women in prison have consistently matched or exceeded rates of HIV among men in prison. Women in prison are three times more likely to have HIV compared to men in prison and are nine times more likely to have HIV compared to women outside.[421] These high rates result from the overlap between conditions and behaviours characteristic of women entering the criminal justice system which put women at an increased risk for HIV infection, such as intravenous drug use, sex work, poverty, racism, and a variety of mental and physical illnesses arising directly from sexual and physical abuse. A 2017 study also found that one third of incarcerated women identify as lesbian or bisexual, compared with less than ten percent of incarcerated men.[422] The high rates of drug use in lesbian and bisexual communities, coupled with poverty, societal prejudice, and stigma may account for their overrepresentation in the prison system.[423]

---

[421] Akilah Wise, "In Prison, Women are 9 Times More Likely to be HIV-Positive"; Anne S. De Groot, M.D. "Alarming Statistics About Incarcerated Women," *Positively Aware: The Journal of Test Positive Aware Network* (July/August 2001): 19, box 8, fol. 247, Greenspan papers, LGBT Community Center.

[422] The study found that 42.1 percent of women in prison and 35.7 percent of women in jail identify as sexual minorities, compared to 9.3 percent of men in prison and 6.2 percent of men in jail. Researchers based the findings on data from the National Inmate Survey (2011-2012) and also found that sexual minorities "experience higher rates of mistreatment, harsh punishment, and victimization." I.H. Meyer et al., "Incarceration Rates and Traits of Sexual Minorities in the United States: National Inmate Survey, 2011-2012," *American Journal of Public Health* (February 2017): 238-239, accessed February 2020, https://williamsinstitute.law.ucla.edu/wp-content/uploads/Meyer_Final_Proofs.LGB_.In_.pdf; see also Aleks Kajstura, "Women's Mass Incarceration: The Whole Pie 2018," October 29, 2019, accessed January 2020, https://www.prisonpolicy.org/reports/pie2019women.html

[423] In the 1990s, drug convictions became the primary reason for women's incarceration. President Ronald Reagan's "war on drugs" intensified policing and new drug sentencing laws that politicians deployed in this "war" caused the massive expansion of the US prison population from the 1980s onwards. In New York, between 1982 and 1989, the number of women entering prison increased more than 500 percent, from 337 to 2,264. Convictions for violent crimes decreased, while drug sentences rose from 67 in 1982 to 1,641 in 1989. Francis X. Clines, "An Unequal Justice: Little Aid for Hard-Time Sisterhood," *New York Times*, July 10, 1992, p. B1.; Law *Resistance Behind Bars*; 159-170; Hinton, *From the War on Poverty to the War on Crime*, esp. chapter 9, 307-332.

Despite the high number of sexual minority women and women living with HIV and AIDS in prisons, for nearly forty-years various local, state, and federal prison systems have continually failed to take adequate steps to curb the spread of the virus in women's prisons, mirroring society's slowness to recognise the specific risks and needs of women in the US AIDS epidemic at large. The lack of focus on HIV in women's prisons is especially striking given that from the mid-1980s onwards, studies repeatedly found that women in jails had higher rates of infection than male inmates.[424] By the 1990s, as rates of HIV among women both in and out of prison climbed, women had also become the fastest growing group within the prisoner population.[425]

Similar to other arenas of the US AIDS epidemic, the political and public health response to the issue of HIV in women's prison in the 1980s came after its discovery in correctional facilities for men. Between November 1981 and October 1982, the CDC received reports of several male prisoners diagnosed with Kaposi's sarcoma and *Pneumocystis* carinii pneumonia—two diseases that doctors would soon link to the newly discovered AIDS—in

[424] A 1988 study conducted in New York state showed that 18.8 percent of women prisoners tested HIV-positive compared with 17.4 percent of male prisoners. In Riker's Island jail in the 1990s, 26 percent of women and 12 percent of men tested HIV-positive. A 1985 study conducted in Maryland state showed that 15.4 percent of all incoming women inmates were HIV-positive compared to 7.0 percent of all incoming male inmates, and that 60 percent were known intravenous drug users. Perry F. Smith, MD, et al., "HIV Infection among Women Entering the New York State Correctional System," *American Journal of Public Health* 81, no. Suppl (May 1, 1991): 35, accessed February 2020, available at: https://doi.org/10.2105/AJPH.81.Suppl.35; Matthew Purdy, "As AIDS Increases Behind Bars, Costs Dim Promise of New Drugs," *New York Times*, May 26, 1997, 2; DHHS, PHS & CDC, "Supplement to the Quarterly Report to the Domestic Policy Council of the Prevalence and Rate of Spread of HIV in the United States," July 26, 1988, box 11, fol. July 26, 1988, Domestic Policy Council Meeting Re: AIDS, 5, 13, Beryl W. Sprinkel files, RRPL; Women and AIDS Resource Network, "The Problem," undated, Subject file: AIDS, LHA; Kim Jackson, "Patriarchal Justice and the Control of Women," *Studies on the New Left* XIV, nos. 1 & 2, Spring-Summer 1989, 153, box 8, fol. 247, Greenspan papers, LGBT Community Center Archive.

[425] According to The Sentencing Project, although many more men are in prison than women, the rate of growth for female imprisonment has been twice as high as that of men since 1980. See the Sentencing Project, Fact Sheet: Incarcerated Women and Girls, updated June 2019, accessed February 2020, https://www.sentencingproject.org/wp-content/uploads/2016/02/Incarcerated-Women-and-Girls.pdf Between 1981-2000, the percentage of women with AIDS rose from 8.0 percent to 22.6 percent. See Table 1. "Number and percentage of persons with AIDS, by selected characteristics and period of report—United States, 1981-2000," in CDC, "HIV and AIDS—United States, 1981-2000," *MMWR* 50, no. 21 (June 1, 2001): 43-434. Accessed February 2020, https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5021a2.htm

New York State correctional facilities. The agency had also received reports of infected inmates in New Jersey State correctional facilities.[426] The discovery of immunodeficiency among small groups of male inmates in this period drove investigators to measure the incidence of the epidemic among all prisoners. The identification of HIV as the cause of AIDS in 1984 and the development the following year of the ELISA test—a blood test capable of detecting the presence of antibodies to the virus—facilitated these efforts.[427]

In late 1985, the National Institute of Justice, along with the American Correctional Association, began its first study of HIV/AIDS in the fifty state prison systems, the Federal Bureau of Prisons, and thirty-seven city and county jails. The surveys, conducted annually through 1997, revealed the prevalence of HIV/AIDS among prisoners in states such as New York, New Jersey, California, Florida, and Texas.[428] These investigations, along with studies carried out since, have confirmed the higher prevalence of infectious diseases such as HIV and tuberculosis among prisoners than among people outside prison.[429] The discovery of the high concentration of HIV in prisons in the 1980s led politicians, prison officials, prisoner rights advocates, and public health professionals to debate how best to halt the virus' spread among prisoners and to the outside community upon their release.[430] The steps prison authorities took to address the issue of AIDS in prison in the 1980s and 1990s varied state by state and facility by facility. Some took the public health community's advice and made condoms, drugs, and cleansing solution to sanitize hypodermic needles available in their prisons. Others refused, believing that such measures condoned homosexual activity and

[426] CDC, "Acquired Immune Deficiency Syndrome (AIDS) in Prison Inmates—New York, New Jersey," *MMWR* 31, no. 52 (January 7, 1983): 700-701.
[427] Kunzel, *Criminal Intimacies*, 227.
[428] A.R. Jonsen and J. Stryker, "National Research Council (US) Panel on Monitoring the Social Impact of the AIDS Epidemic," in *The Social Impact of AIDS in the United States* (Washington, D.C.: National Academies Press, 1993), accessed February 2020, available at: https://www.ncbi.nlm.nih.gov/books/NBK234573/
[429] Penal Reform International, Global Prison Trends 2015, 18, accessed February 2020, https://cdn.penalreform.org/wp-content/uploads/2015/04/PRI-Prisons-global-trends-report-LR.pdf
[430] "WHO takes critical look at AIDS in prison issue," *New York Amsterdam News*, January 9, 1988, 14.

prohibited drug use. Instead, they tested and segregated prisoners found to carry HIV, arguing that isolation protected not only uninfected inmates but HIV-positive prisoners themselves.[431]

The FDA's approval of the antiretroviral drug AZT in 1987 and of combinations of three antiretroviral agents (also known as antiretroviral therapy; ART) in 1996 dramatically improved the health of many people living with HIV and AIDS. Since 1996, the government recommendations for HIV medications urged three-drug combination therapy for "all patients with symptoms ascribed to HIV infection."[432] The NIH strongly discouraged using a combination of two drugs, or one drug alone, as it could lead to drug resistance and even death. As new treatment options became available to people with HIV outside prison, the increased cost of distributing more effective antiretroviral medication informed how correctional authorities responded to the problem of AIDS in prison in this period.

Prison authorities varied in their approach to dealing with the problem of AIDS in prison because of the costly treatment. According to journalist Matthew Purdy, because the expense

[431] Vermont and Mississippi made condoms available in their state prisons by the mid-1980s, with city jails in Washington, D.C., New York City, San Francisco, and Philadelphia shortly following suit. A jail in Houston made bleach available to inmates with instructions on how to clean needles. Other local prison boards ignored these recommendations, arguing that such measures would facilitate illegal and prohibited drug use and same-sexual activity. Thomas Ferrick Jr. and Michael B. Coakley, "City says no to condoms for inmates," *Philadelphia Inquirer*, August 28, 1988; Charles W. Colson, "Condoms: No Way to Control AIDS in Prison," *Washington Post*, June 26, 1991. Prisoners, like immigrants, military applicants, and women giving birth, comprised a population that were already registered and therefore readily available for testing. Marte and Anastos, "Women—The Missing Persons in the AIDS Epidemic Part II," 12. In 1987, Colorado became the first state prison system to test and segregate HIV-positive male prisoners. By 1989, sixteen state and federal prison systems conducted mandatory HIV antibody screening of all incoming inmates, all current inmates, and all inmates at the time of their release. A total of twenty states segregated all those diagnosed with HIV. Matthew Purdy, "As AIDS Increases Behind Bars, Costs Dim Promise of New Drugs," *New York Times*, May 26, 1997, 1-2; Memorandum from Otis R. Bowen to Beryl W. Sprinkel, Chairman, Council of Economic Advisors from the Secretary, "Assessing the Benefits of Testing for AIDS," July 20, 1987, 1-2, box, fol. 2, Sprinkel files, RRPL. For more on the issue of HIV testing in prison, see Kunzel, *Criminal Intimacies*, 232.

[432] Anne-Marie Cusac, "'The Judge Gave Me Three Years. He Didn't Sentence Me to Death': Prisoners with HIV deprived of proper care," first published in *The Progressive*, July 2000, reprinted in *Prison Nation: The Warehousing of America's Poor*, ed. Paul Wright and Tara Herivel (New York: Routledge: 2003), 195.

of treating an HIV-positive inmate rose from approximately $2,000 in the 1980s to approximately $13,000 in the 1990s with the development of ART, "drugs are not being widely prescribed in some prisons even though doctors acknowledge that it is unethical not to."[433] Jan Diamond, a physician at the California Medical Facility at Vacaville State Prison, similarly explained how the introduction of AZT in 1987 shifted prison authorities' priorities over testing. For a long time, the California legislature wanted to institute mandatory testing of prisoners, followed by quarantine of the infected, ostensibly to curb transmission. However, when "AZT became accepted therapy for treating asymptomatics, they quickly figured out how much it would cost to really know who had the virus and they dropped their push."[434] States willing to spend more money to address AIDS were therefore not necessarily more progressive. Instead, as former inmate John Zeh noted, less funding often resulted in fairer treatment in the form of reduced mass testing, less segregation, and the early release for people with AIDS needing costly long-term care.[435] The high cost of treating HIV drove other, more progressive prison officials, such as William Hall, the correctional assistant director for health services in Washington, D.C., to distribute condoms and clean needles for the sake of preventing the spread of the virus among inmates.[436]

While Hall recognised the financial and medical efficacy of providing condoms as HIV prevention in male prisons, few acknowledged the need to take comparable steps to prevent woman-to-woman transmission of HIV in women's prisons, either through education or supplying prophylactics including dental dams, condoms (adapted for woman-to-woman

[433] Purdy, "As AIDS Increases Behind Bars," 1.
[434] Quoted in Jonsen and Stryker, "National Research Council (US) Panel on Monitoring the Social Impact of the AIDS Epidemic," *The Social Impact of AIDS in the United States*, accessed February 2020, available at: https://www.ncbi.nlm.nih.gov/books/NBK234573/
[435] John Zeh, "The Agony of AIDS Inside and Out," *Studies on the New Left* XIV, nos. 1 & 2, Spring-Summer 1989, 151.
[436] Amy Goldstein, "AIDS Plan Creates Prison Paradox: Issues Collide in D.C. Proposal to Distribute Condoms to Inmates," *Washington Post*, May 19, 1992.

protection), or latex gloves. While the onset of HIV and AIDS did cause some prison authorities to more closely police women's physical contact, the lack of concern about the sexual transmission of HIV among women prisoners perpetuated the "myth of lesbian immunity" that was prevalent in some public health and grassroots lesbian circles and assumed that women could not contract or transmit HIV to each other.[437] Aware of the prevalence of same-sex activity in women's prison and the possibility of woman-to-woman transmission through blood or vaginal fluids, Felicia Davidson, a programme coordinator at the Women's Project in Little Rock, Arkansas, advised women to use bread sacks, cookie wrap paper, or any kind of barrier to keep from sharing fluids, as "some protection is better than none."[438] In April 1993, one lesbian inmate at the New York Albion Correctional Facility wrote to the LAP explaining that prison officials:

> Say females contract AIDS from males, and cannot contract it from female-female contact. I don't believe that! I have been gay for 12 years—never did drugs or had a transfusion—but I was with another female who was positive. She told me this after I tested positive.[439]

The inmate asked LAP to "please send me everything you have on gay women and HIV" due to the lack of resources on the disease available to women at her facility.[440]

[437] Kunzel, *Criminal Intimacies,* 309.
[438] Kelly Safreed Harmon, "HIV and Incarcerated Women," *Positively Aware: The Journal of Test Positive Aware Network* (July/August 2001): 21, box 8, fol. 247, Greenspan papers, LGBT Community Center. In March 1992, the Come Into the Sun Coalition reiterated that "any training should emphasize the importance of safer sex practices as they relate to the transmission of the AIDS virus, to other sexually transmitted diseases, and to the possibility of becoming pregnant. See "Come into the Sun: Findings & Recommendations on the Needs of Women and Girls in the Justice System," March 1992, 15, box 7, fol. 218, Greenspan papers, LGBT Community Center.
[439] Letter from P.A./Albion Correctional Facility to LAP, reprinted in *LAP Notes*, Issue no.1 (April 1993): 12, BWHBC records, Schlesinger Library.
[440] P.A./Albion Correctional Facility to LAP.

In many instances, the scaling up carceral state did not prepare for women's needs. The slowness on the part of prison authorities to respond to the reproductive and chronic nature of women's illnesses was in part a consequence of a prison system built around the needs of the predominantly male prisoner population. Writing about poor health conditions in US prisons for women during the 1980s and 1990s, sociologist Nancy E. Stoller noted that "the health of incarcerated women has historically been worse than that of men, both because of the nature of the population (e.g., higher rates of drug use) and because prison health facilities, policies, and practices are typically prepared with men in mind."[441] As prisoner rights advocate and author Victoria Law has similarly argued, because politicians, the public, and the media have often chosen to overlook women in prison, prison issues are seen as masculine and male-dominated, "dismissing prison issues that are distinctly feminine (e.g. the scarcity of sanitary hygiene products, the lack of medical care specifically for women, especially prenatal care, and threats of sexual abuse by guards)."[442] The lack of maternity and gynaecological care available to women in prison was particularly dangerous for women living with HIV at high risk for cervical cancer and other reproductive health complications.[443] Although the CDC spent more money per capita in the 1990s on health care for women than men—about $1,000 more in 1994—the Female Inmate Health Issue Task Force found that incarcerated women still got less effective and efficient healthcare than men.[444] As was the case outside prison, authorities treated women prisoners with HIV as an afterthought in terms of the time, money, and resources spent on AIDS.

[441] Nancy E. Stoller, "Project Title: Declining health conditions in U.S. prisons for women: A twenty-five-year perspective," 1998, 2, box 8, fol. California grant/state, Stoller papers, UCSF.
[442] Law, *Resistance Behind Bars*, 4.
[443] Stoller, "Declining health conditions in U.S. prisons for women," 3.
[444] Siegal, "Dying Behind Bars," 17.

Most prison systems employed medical protocols and allocated health care resources using a healthy, young male as its model prisoner. Dr Corey Weinstein, former Chair of the Jail and Prison Health Committee and member of the Governing Council of the American Public Health Association, explained that the "sick call" system in which prisoners only received care when they requested it:

> Was developed for the military, where most of the people are healthier than the norm. It works for the military because if you have chronic problems, you won't be in the military to begin with. Here you have the opposite. You have a population of women who are expected to be at risk and to have chronic problems. [Prison officials] cannot meet the challenge of women with chronic illnesses, and they have no backup.[445]

This military-style model that Weinstein described required women with health problems to show up at sick call and convince a prison guard with minimal medical training that the problem was serious enough to warrant a doctor's attention. This requirement was particularly challenging for women with chronic illnesses as it made their ability to secure the required regular treatment and attention dependent on the whim of individual prison guards who they reported often failed to take their health complaints seriously.[446] One inmate at CCWF who suffered from sickle cell anaemia reported that, because the prison staff frequently failed to provide her with the consistent medical care needed to treat her condition, every month "like clockwork" she went into crisis and was rushed to the closest medical community centre for emergency care. She explained that the centre, "more or less stated that they don't do preventative care."[447] Most prison authorities probably favoured the sick call

[445] Quoted in Siegal, "Dying Behind Bars," 17.
[446] Legal Services for Prisoners with Children, "Protecting Basic Human Rights," 1; Siegal, "Dying Behind Bars," 17.
[447] Siegal, "Dying Behind Bars," 19.

system because it was cheaper than providing continuous care for women's long-term, chronic, and costly healthcare needs, such as treatment for sickle cell anaemia.[448]

Even when treating chronic illnesses, the delivery systems in prison were often inefficient and inhumane. In some facilities, prison officials made women with HIV and other chronic illnesses line up outdoors once a day to receive their daily bag of medicine. What was otherwise known as the "pill line" violated confidentiality while women who were too ill to line up did not get their drugs.[449] The pill line made it difficult for women with long-term illnesses to comply with complicated instructions on when and how to take medication, putting them at high risk for developing drug resistance.[450] Women living with HIV in prison often quit their treatment as a result of the inconsistency in medicine distribution, not to mention the hardship of standing in line in poor weather conditions.[451] As the carceral state ramped up, women, who suffer disproportionately from chronic as well as reproductive health complications, had to navigate health delivery systems that were designed for healthy men.[452]

---

[448] According to a 2017 study by the Pew Charitable Trust, while women make up a small portion of state prison populations, they tend to have outsized and sometimes costly health needs. They noted that women are more likely than prisoners overall to report a current or past chronic condition, and their rates of mental illness are substantially greater, which partly results from high rates of childhood sexual abuse and post-traumatic stress disorder. They also found that treating chronic conditions is a growing challenge and expense in state prisons. See "Prison Health Care: Costs and Quality: How and why states strive for high-performing systems," October 2017, 29, accessed November 2019, http://www.pewtrusts.org/~/media/assets/2017/10/sfh_prison_health_care_costs_and_quality_final.pdf A prison policy study from 2004 similarly found that chronic conditions are expensive to treat and represent a major financial burden to the prison systems. See Chad Kinsella, "Corrections Health Care Costs," (January 2004), 2, accessed February 2020, https://www.prisonpolicy.org/scans/csg/Corrections+Health+Care+Costs+1-21-04.pdf

[449] Carmen Retzlaff, "Can HIV Care Click in the Clink?" *POZ*, April 2004, 24, box 8, fol. 247, Greenspan papers, LGBT Community Center.

[450] Retzlaff, "Can HIV Care Click in the Clink?" 24.

[451] Judy Greenspan, "Voices from the Chowchilla Women's Prison," *Prison Legal News (Women Organized to Respond to Life Threatening Diseases, Oakland, CA)*, March 15, 1994, accessed February 2020, https://www.prisonlegalnews.org/news/1994/mar/15/voices-from-the-chowchilla-womens-prison/

[452] A 2015 report from the Bureau of Justice Statistics found that among prisoners and jail inmates, women were more likely than men to report ever having a chronic condition. Sixty-seven percent of women in jails and sixty-three percent of women in prison report chronic health conditions. See Laura M. Maruschak and Marcus Berzofsky, "Medical Problems of State and Federal Prisoners and Jail Inmates, 2011-12," Washington: Bureau of Statistics (2015), revised October 4, 2016, accessed February 2020:

The inefficient and inhumane health delivery systems used in many women's prisons drove some women to begin organising for better conditions. Women in Bedford Hills, a maximum-security prison for women in Westchester County, New York, where the rates of HIV were particularly high, were some of the first to begin educating, counselling, and building a community of support.[453] Among those who led the early efforts were Kathy Boudin and Judith Clark, former Weather Underground members who were incarcerated in Bedford Hills for the role they played in the 1981 Brink's robbery.[454] As lifetime radical activists and political prisoners, the grassroots experience Clark and Boudin brought to the prison may have influenced their leadership in the organising efforts among its women prisoners. Other women at Bedford Hills, including Katrina Haslip, and Doris Moices, Aida Rivera, and Gloria Boyd were similarly moved to act because of the mistreatment they and other women with HIV and AIDS suffered at the facility.

Haslip, Clark, Boudin, Moices, Rivera, and Boyd vowed to educate themselves and the rest of the prison community about HIV in an effort to combat mistreatment, as ignorance, fear, and denial typified staff and inmate attitudes towards the disease at Bedford Hills. Prison

---

https://bjs.gov/content/pub/pdf/mpsfpji1112.pdf The reproductive issues of women make delivering healthcare more complicated for women than men and are an additional challenge to healthcare services within prisons. These include menstruation, pregnancy, childbirth, breastfeeding, and menopause. The diagnosis of gynaecological conditions can depend on specific medical equipment that may not be available in correctional facilities. International Committee of the Red Cross: Health in Prison: Looking after women in a man's world, February 27, 2009, accessed February 2020, https://www.icrc.org/en/doc/resources/documents/interview/women-health-prison-interview-020309.htm

[453] Kathy Boudin and Judith Clark, "Community of Women Organize Themselves to Cope with the AIDS Crisis: A Case Study from Bedford Hill Correctional Facility," *Social Justice* 17, no. 2 (40) (Summer 1990): 90.

[454] Clark and Boudin drove the two getaway cars that assisted the Brink's robbery. Six members of Black Liberation Army and four former members of the radical left-wing group the Weather Underground stole $1.6 million in cash from a Brink's armoured car at the Nanuet Mall in Nanuet, New York, killing a security guard and two policemen in the process. Prison officials considered Clark and Boudin major security threats for their role in the robbery and their links to the Black Liberation Army. Clark spent her first month at the facility in solitary confinement in order to prevent a repeat of the 1979 prison breakout of Assata Shakur, a fellow Black Liberation Army leader, from the Clinton Correctional Facility for Women in New Jersey. In 1985, believing that she was plotting her escape, prison staff moved Clark back to solitary confinement where she spent a further two years. Tom Robbins, "Judith Clark's Radical Transformation," *New York Times*, January 15, 2012.

guards isolated women known to have HIV in the In-Patient Care Unit (ICU) where the medical staff often knew little about the disease and were afraid to have physical contact with their patients.[455] Officers interacting with HIV-positive women often wore gloves and masks, an unnecessary measure—as HIV was known not to be spread through casual contact—that stoked fears among the inmates.[456] The six women frequently visited the ICU to provide contact and counselling and also helped bathe and cook for patients. They described women at the facility living:

> In a state of constant anxiety over whether or not we would test positive for HIV. Locked up with one another, sharing the same showers, kitchen, living space, we felt panic…We knew that we would have to help ourselves and each other. We started ACE (AIDS Counseling and Education) because we felt that as prisoners, we would be the most effective in educating, counselling, and building a community of support.[457]

Building on the consciousness raising tradition of the feminist movement in the 1960s and 1970s, the women at Bedford Hills set up prison support groups that similarly took women's stories and perspectives seriously, but which also educated women about HIV and gave them accurate information about its causes, treatments, and transmissions. They petitioned the prison administration for permission to create the AIDS Counseling and Education (ACE)

[455] Clyde Haberman, "Of Revenge, Redemption and Parole," *New York Times*, August 8, 2003.
[456] Boudin and Clark, "Community of Women Organize Themselves to Cope with the AIDS Crisis," 93.
[457] The Women of the AIDS Counseling and Education (ACE) Program, Bedford Hills Correctional Facility, New York in *Wall Tappings: An International Anthology of Women's Prison Writings, 200 to the Present*, ed. Judith A. Scheffler (New York: CUNY, 2002), 28.

programme at Bedford Hills, one of the first and most comprehensive prison support groups for women prisoners in the country.[458]

The prison superintendent at Bedford Hills, Elaine Lord, approved ACE in early 1988, while remaining apprehensive of the potentially disruptive consequences of the educational and group work of her prisoners. In particular, she was concerned that the cooperation and mutual support developing among prisoners might challenge the staff's authority and threaten prison security.[459] Her concern led her to shut ACE for six months in the summer of 1988. A year later, she stopped ACE members meeting at their regular time, using their meeting room, giving educational presentations, or referring to themselves as "counsellors."[460] ACE perhaps faced so much administrative interference because of the involvement of Boudin and Clark. Prison officials feared that the one-to-one peer counselling sessions Clark and Boudin offered might lead to organising around other, more disruptive issues. The prison administrators also banned educators from the New York Montefiore Hospital holding training sessions at the facility after they suggested that the New York Department of Correctional Services lift its ban on condoms and dental dams in women's prisons.[461]

ACE members continued to implement their programme without this administrative support. They helped women to prepare for their medical examinations, accompanied women to consultations hoping to improve communication between patients and medical staff, and led educational seminars to women throughout the facility. The New York AIDS Institute

[458] Haslip, "A Community of Women: Living with AIDS," in *Wall Tappings*, 29. For more on the ACE programme, see Kathy Boudin et al., "Voices: Women of ACE (AIDS Counseling and Education), Bedford Hills Correctional Faciltiy," in *Women AIDS Activism*, ed. Banzhaf et al., 143-155 and Boudin and Clark, "Community of Women Organize Themselves to Cope with the AIDS Crisis," 90-109.
[459] Law, *Resistance Behind Bars*, 37.
[460] Members of AIDS Counseling and Education ACE Program at Bedford Hills, *Breaking the Walls of Silence: AIDS and Women in a New York Maximum Security Prison* (New York: Overlook Press, 1998), 71.
[461] Law, *Resistance Behind Bars*, 37.

awarded the programme a $250,000 grant that allowed the inmates to create several paid staff positions for prisoners as well as hire an outside coordinator.[462] Over the course of several years, the women compiled a curriculum that addressed, among other topics, HIV transmission, risk reduction, HIV testing, strategies for treatment, and social issues pertaining to women and AIDS. In 1998, they published nine education and counselling workshops in their book, *Breaking the Walls of Silence: AIDS and Women in a New York State Maximum Security Prison* that followed the model of *Women, AIDS, Activism* (1990) and the *New Our Bodies, Ourselves* (1992) in providing women with accurate information about HIV and AIDS.

Katrina Haslip also worked with fellow inmate T. J. Rivera to set up AIDS Counseling and Education on the Outside (ACE-OUT), ACE's sister programme that helped women transition back into the community upon release, assisting with housing, medical care, drug treatment, and custody issues.[463] After her release from Bedford Hills in 1990, Haslip joined the Upper Manhattan Task Force on AIDS and was at the forefront of protests to expand the definition of AIDS to include infections involving the cervix, uterus, and ovaries that affected women with HIV.[464] She spoke about her infection at conferences, protests, and outreach events; met with CDC officials in private, and held them accountable in public in an effort to push for the new definition. Haslip died of AIDS-related complications in 1992 at the age of 33, one month before the CDC changed its AIDS definition enabling a segment of women to access health and social services previously unavailable to them.[465] Although some women

[462] Both Boudin and Clark were hired as two of ACE's original team of twelve prisoner staff members. Eight months later, the Bedford Hills administration removed them, feeling they had "undue influence." Both continued to volunteer as ACE members. Boudin and Clark, "Community of Women Organize Themselves to Cope with the AIDS Crisis," 99; Law, *Resistance Behind Bars*, 246.
[463] Clines, "An Unequal Justice."
[464] Navarro, "An AIDS Activist Who Helped Women Get Help Earlier," E9.
[465] New York Times Obituary, "Katrina Haslip Dies; AIDS Worker Was 33," *New York Times*, December 3, 1992, 20.

like Kathy Boudin and Judy Clark had arrived at Bedford Hills politically active and with experience of organising on behalf of themselves and others, Haslip embodied the many women for whom the shock and horror of incarceration moved them to fight for the improved treatment of women living with HIV and AIDS in and beyond prison, demonstrating how prisons served as a central arena for the development of women's healthcare activism in the 1980s and the 1990s.

The fact that women rarely rioted in the ways more commonly associated with male prisoners did not make them passive.[466] Instead, they took a different approach, setting up prison support groups with the aim to educate one another and petition for a better quality of life for inmates. Other women prisoners across the country used ACE to model their own support groups. Linda Evans and Laura Whitehorn modelled their Pleasanton AIDS Education and Counselling Programme (PLACE) at California's Federal Correctional Institution at Pleasanton on ACE.[467] At the York Correctional Institution in Connecticut, Felicia Crowe, a woman prisoner with HIV, similarly wrote letters to the Warden, the medical unit, the mental health unit, and civil liberties until they permitted her to start an HIV support group.[468] These initiatives also mirrored ACE in that prison officials took similar steps to stop women's initiatives when they perceived them as threatening the prison order. Prison staff frequently put women who agitated for change in the Special Housing Unit (SHU). Speaking out or

[466] For an account of the conditions that led to the 1971 Attica Prison Uprising in New York, See Heather Ann Thompson, *Blood in the Water: The Attica Prison Uprising of 1971 and Its Legacy* (New York: Pantheon Books, 2016).
[467] Linda Evans started PLACE while serving a 45-year-sentence for a conviction of using false identification to purchase legal weapons. She faced additional charges that she had "conspired to resist U.S. government policies and practices through the use of violent and illegal means." She spent fourteen years in prison and was released on parole on August 6, 1999. Laura Whitehorn was incarcerated for her role in the 1983 United States Senate bombing and she also served 14 years in prison. See Marilyn Kalman and Rachel Lederman, "Talking with Three Lesbian Political Prisoners," *Sinister Wisdom* 37 (Spring 1989): 101, LC Periodical PS 508 W7 S54.
[468] Felicia Crowe, "Women Prisoners at Niantic, Ct.," *Women Alive*, Autumn 1995, 8, Subject file: AIDS, LHA.

organising also jeopardized some women's chances of parole.[469] Despite the potential penalties, and often without administrative approval, women prisoners continued to organise to challenge the conditions of their confinement in facilities across the country, eventually connecting with outside support.

Through Prison Walls

Across the country from Bedford Hills, the egregious medical situation in California's women's prisons in the early 1990s brought many women into activism for the first time. One of the first preventable deaths that mobilised women at the Central California Women's Facility (CCWF) in Chowchilla, California, involved Dianna Reyes, a 43-year-old Hispanic woman with diabetes. On 18th June 1991, Reyes had been in the sick-call line trying to get her insulin. Feeling ill and irritated at the insolence of the medical staff, Reyes became involved in a physical altercation with another inmate. Officials sent them both to Administrative Segregation for a 10-day disciplinary isolation, during which time prison staff refused to give Reyes any medical attention. Her health severely deteriorated until officers eventually realised something was wrong and transferred her directly to the hospital. A short time later, doctors pronounced her dead. According to prisoner Linda Eagerton, officials said that Reyes had died of natural causes, and a total of ten years were added to the sentences of the women who refused to work that day in protest over Reyes' mistreatment.[470] Reyes' death spoke to the medical negligence that was commonplace in California's women's prisons in the 1990s and her mistreatment demonstrated what the tough on crime politics, begun in the 1980s and accelerated in the 1990s, looked like in practice.

[469] The California Department of Corrections and Rehabilitation (CDCR) prohibited prisoner organising without the Warden's specific approval. Law, *Resistance Behind Bars*, 8.
[470] Linda Eagerton, "Dianna Reyes," May 21, 1994, 1-2, box 5, fol. 181, Greenspan papers, LGBT Community Center.

The 1990s marked the rise of the carceral state and the increase of women's imprisonment. In 1994, President Bill Clinton signed the Violent Crime Control and Law Enforcement Act, which dramatically increased budgets for policing and prisons, created sixty new federal death penalty offenses, and eliminated funding that would allow prisoners to get a college education.[471] That same year, California voters approved Proposition 184, also known as "three strikes" sentencing that imposed automatic life sentences for all third felonies.[472] The state of California also embraced "zero tolerance" policing and harsh sentencing practices that swelled their prisoner population. By the 1990s, the state incarcerated the most people in the country. Between 1980 and 2000, the number of women in California's jails and prisons had increased five-fold from 4,432 to 23,597.[473] In October 1990, the state opened CCWF, the largest women's prison with the only death row for women in the country.[474] Five years later, the Valley State Prison for Women (VSPW) opened across the road from Chowchilla. Located about 150 miles southeast of San Francisco and covering 640 acres of land, the two compounds on either side of Road 24 constitute the largest women's prison complex in the world. It was no coincidence that CCWF became a site for prison activism, especially when it came to women with HIV/AIDS. With the high stakes of life and death, women met abuse with powerful activism.

Women faced a number of obstacles to accessing medical care in California's correctional facilities. In November 1994, the California legislature passed a law allowing the CDC to charge inmates a five dollar co-pay for each medical visit they requested, even if they did not

[471] Murakawa, *The First Civil Right*, 113-147.
[472] Alexander, *The New Jim Crow*, 90-91.
[473] Amy Pétre Hill, "Death Through Administrative Indifference: The Prison Litigation Reform Act Allows Women to Die in California's Substandard Prison Health Care System," *Hastings Women's Law Journal* 13, no. 2 (Summer 2002): 231.
[474] Peter Applebome, "Women in U.S. Prisons: Fast-Rising Population," *New York Times*, June 16, 1987.

get to see a doctor. The CDCR intended the fees to deter prisoners from allegedly "unnecessary" doctor's visits. However, without access to jobs that paid the minimum wage, prisoners depended on jails and prisons to provide for their basic needs, including their health care, and the introduction of the co-pay health system put basic care out of the reach of many women.[475] One inmate explained that "there have been many times that I have not had the money to purchase necessary medical supplies because I have been forced to use my limited funds to pay $5 for each medical visit."[476] As women also needed to pay for basic personal hygiene products, including menstrual products, the cost of co-pay was a strong disincentive, even for those seriously sick, to seek medical attention.

Women held in California's prisons also struggled to gain access to a medically trained doctor. There was no licensed infirmary at CCWF, and prison officials refused to pay more to hire an HIV/AIDS medical specialist or gynaecologist. Women with serious illnesses reported having to wait weeks to see a medically trained doctor, and prison guards with limited vocational nursing skills, renamed minimally trained Correctional Officers, or Medical Technician Assistants (MTAs), examined and diagnosed the women themselves.[477] Due to their limited or non-existent medical training, MTAs frequently misdiagnosed women and prescribed the wrong drugs which led to further illness and sometimes death. For example, one woman with HIV-related thrush in her mouth reported being given vaginal suppositories to eat by the MTA treating her when the lozenges she needed were unavailable.[478] MTAs also misdiagnosed pregnant inmate Elaine Greatneyese's stomach

[475] Wendy Sawyer, "The steep cost of medical co-pays in prison puts health at risk," *Prison Policy Initiative*, April 19, 2017, accessed February 2020, https://www.prisonpolicy.org/blog/2017/04/19/copays/
[476] California Coalition for Women Prisoners (CCWP) members, "Women Sue for Healthcare," *The Fire Inside*, Issue 1 (June 1996): 2, box 8, fol. 237, Greenspan papers, LGBT Community Center.
[477] "Chowchilla Prison: A Medical Hellhole. California pays prison guards $56,000 a year instead of hiring qualified medical personnel," 1, box 5, fol. 179, Greenspan papers, LGBT Community Center.
[478] "Chowchilla Prison: A Medical Hellhole," 1.

pains and bleeding as a bladder infection when she was in fact entering premature labour. She lost her child.[479] In February 1999, Tina Balagno died one week after securing compassionate release from CCWF as a result of bone cancer which MTAs had left untreated for months and had metastasized to her breasts, spine, and brain.[480] HIV was hard enough to diagnose in women already without the added obstacle of relying on people with minimal medical training to recognise the symptoms in women for treatment.

Inmate Joann Walker believed that the medical neglect, segregation, lack of confidentiality, and the high stress experienced by women prisoners with HIV constituted "murder by proxy."[481] Walker tested HIV positive in 1986 and in 1992, a judge sentenced her to four years and four months in prison for the theft of a $200 jacket.[482] Walker claimed that although CCWF officials offered voluntary testing to all inmates in theory, in practice they frequently denied HIV tests to women who requested one, informing them that they could only be tested if the virus was "medically indicated" meaning that the women would not know their HIV status until they were already visibly sick. This requirement was particularly onerous for women given that the physical manifestations of HIV virus in women are often not visible.[483] Prison officials also denied women with HIV the ability to participate in the Family Visitation Program and did not allow them to work in the prison kitchen or infirmary.[484] Because of the housing segregation and loss of job opportunities and visitation privileges, many women hid their HIV-positive status or did not seek testing. As a result,

[479] Letter from Elaine Greatneyese to Judy Greenspan, undated, box 5, fol. 179, Greenspan papers, LGBT Community Center.
[480] CCWP members, "Tribute to Sherrie Chapman," *The Fire Inside*, Issue 10 (March 1999): 1, box 8, fol. 237, Greenspan papers, LGBT Community Center.
[481] Poster, Coalition to Support Women Prisoners at Chowchilla (CSWPC), "Stop the Murder of Women Prisoners with AIDS at Chowchilla!" 1994, box 5, fol. 179, Greenspan papers, LGBT Community Center.
[482] Noelle Hanrahan, "To die in Chowchilla," *San Francisco Bay Guardian*, January 26, 1994, 9.
[483] CSWPC, "Editorial Response to February 1 Opinion Page article, 'Inmates are out of line,'" 1-2, box 5, fol. 186, Greenspan papers, LGBT Community Center.
[484] CSWPC, "Editorial Response to February 1 Opinion Page article," 1-2.

although the CDC reported that 50 women at Chowchilla had HIV in the early 1990s, as was the case because of under-reporting and misdiagnosis outside prison, Walker argued that the agency had no real idea of the actual number of HIV-positive women at the prison.[485]

The discriminatory treatment of HIV-positive women at CCWF also deterred inmates from getting tested and seeking treatment. Guards segregated all HIV-positive women in C-Yard and put up signs in every yard reading, "Beware! There are HIV infected inmate persons housed in this facility!"[486] Women's confinement in a segregated yard automatically disclosed their HIV status. Other confidentiality violations at CCWF included a Xeroxed list of women with HIV being circulated in the prison yard after an administrator had left it on their desk.[487]

These persistent healthcare violations moved Charisse Shumate, who was serving a life sentence for killing her abusive partner, to help inmates who, like her, suffered from sickle-cell anaemia and other chronic health complications. CCWF did not hire a haematologist for women's sickle cell anaemia, lupus, and other blood diseases, and Shumate only received a blood transfusion for her illness once every three months instead of the more regular transfusions necessary for severe and persistent anaemia.[488] Shumate began educating women about the complications of sickle cell anaemia and HIV in women, and the necessary treatment while fighting to receive the proper medical care for her illness and advocating for the right to compassionate release for terminally ill prisoners.

[485] CSWPC, "Editorial Response to February 1 Opinion Page article," 1-2.
[486] Greenspan, "Voices from the Chowchilla Women's Prison."
[487] Flyer, "The California Department of Corrections (CDC) Is Killing Women Prisoners with HIV/AIDS," box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[488] CCWP, "Tribute to Charisse Shumate," 1.

Instead of supporting women, prison officials hampered their efforts to learn more about HIV/AIDS, censoring the educational materials sent to them from outside organisations such as ACT UP/San Francisco, the ACLU National Prison Project, and the San Francisco AIDS Foundation. In June 1993, HIV-positive inmate Brenda Lee Ivy wrote to AIDS advocate Paul Collins requesting HIV information, and he replied one month later to inform her that "on July 26, 1993, as per your request, I mailed to you a package containing literature on HIV/AIDS. Unfortunately, that package was returned to me today, stamped by your correctional facility as unauthorized correspondence."[489] Inmate Gina Marie Caruso told the ACLU National Prison Project that "all of our mail is read and censored before it goes out of this institution…you must understand the length and chance I'm taking to be heard. I'm not the only one that has something to say, there are several hundred women that are willing to speak out if only someone would listen."[490] In order to stop prison officials censoring her letter, Caruso sent it out with her cellmate on her release date.

Joann Walker, Gina Marie Caruso, and their peers were conscious that bringing the inhumane situation inside CCWF to the attention of outside lawyers, activists, and politicians who had more resources and greater political clout would increase their chances of improving health care at the facility. Advocacy groups such as Legal Services for Prisoners with Children (LSPC) began receiving letters from women at CCWF almost as soon as the facility opened in late 1990.[491] Twillah Wallace, a prisoner living with HIV at CCWF, wrote to California Assemblywoman Barbara Lee, acknowledging that "there are many important issues that

[489] Letter from Paul Collins to Brenda Lee Ivy, August 2, 1993, box 5, fol. 181, Greenspan papers, LGBT Community Center.
[490] Gina Marie Caruso, "Help!", undated, 1, box 5, fol. 181; Urszula Wislanka, "Mail Restrictions Raise the Question: What Makes Us Human?" *The Fire Inside*, Issue 6 (May 1997): 5, box 8, fol. 237, Greenspan papers, LGBT Community Center.
[491] Legal Services for Prisoners with Children, "Shumate v. Wilson," 1, box 8, Stoller papers, UCSF.

need the attention of someone from the outside and someone of power, as yourself."[492] Women contacted other politicians, attorneys, and legal services in California and other states trying to get news out and make contact with outside organisations.

News of inmate complaints brought Catherine Campbell of the ACLU National Prison Project from Washington, D.C., and Dr Corey Weinstein to CCWF. In 1992, they both launched independent investigations into the health care at CCWF after they toured the facility and found that women with sickle cell anaemia, HIV, and epilepsy were not receiving their medication for long periods of time. Campbell and Weinstein began conducting independent interviews with women prisoners and collecting data.[493]

In May 1993, Walker wrote to the Prison Issues Committee of ACT UP/San Francisco to tell them how "this system is a murderer of people with AIDS. Too little medical care, too little education, no confidentiality, too small diets and no compassion at all."[494] ACT UP connected Walker to prisoner rights advocate Judy Greenspan. As well as working with ACT UP/San Francisco's Prison Issues Committee, Greenspan was the AIDS Information Director for the ACLU's National Project and director of the Catholic Charities' HIV/AIDS in Prison Project in the Bay Area. She already worked with male prisoners with HIV and her connections with the women's, lesbian and gay, prisoner advocacy, AIDS activist, and criminal justice communities enabled her to become the bridge between the women in prison and outside organisations. In 1993, she launched the California Coalition for Women

[492] Letter from Twillah Wallace to Assembly Person Barbara Lee, undated, box 5, fol. 179, Greenspan papers, LGBT Community Center.
[493] Letter from Elizabeth Alexander of the ACLU to James Gomez, October 3, 1994; Letter from Greenspan to California State Assembly Committee on Public Safety, March 8, 1994; Letter from Joann Walker to Ellen M. Barry, Attorney, April 14, 1994; Interviews with Women at Chowchilla (CCWF) on 8/19/93 w/Corey Weinstein, M.D., and Catherine Campbell, 1, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[494] Judy Greenspan, "Women Campaign for Better Medical Care," *The Fire Inside*, Issue 4 (May 1997): 4, box. 8, fol. 237, Greenspan Papers, LGBT Community Center.

Prisoners (CCWP) that offered grassroots support to women inside California's prisons. Greenspan's social standing within various progressive communities enabled her to bring the largely ignored healthcare struggles of women prisoners to the attention of groups already involved in rights organising in this period. In relaying the women's stories of medical neglect and the difficulty of obtaining information about HIV/AIDS in prison, Greenspan motivated a number of groups to protest the inhumanity of the prison system in the 1990s and into the 2000s especially towards women.

When Walker first wrote to Greenspan in April 1993, she sent her a copy of the proposal for a peer education programme that she and three other African American women living with HIV at the facility—Twillah Wallace, Brenda Lee Ivy, and Deborah Paul—had drafted "to provide support for CCWF inmates who are living with HIV and AIDS; to join the CCWF staff in educating the general population about HIV and AIDS; and to work effectively within the CCWF system and the larger community to promote awareness of our special care needs."[495] Because CCWF had no formal HIV/AIDS education programme, the women endeavoured to start an informal prison support group that mirrored the operation of ACE in Bedford Hills and that would focus on HIV/AIDS, tuberculosis, and Hepatitis C. They submitted the proposal for the prison administration's approval, but the Warden initially ignored it. Greenspan circulated copies widely and asked groups on the outside to send letters of support. With the help of outside pressure, the prison administrators eventually approved the programme on the condition that the four women did not question the prison's rules, policies, and staff's conduct, threatening to write them up or put them in the SHU if they did.[496] Despite its approval, prison officials took no steps to implement the programme and,

[495] Paul, Balagno, and Walker, "HIV/AIDS Task Force Proposal," March 15, 1993, 1-2, box 5, fol. 181, Greenspan papers, LGBT Community Center.
[496] "Chowchilla Prison: A Medical Hellhole," 5; Joann Walker, "From a Woman's Point of View," undated, 10, box 5, fol. 179, Greenspan papers, LGBT Community Center.

in the meantime, the four women went from prison yard to prison yard informally talking to their peers about the disease and giving presentations on HIV.[497] Not long afterwards, officials told Walker that she could no longer provide this peer education due to her "negative" influence on the other women prisoners.[498]

In July 1993, Walker sent Greenspan a copy of a petition she had initiated demanding that prison officials fire David Archer, an MTA who was allegedly abusing women.[499] Over 450 women signed the petition that got Archer removed from C-Yard. While Greenspan was impressed as "petitioning inside under the eyes of the prison guards is quite a feat," she was also alarmed because the "fact that so many signed a petition was a strong signal that medical care was reaching a crisis point at CCWF."[500] One month later, in August 1993, Greenspan wrote to inform James Gomez, the California Director of Corrections of the deep concern and alarm arising from the multiple complaints she had received from HIV-positive women prisoners at CCWF, including over the lack of medical care for women prisoners and the censorship of HIV/AIDS educational material. Greenspan, who had copied journalists from leading local and national newspapers into the letter, argued that these actions abetted the spread of HIV/AIDS and created a life-threatening, emergency situation at the prison, and that she, writing on behalf of ACT UP/San Francisco, demanded an immediate investigation of medical services at the facility.[501]

[497] Hanrahan, "To die in Chowchilla," 9.
[498] Interviews with Women at Chowchilla (CCWF) on 8/19/93 w/Corey Weinstein, M.D., and Catherine Campbell, 1, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[499] Judy Greenspan, "Joann Walker—A Fighter and a Legend in Her Time," undated, 1, box 5, Greenspan papers, LGBT Community Center.
[500] Greenspan, "Joann Walker," 1.
[501] Letter from Judy Greenspan to James Gomez, August 13, 1993, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.

Due to the absence of institutional services for women with terminal illnesses at CCWF, prisoners also pushed for the compassionate release of dying inmates. In late October 1993, Walker called Greenspan to tell her about her roommate, Betty Jo Ross, a 35-year-old woman with AIDS who was seriously ill. Ross suffered from a series of serious AIDS-related ailments, including dementia, Micobacterium Avim Complex, Cytomegalovirus retinitis, a T-cell count of one and the doctor had told her that she had fewer than six months left to live. Walker insisted that Ross should be granted compassionate release, but James Gomez denied this request twice on the grounds of Ross' "uncontrollable conduct and pattern of assaultive behaviour."[502] Walker was furious and wanted ACT UP/San Francisco and other groups to do something immediately. She began a petition for Ross' release inside the prison which over 1,000 prisoners, all risking punishment, signed. She also made signs reading "Free Betty Jo," and "Don't let the system kill another PWA" which the inmates pinned to their clothing. Outside, ACT UP began a "Send Betty Jo Ross Home for Christmas" fax and phone campaign and organisations such as the Mobilization Against AIDS sent Gomez letters "strongly recommend[ing] that the inmate be granted an early release."[503] To the amazement of outside organisations who had doubted Walker's ability to do anything to free Ross, the CDCR released her on 5th January 1994.[504]

Winning the compassionate release of Betty Ross was a remarkable victory for the women in CCWF and it helped attract further outside support for their cause. A few weeks after Ross' release, on 29th January, the California Coalition for Women Prisoners held their first demonstration at the gates of the prison to demand quality medical care for the women inside.

[502] Letter from James Gomez to Teena Farmon (Warden), October 28, 1993, box 5, fol. CCWF (4 of 11), Greenspan papers, LGBT Community Center.
[503] Flyer, "Send Betty Jo Ross Home for Christmas"; Letter from Mike Shriver, Executive Director of Mobilization Against AIDS to James Gomez, January 3, 1994, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[504] Greenspan, "Joann Walker," 2.

Over one hundred people from the Bay Area and central Californian organisations, including ACT UP/San Francisco, the San Francisco Lesbian Avengers, the San Francisco AIDS Foundation, and LSPC, picketed the prison to support the prisoners' four demands: "quality medical care for all women (including an HIV/AIDS medical specialist); high nutritional diets and vitamin supplements for HIV+ prisoners; the compassionate release for all prisoners with AIDS and other terminal illnesses; support the peer education programme and stop the censorship of AIDS education materials."[505] Protestors also read a solidarity statement from the women inside, asserting that "the release of Betty Jo Ross was a huge battle to be won. But the war is not over. We hope that you will continue to support us in the days ahead as we fight together for quality health care and a better life for women prisoners."[506] Greenspan sought the support of lesbian and gay groups, saying that "many of the women inside Chowchilla are lesbians—and many are lesbians of color who are fighting the worst forms of homophobia inside the prisons, compounded with the stigma of having HIV and AIDS."[507] She raised $800 to assist protestor travel to the demonstration from the organisation *Resist*.[508] Walker herself "wrote a lot of the media in this area, trying to get as much media coverage as we can," securing radio interviews and a one-page profile on her three days before the protest

[505] Joann Walker, "Letter from Chowchilla PWA," *Out of Control—Lesbian Committee to Support Women Political Prisoners*, Issue no. 21 (January 1994): 1, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[506] HIV+ Women Prisoners at Chowchilla, "Solidarity Statement from the Women at Chowchilla," January 29, 1994; Judi Parks, "Protest on Behalf of Women Prisoners with HIV this Saturday," *Bay Area Reporter*, January 27, 1994, 11, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[507] Judi Parks, "Protest on Behalf of Women Prisoners with HIV this Saturday," 11.
[508] Letter from Nancy Moniz for the Board of Resist to Judy Greenspan, January 28, 1994, box 5, fol. CCWF (4 of 11), Greenspan papers, LGBT Community Center.

in the *San Francisco Bay Guardian*.[509] Attorneys from the *Human Rights Watch* also interviewed her.[510]

In the wake of the protest, CCWF officials assured the press of the adequacy of their medical services. Toby Wong, the public information officer, dismissed the women's claims outright as "biased."[511] Wong headed a powerful public relations office at CCWF that often successfully discredited the women inside, resulting in editorials such as one published in the *Merced Sun-Star* criticising women in Chowchilla for demanding "better than standard care," an argument that authorities commonly used to dismiss prisoners' requests for humane treatment.[512]

The dismissive response to the women's demands from people like Wong jarred with the deaths of four more women in the space of a few weeks in early 1994.[513] In January, Sonja Staples died of pneumonia and other AIDS-related complications. Her cellmates had tried in vain for months to get her preventative care, but MTAs had refused to diagnose her as HIV-positive. Jackie Jenkins, another prisoner with AIDS, then became noticeably ill after working with pesticides on the prison's farm for nine months. Her cellmates had similarly tried to get Jenkins appropriate medical care inside prison, and officials moved her to an outside hospital just before she died from Kaposi's sarcoma and other AIDS-related

[509] Letter from Walker to Greenspan, January 19, 1994; Walker, "Letter from Chowchilla PWA"; Hanrahan, "To die in Chowchilla," 9; Parks, "Protest on Behalf of Women Prisoners with HIV this Saturday," 11; Robert R. Phipps, "Prison's medical care protested," *Merced Sun-Star*, January 29, 1994, A3; Robert R. Phipps, "Protesters will decry treatment of inmates," *Madera Tribune*, January 29-30, 1994, 1-2; Parks, "Activists Rally at Chowchilla for Better Prisoner Healthcare," *Bay Area Reporter*, February 3, 1994, 11, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[510] Letter from Joann Walker to Ellen M. Barry, April 14, 1994, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[511] Phipps, "Prison's medical care protested," 1-2.
[512] CSWPC, "Editorial Response to February 1 Opinion Page article," 1-2.
[513] Phipps, "Prison's medical care protested," 1-2.

illnesses.[514] Molly Reyes died one month later, on 25th February. After 50-year-old Reyes began throwing up blood and body tissue in her unit, it took over an hour for medical staff to respond to the officer calling for help and she died of an internal organ rupture four hours later in a make-shift infirmary.[515] These women's deaths were a stark reminder of how little care the women received.

Walker herself became seriously ill with severe headaches in March, but every time she visited the sick call, the staff sent her away with the ibuprofen drug Motrin.[516] In April, she began coughing up blood and staff sent her to the outside medical centre in Merced where doctors diagnosed her with fungal meningitis that had spread throughout her system. Following a three-week-long fax and phone campaign to both the Warden and Director of the Department of Corrections James Gomez, the prison granted Walker compassionate release. Two months later, on 13th July, she died of AIDS-related complications at her home in San Francisco.[517] After her death, Twillah Wallace wrote that "the struggle will not end because you are gone," and although Walker did not live long enough to see her efforts to improve the health care at CCWF realised, she was instrumental in focusing public attention on the situation inside the prison. Through her prolific writing on the situation inside CCWF she had become the key spokesperson for women prisoners with HIV and many of her articles captured outside media attention.[518] Her death, along with the deaths of Staples, Jenkins, and

[514] Joann Walker, "The Murder Plot Thickens," December 5, 1993, 1, box 5, fol. CCWF (4 of 11), Greenspan papers, LGBT Community Center.
[515] Joan Walker, "Dropping Like Flies," reprinted in Greenspan, "Struggle for Compassion: The Fight for Quality Care for Women with AIDS at Central California Women's Facility," *Yale Journal of Law & Feminism* 6 no. 2 (1993): 393.
[516] Catherine Campbell, "Interview with Joanne Walker on 4/22/94 in the Merced Community Hospital," 25 April 1994, 2-4, box 5, fol. CCWF, Greenspan papers, LGBT Community Centre.
[517] CCWP members, "Tribute to Joann Walker," *The Fire Inside*, Issue 1 (June 1996): 1, Greenspan papers, box 8, fol. 237; Miriam Berman, "Joann Walker, Prison Organizer, Granted Compassionate Release," undated, 1, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[518] Letter from Joan Walker to Judy Greenspan, December 22, 1993; Letter from Judy Greenspan to Joann Walker, July 1, 1993, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.

Reyes prompted outside activists and lawyers to call for immediate, impartial legislative investigations.[519]

A few months before Walker's death, in the spring of 1994, Greenspan had contacted Amnesty International and the US Department of Justice (DOJ) to inform them that CCWF was providing inadequate medical care and services to women prisoners with HIV and AIDS and other medical problems and to ask them to investigate the conditions at the prison.[520] She also sent articles and statements about the treatment of HIV-positive women to large media outlets such as the *San Francisco Chronicle* as "national coverage of this unique struggle, involving women prisoners organising on the inside and the Coalition demonstrating on the outside, is essential to save lives and win better health care for the women at Chowchilla."[521] A few months later, Arthur E. Peabody of the DOJ informed Greenspan of his office's intention to initiate an investigation of her allegations pursuant to Title II of the American's with Disabilities Act and Section 504 of the Rehabilitation Act of 1973 that prohibited discrimination against individuals with disabilities.[522]

DOJ investigators visited CCWF in August 1994 to begin interviewing women prisoners. In September, after two years of independent investigations, ACLU attorney Catherine Campbell believed that she and Dr Weinstein had gathered enough evidence to launch a

[519] Twillah Wallace, "A Tribute to Joann Walker, a Dear Friend," 1994, 1, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[520] Letter from Judy Greenspan to Amnesty Representative, March 31, 1994; Letter from Judy Greenspan to Richard Waters US Department of Justice, April 13, 1994, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[521] Letter from Greenspan to Susan Sward at the San Francisco Chronicle, March 22, 1994, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[522] Title II of the American's with Disabilities Act prohibited discrimination against qualified individuals with disabilities on the basis of disability by State and local governments. Section 504 of the Rehabilitation Act of 1973 prohibited discrimination against qualified individuals with disabilities on the basis of disability programmes or activities that received Federal financial assistance. AIDS counted as a disability. Letter from Arthur E. Peabody to Judy Greenspan, February 3, 1995, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.

major class action lawsuit against the CDCR. Within a year, Campbell, Elizabeth Alexander of the National Prison Project, Ellen Barry of the Legal Services for Prisoners with Children, and eight other attorneys filed a suit in the US District Court for the Eastern District of California against California prison officials on behalf of state prisoners and parolees who were under the custody and control of the CDCR. While lawyers, prisoner rights advocates, and politicians were already alert to the issue of HIV/AIDS in male prisons, the DOJ investigation and subsequent class action lawsuit marked a turning point in legal advocates using the medical mistreatment of women prisoners with HIV and AIDS to consider the inhumanity of the prison system especially toward women.[523]

From the Cell to the Court

The eleven attorneys' efforts to challenge the egregious health care in California's women's prisons built upon the work of earlier civil rights lawyers who from the late 1960s onwards began suing prison systems in the federal courts and arguing that prison conditions across the nation violated the Eighth Amendment's prohibition against cruel and unusual punishment.[524] In 1972, the ACLU established the National Prison Project to defend the civil and constitutional rights of prisoners.[525] In the 1976 case *Estelle v. Gamble*, the US Supreme Court had ruled that jails and prisons had a constitutional obligation to provide health care to those in custody:

[523] Letter from Judy Greenspan to Judith M. Dodd, June 29, 1994; Letter from Judy Greenspan to Twillah Wallace, June 10, 1994, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[524] Hill, "Death Through Administrative Indifference," 231.
[525] ACLU National Prison Project, accessed February 2020, https://www.aclu.org/other/aclu-national-prison-project

> Deliberate indifference to serious medical needs of prisoners constitutes the unnecessary and wanton infliction of pain…proscribed by the Eighth Amendment. This is true whether the indifference is manifested by prison doctors in their response to the prisoner's needs or by prison guards in intentionally denying or delaying access to medical care or intentionally interfering with the treatment once prescribed.[526]

The women's numerous claims that the state had endangered them by, among other things, limiting sick calls, using unqualified medical personnel, denying medical care based on cost, and failing to provide appropriate chronic care management appeared to put the California prison officials in violation of this ruling. However, in order to prove that the officials had violated the constitution, the law placed a burden on women to prove that the deprivation alleged was sufficiently serious, and that the officials had acted with deliberate indifference to an inmate's health and safety.[527]

On 4th April 1995, twenty-six inmates at CCWF in Chowchilla, along with the California Institute for Women (CIW) in Frontera, California, filed their class action lawsuit in the US District Court for the Eastern District of California. US District Judge William B. Shubb presided over the lawsuit, and the numerous list of defendants included—most notably—Pete Wilson, the Governor of California, as well as the California Director of Finance, the Secretary of Youth and Adult Correctional Agency, the Director of the California Department of Corrections (CDC), and the Deputy Director for Health Care Services for the Department of Corrections.[528]

---

[526] Estelle v. Gamble, 429 U.S. 97 (1976): 104-105, accessed February 2020, http://cdn.loc.gov/service/ll/usrep/usrep429/usrep429097/usrep429097.pdf
[527] Mike McKee, "State Settles Suit Over Prison Medical Care," *The Recorder*, No. 146, July 30, 1997, 2, box 8, fol. Shumate files @ UCSF, Stoller papers, UCSF.
[528] Charisse Shumate v. Pete Wilson, 95-619, (E.D. Cal., 1995), accessed February 2020, https://www.clearinghouse.net/detail.php?id=582

The plaintiffs were not seeking money, but structural reform of the prison systems' "knowing and deliberately indifferent failure to provide necessary care for serious medical needs" as well as relief to remedy alleged "policies, practices, acts, and omissions evidencing and constituting deliberate indifference to the rights of prisoners and violating the Cruel and Unusual Punishment Clause of the Eighth Amendment."[529] Attorneys chose Charisse Shumate as the lead plaintiff, and in the ensuing case, *Shumate v. Wilson*, the complaint alleged that defendants supplied inadequate sick calls, triage, emergency care, nurses, urgent care, chronic care, speciality referrals, medical screenings, follow-up care, examinations and tests, medical equipment, medications, speciality diets, terminal care, health education, dental care, and grievance procedures, and that the provision of medical care featured unreasonable delays and disruptions in medications.[530] Although the suit focused on two women's prisons—CCWF and CIW—Nina Siegal of the San Francisco *Bay Area* found that "many of the problems alleged in the suit (and confirmed by various independent organisations) result from systemic problems built into the health care delivery system in women's prisons" following a nine-month investigation.[531]

During the 1980s, as HIV and AIDS spread throughout the national prisoner population, the ACLU began challenging inadequate medical care for prisoners living with the virus, as well as their forced segregation, and exclusion from jobs, and other prison programmes. The organisation filed a number of lawsuits on behalf of male prisoners against various State Departments of Corrections in an effort to challenge the policies and practices pertaining to the care, custody, and confidentiality issues of inmates with AIDS, AIDS-Related Complex

[529] Charisse Shumate et al., Plaintiffs, v. Pete Wilson, et al., Defendants. Class Action Complaint (April 4, 1995), 18, accessed February 2020, https://www.clearinghouse.net/chDocs/public/PC-CA-0011-0001.pdf
[530] Shumate et al., Plaintiffs, v. Wilson, et al., Defendants. Class Action Complaint (April 4, 1995), 1-18.
[531] Nina Siegal, "Dying Behind Bars," 17.

(ARC), or HIV infections.[532] Because these suits predominantly involved male prisoners, the settlements frequently failed to address the distinct needs of women living with HIV in prison.

Around the same time that the women at CCWF and CIW filed their lawsuit, ten male California prisoners filed a complaint similarly alleging that the CDCR's inadequate medical care system violated the Cruel and Unusual Punishment Clause of the Eighth Amendment, as well as the Americans with Disabilities Act and section 504 of the Rehabilitation Act. As attorneys had named no woman as a plaintiff in the case, the CDCR were able to exclude provisions for pregnancy-related and gynaecological care and breast and cervical cancer in the settlement agreement.[533] In contrast, the class action lawsuit that Campbell of the ACLU, Elizabeth Alexander of the National Prison Project, Ellen Barry of the Legal Services for Prisoners with Children, and eight other attorneys brought on behalf of California's women prisoners in 1995 was therefore critical in bringing into question the basic healthcare rights of women prisoners with HIV and AIDS in this decade.

As *Shumate* progressed, Greenspan and the CCWP believed that "nothing will change unless we keep up a high level of public protest and scrutiny," they held regular protests outside CCWF and CIW, the California Department of Corrections in San Francisco, and the

[532] Class action lawsuits included: Gates v. Deukmejian, 1987 (Cal.), Doe v. Meachum, 1988 (Conn.), Harrvis v. Thigpen, 1990 (Al.), Austin v. Pennsylvania Dept of Corrections, 1990 (Pa.) ACLU AIDS Project, Docket (October 1991) "each month, the AIDS Project's staff assistants handle more than 100 HIV-related requests. This year (1991), we have received more than 200 requests for information about the Americans with Disabilities Act alone." All involved male prisoners. Resource in Subject file: AIDS, LHA.

[533] According to an objection brief filed by Legal Services for Prisoners with Children, the settlement agreement failed to provide adequate standards for pregnancy-related care, health assessments and follow-up treatments for breast and cervical cancer, gynaecological problems, health conditions related to surviving sexual, mental or physical abuse, annual pap smears, especially for women with HIV, and testing for the virus linked to cervical cancer. Plata v. Davis, 329 F.3d 1101 (9th Cir. 2003): 2-20, accessed February 2020, https://casetext.com/case/plata-v-davis

Sacramento Federal Courthouse.[534] Dorsey Nunn and Karen Shain of the Legal Services for Prisoners with Children told Greenspan that "lawsuits are not only fought in courtrooms, they are also fought in the public eye, through the media," and, aware of the importance of the continued support and involvement of community organisations, groups, and individuals, Greenspan helped the women at CCWF launch *The Fire Inside*, a quarterly newsletter that publicised women's perspectives and experiences of the prison.[535]

The women gained support from several other women's and prisoners' rights groups who saw the mistreatment of women with HIV/AIDS in CCWF as evidence of the inhumanity of the entire US prison system. As two activists who protested outside Chowchilla in 1996 wrote for *The Fire Inside*:

> We want to stop the rage to punish, which appears in…the incredible growth of the number of prisoners. Most importantly, we want to show that just because 'they' put ever more women in prison does not mean that we forgot about them. Our signs and banners carried the names of women who died in prison and our demands for medical care, rehabilitation, drug treatment and educational opportunities instead of more resources for prison construction.[536]

Another writer used the mistreatment of women on death row at CCWF to critique the wider operation of capital punishment in the country, writing that "we need to increase the visibility

[534] CCWP members, "Women Sue for Healthcare," *The Fire Inside*, Issue 1 (June 1996): 3, box 8, fol. 237; Judy Greenspan, "Women Campaign for Better Medical Care," *The Fire Inside*, Issue 4 (May 1997): 4, box 8, fol. 237, Greenspan papers, LGBT Community Center.
[535] Letter from Dorsey Nunn and Karen Shain to Judy Greenspan, March 14, 1995, box 5, fol. CCWF; Letter from Judy Greenspan to Lynn McCoy, November 30, 1997, box 9, fol. 280, Greenspan papers, LGBT Community Center.
[536] Urszula Wislanka and Dana Ryan, "'We Love You Sisters Inside'—CWWP Protest in Chowchilla," *The Fire Inside*, Issue 2 (September 1996): 1, box 8, fol. 237, Greenspan papers, LGBT Community Center.

of the women on death row as part of the battle against the death penalty," tying disparities in sentencing, including who gets sentenced to death, to racism and violence against women.[537] Evidence of the mobilising capabilities of the coalition to support women in Chowchilla, in the May 1997 edition of *The Fire Inside*, Assata Shakur, former member of the Black Liberation Army and political prisoner who in 1979 had escaped from the Clinton Correctional Facility for Women in New Jersey and was living in Cuba, was pictured wearing a CCWP tee shirt in support of the women.[538] Other support came from Women Organised to Respond to Life-Threatening Diseases, California Prison Focus, Abolition Road, LSPC, Women's Positive Legal Action Network, Justice Now (Justice Network on Women), the Lesbian Avengers, and ACT UP.

While activists continued to show up for women prisoners on the outside, on the inside CCWF officials threatened the *Shumate* plaintiffs with retaliatory treatment. Shumate claimed that officials labelled her a troublemaker for her involvement in the trial and that she had agreed to be the lead plaintiff "knowing the risk could mean my life in more ways than one." As the lead plaintiff, her complaint was the first brought against the CDCR, which described how the "defendants have periodically delayed and interrupted her medication and have denied her a medically necessary special diet" for her "sickle cell anaemia, heart problems, pulmonary hypertension and asthma."[539] Despite the threat of reprisal, Shumate also stated that she would "do it all over again. If I can save one life from the medical nightmare at CCWF Medical Department then it's well worth it."[540] Staff similarly warned

[537] Editorial, "Death Penalty is Wrong," *The Fire Inside*, Issue 4 (May 1997): 6, box 8, fol. 237, Greenspan papers, LGBT Community Center.
[538] In *The Fire Inside*, Issue 4 (May 1997): 6, box 8, fol. 237, Greenspan papers, LGBT Community Center.
[539] Shumate et al., Plaintiffs, v. Wilson, et al., Defendants. Class Action Complaint (April 4, 1995), 2.
[540] Charisse Shumate, "The Battle Must Go On," *The Fire Inside*, Issue 4 (May 1997): 1; Charissa Shumate, "The Pros and Cons of Being a Lead Plaintiff," *The Fire Inside*, Issue 6 (December 1997): 2, box 8, fol. 237, Greenspan papers, LGBT Community Center.

Marcia Bunney, a *Shumate* plaintiff who had also helped start Members of Convicted Women Against Abuse (CWAA), a support group for battered women at the prison, that continuing her legal activities would cost her any chance of obtaining a parole date.[541] Possibly to avoid such threats, two HIV-positive plaintiffs brought their complaint anonymously as Jane Doe I and Jane Doe II. The total of twenty-six complaints chronicled the systemic medical abuse and neglect at both women's prisons.

On 11th August 1997, in what was initially celebrated as a "win" for the women, after two years of litigation and negotiation, the CDCR agreed to a court-approved settlement.[542] They pledged to bar untrained prison employees (MTAs) from making judgements about prisoners' medical care, that their prisons would provide medicines without undue lapses or delays, and that medical staff would offer preventative care, including pelvic and breast exams, pap smears, and mammograms.[543] The settlement also included provisions for maintaining the confidentiality of inmates who had HIV, which meant stopping peer counsellors offering HIV tests to inmates.[544] A number of women at CCWF wrote to Greenspan concerned that this measure would "wipe the peer counselling programme out. Peer counsellors won't even be able to sign an inmate up to test. That's 98% of our jobs right now. With that restriction, CCWF will do what it has wanted to do for so long and either wipe the programme out altogether or drop it to one or two peers."[545] Greenspan admitted that she too was "deeply concerned about not only the confidentiality provisions but the entire outcome of all of our hard work."[546] Another inmate wrote to Judge William B. Shubb to inform him that "the

[541] Law, *Resistance Behind Bars*, 9.
[542] Karen Shain, "Women Prisoners Win Shumate Case!"
[543] Charisse Shumate et al., Plaintiffs, v. Pete Wilson, et al., Defendants. Settlement Agreement (August 11, 1997), 2-18, accessed February 2020, https://www.clearinghouse.net/chDocs/public/PC-CA-0011-0004.pdf
[544] Shumate et al., Plaintiffs, v. Wilson, et al., Defendants. Settlement Agreement (August 11, 1997), 17.
[545] Letter from McCoy to Greenspan, August 11, 1997, 1-2, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[546] Letter from Greenspan to McCoy, November 30, 1997, box 9, fol. 280, Greenspan papers, LGBT Community Center.

wording of the settlement has done a magnitude of damage" and imploring him to please not "allow them to tie our hands or set the program back in our efforts to help women inmates."[547] Foreshadowing the struggles to come, Maria Bunney also expressed being "saddened by the knowledge that [prison officials] will never live up to this agreement, and I wonder how many women will have to die here before they make a change."[548] On 22nd December 1997, despite the women's concerns, Judge Shubb approved the settlement and dismissed the case.[549]

Under the terms of the *Shumate* settlement, the CDCR agreed to allow an independent court-appointed team of five medical experts to monitor the prison's compliance for two eight-month periods. The initial report in November 1998 revealed that the facilities did not adhere to state standards in eleven key medical areas. Although the CDCR failed the first assessment, the final report that independent assessors issued in December 1999 stated that CIW and CCWF substantially complied with the *Shumate* settlement terms, meeting the criteria of most of the parties' settlement provisions. Because the CDCR passed the second assessment, they requested unconditional dismissal of the case. While the medical care at these institutions did initially appear to improve, a series of scandals in 2000, including delays in treatment, sham medical test results, and accusations of administrators tampering medical records, called these improvements into question. These incidents drove the prisoners' attorneys to submit a motion to the court to reopen the case. Judge Shubb denied

[547] Letter from Beatrice Smith-Dyes to Judge Shubb, August 12, 1997, 3, box 9, fol. 280, Greenspan papers, LGBT Community Center.
[548] Karen Shain, "Women Prisoners Win Shumate Case!"
[549] The total 56 settlement provisions included medical screening, privacy of medical information at screening; forms for release of information to outside providers; continuity of medications; special medical diets; social workers for the terminally ill; staff training for mental care; training regarding HIV confidentiality; and pill lines and confidentiality. Shumate v. Wilson, 95-619, (E.D. Cal., 1995).

the motion and dismissed *Shumate* with prejudice, meaning that the plaintiffs could never bring it again. The case was closed in August 2000.[550]

As the suit itself did not force the CDCR to substantially improve its provision of medical care in its women's prisons, the women and their advocates continued to pursue legal redress of the ongoing medical abuse at these facilities. Two months after the *Shumate* dismissal, on 11th and 12th October 2000, State Senator Richard Polanco (D-Los Angeles), Chair of the Joint Subcommittee on Prison Construction and Operations, led a two-day Joint Legislative Committee on Prison Construction and Operations hearing into prison conditions at two of California's women's prisons, CCWF and VSPW. During the hearing, fifteen women prisoners from CCWF and VSPW, as well as CIW, including Charisse Shumate and other *Shumate* plaintiffs, each spoke to the daily medical malpractice that the women in those facilities experienced. Three accounts drew attention to the prison policy of not informing women who tested positive for Hepatitis C. As a prisoner co-infected with HIV and Hepatitis C, Judy Ricci, who earned the nickname Dr Juju for teaching herself about both diseases and then educating others at CCWF, described the end-stage liver disease of a fellow co-infected inmate who had died the previous month:

> The first woman that died on September 6, 1999, I had seen this woman running around for months. She had pieces of Tampax and Kleenex stuffed up in her nose to stop the flow of blood. Her stomach (she was a little skinny woman) looked like a basketball…Her eyes were literally the color of a pumpkin. I had never approached

[550] In response to an increase in prisoner litigation in the federal courts in this period, Congress passed the 1996 Prison Litigation Reform Act that prevented lawyers from bringing a new suit for injunctive relief for prisoners in the federal court. Charisse Shumate, et al., Plaintiffs, v. Pete Wilson, et al., Defendants. Order of Dismissal (August 21, 2000), 1-3, accessed February 2020, https://www.clearinghouse.net/chDocs/public/PC-CA-0011-0008.pdf

> this woman, because while I knew what she had…I didn't want to break her confidentiality and I didn't want to offend her. But I couldn't help asking her, 'Do you need some help?'...As a person who was informed, I could see and I knew what was happening to her, and it hurt that much worse, but anybody, even an untrained eye, could see that she was going to die. How did they release her from the hospital in this condition?[551]

The women also described the lack of counselling and information provided to women with chronic illnesses and the steps they had taken to fill these gaps. In addition, they spoke of sexual abuse and the administration's retaliatory actions against the women who participated in *Shumate*, knowing that after the hearings they would return to prison where, out of public sight, they risked similar reprisal. What State Senator Cathie Wright (R-Simi Valley) heard over the course of those two days had "curdled [her] stomach," and the hearing concluded with lawmakers promising a follow-up study and recommendations, and the US District Court in Sacramento agreeing to ratify a legal settlement in December.[552] Despite their involvement in the hearing, the legal settlement did not cover VSPW, the second largest prison across the road from CCWF.[553]

Women continued to die in California's prisons despite this legal settlement reached on behalf of 5,000 women. *Shumate* plaintiff Brenda Otto died less than a month after attorneys filed the suit. She had suffered three strokes and staff denied her treatment in the infirmary.[554]

---

[551] Judy Ricci testimonial reprinted in Judy Greenspan, "Positive Women Prisoners Speak Out," *Positively Aware: The Journal of Test Positive Aware Network*, July/August 2001, 18, box 8, fol. 247, Greenspan papers, LGBT Community Center.
[552] Sabin Russell, "State Probing 5 Recent Deaths of Female Inmates at Chowchilla," *San Francisco Chronicle*, December 13, 2000, 1, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[553] Katie Szymanski, "Medical conditions worsen inside state prison for women," *Bay Area Reporter*, December 14, 2000, 3, box 5, fol. CCWF, Greenspan papers, LGBT Community Center.
[554] CCWP members, "Women Sue for Healthcare," *The Fire Inside*, Issue 1 (June 1996): 1-2, box 8, fol. 237, Greenspan papers, LGBT Community Center.

When Carolina Paredes entered CCWF in August 1999, she requested medical attention for abdominal pains. Medics gave her a pelvic exam but did not diagnose her with uterine cancer until October. The six cycles of chemotherapy that Paredes needed were continually interrupted because prison staff failed to transfer the required bloodwork and chemotherapy drugs with Paredes during her chemotherapy visits. In May 2000, doctors gave her a terminal diagnosis of six months or less. She died alone, on 14th December 2000, just over a year after entering the prison.[555] The neglect leading to Paredes' death was not an anomaly. Seven more women died between November and December three of whom had HIV. A total of sixteen women died at CCWF in 2000, nine women having died in 1999 and ten in 1998.

These women's deaths drew renewed public attention to the situation inside the prison.[556] Amnesty International maintained that an "independent investigation into the deaths at California prison [was] urgently needed."[557] The seven deaths in December 2000 persuaded CDCR officials to allow another independent team of medical doctors to review the women's records, but their actions were not enough to prevent another eight women, including Twillah Wallace, to die in a seven-week period in 2001.[558] Shumate also died at CCWF on 4th August 2001.[559] The Board of Prison Terms had recommended clemency for Shumate rather than

[555] Silja J.A. Talvi, "Eight Prisoner Deaths in California Women's Prison," *Prison Legal News*, May 15, 2001, accessed February 2020, https://www.prisonlegalnews.org/news/2001/may/15/eight-prisoner-deaths-in-california-womens-prison/
[556] Jim Davis, "3 prison deaths questioned: An independent inquiry is sought at Chowchilla facility," *The Frenso Bee*, December 20, 2000, 5; Eric Baily, "Deaths of Women in State Prison Probed," *Los Angeles Times*, December 20, 2000, A5; Sabin Russell, "State Probing 5 Recent Deaths of Female Inmates at Chowchilla," 1; Russell, "Two More Die at Women's Prison in Chowchilla: Three of Seven Recent Deaths Under Investigation," *S.F. Chronicle*, December 20, 2000, box 5, fol. CCWF (4 of 11), Greenspan papers, LGBT Community Center.
[557] Amnesty International Press Release, "USA: Independent investigation into deaths at California prison urgently needed," December 2000, 1; According to Lauren Leslie from the Legal Services for Prisoners with Children, the CDC decided to bring in an outside medical group "because of the pressure we brought on them." Box 5, fol. CCWF (4 of 11), Greenspan papers, LGBT Community Center.
[558] Dr. Kathleen Clonan, a professor at University of California at San Francisco medical school and a member of the independent review team, reported that the deaths of three of these women remained unexplained. Russell, "State Probing 5 Recent Deaths of Female Inmates at Chowchilla," 1; Russell, "Two More Die at Women's Prison in Chowchilla," box 5, fol. CCWF (4 of 11), Greenspan papers, LGBT Community Center.
[559] CCWP History, accessed February 2020, http://www.womenprisoners.org/resources/ccwp_history.html

compassionate release which required the governor's approval. Because a judge had sentenced her to life in prison for killing her abusive partner, then-Governor Gray Davis refused to approve the Board's recommendation, and she died, isolated from wider society, in prison.[560]

Similar to other women, Shumate had suffered from mistreatment at the hands of mostly male prison guards and officials who refused to take her healthcare needs seriously. She had also suffered as a consequence of living in a scaled-up prison system that had failed to prepare for her chronic health needs. The efforts of Shumate and her peers to access efficient and humane treatment in prison was striking given how much was against them. Nonetheless, the actions on the part of prison officials to quash their protests were matched by the efforts of women to get their stories out. As prison guards frequently dismissed women's complaints and punished those who agitated for change, women believed that securing outside recognition and support was the best chance they had to hold the prison system accountable for medical neglect and other acts of mistreatment. After a remarkable five-year legal battle, their deaths at the hands of a failed carceral system also highlighted what little power women had to effect change.

Conclusion

As this chapter has demonstrated, women could not protect themselves from the threat of HIV with education alone. Instead, the mistreatment and suffering of women with HIV and AIDS in women's prison in the 1990s and early 2000s showed the stakes of what happened

[560] Cassie M. Pierson, *Memorial for Charisse Shumate*, spoken at the First Unitarian Church, San Francisco, CA, September 23, 2001, quoted in Law, *Resistance Behind Bars*, 40; CCWP, "Charisse Shumate, A Warrior, a Friend, an Inspiration," *The Fire Inside*, Issue 19 (Fall 2001): 1, box 2, fol. Newsletters/Publications, Stoller papers, UCSF.

when the system failed, resulting in misdiagnosis and frequent death. The expanding carceral state in the late twentieth century was ill prepared to deal with women's chronic and reproductive healthcare needs, and the prison support groups that women set up within correctional facilities in this period were radical in making space for women in a system built for men. Much of what the women at the CCWF achieved in prompting regulatory investigations and bringing a court case against the CDCR came both from the alliances they built within the prison through prison support groups and the connections they made with advocates through reaching out. The efforts of the CCWP and other advocate organisations also did not end with *Shumate* and the subsequent hearings. They continued and expanded their work, regularly visiting and corresponding with women at CCWF and CIW, advocating for compassionate release for women with terminal illnesses, and raising public awareness about the specific issues facing women in prison.[561] The steps women in prison and their advocates took to challenge the conditions of their confinement were pivotal in raising public awareness of the inhumanity of the carceral state, especially toward women with HIV and AIDS, at the turn of the twenty-first century.

Following *Shumate*, the advocates who had worked on the trial wanted to use the data collected as part of the lawsuit in order to publicise the conditions at CIW and CCWF and provide an analysis of the sources of health and illness in the state system, including the role of conditions in the system, such as overcrowding and understaffing, and the role of health care services, such as delays in screening and lack of access to specialists. They said that "the object of the analysis of the data has to be to go beyond what is known for the lawsuit."[562] They did not want all the hard work that they had already done—compiling medical records,

[561] For more on their ongoing work, see California Coalition for Women Prisoners, accessed February 2020, http://womenprisoners.org/about/000085.html

[562] "Research Plan: Analysis of data collected in Shumate," September 11, 1998, 1, box 8, fol. Calif. grant/state. Stoller papers, UCSF.

interviews, witness summaries, monitoring reports—to go to waste. Instead, they hoped it would help to not only challenge the egregious damage done to specific women because the system was not working or sometimes worked inadequately, but the suffering that occurred as an intended part of an inhumane, ramped up carceral state.

Twenty years later, through legislation such as the First Step Act of 2018, criminal justice advocates are seeing some political gains in their efforts to make federal and state prison systems more humane for the millions of Americans behind bars, including women with chronic and reproductive health illnesses such as HIV.[563] Despite this progress, the medical abuses currently being carried out against an unknown number of women held in immigration detention centres make the need for a more humane approach to imprisonment ever the more urgent.[564] As was the case for women dealing with reproductive and chronic illnesses in the previous decades, accessing treatment remains a central problem for women living within the criminal justice system in the United States.

Chapter five shows that, whether in or out of prison, women with HIV have had to navigate a healthcare system that is made and modelled for men. As the activism of the women in this and the next chapter attest to, women continued to suffer from, and struggle against, gendered treatment issues to do with living with HIV after the 1996 introduction of anti-retroviral therapy (ART). With new and highly effective drugs now available, overcoming the economic and power obstacles of access to medication marked the next evolution in women's

[563] The act, among other things, restricts the use of restraints on pregnant women, expands compassionate release for terminally ill patients, places prisoners closer to family in some instances, and improves feminine hygiene in prison. Anjana Samant, "The First Step Act is a Small Step for Incarcerated Women," December 27, 2018, accessed February 2020, https://www.aclu.org/blog/prisoners-rights/women-prison/first-step-act-small-step-incarcerated-women

[564] Isabela Dias, "When ICE Emptied Out an All-Women Detention Center in Texas, Chaos Ensued," *Texas Observer*, November 6, 2019, https://www.texasobserver.org/ice-karnes-all-women-detention/

fight against AIDS. As well as working to expand women's access to available medicine, women have also fought to get women's healthcare needs on the latest HIV prevention agenda. In the twenty-first century, in a radically new treatment era, many of the new ways of dealing with old problems continued to perpetuate gender inequities.

***

Chapter Five

The Fight to End AIDS, 1996-2020

In 2009, University of California, Irvine (UCI) law professor Jane K. Stoever published a paper on her work with victims and survivors of domestic violence. In it, she detailed the numerous threats and physical violence levelled against women who have attempted to negotiate condom use in the context of HIV/AIDS. One woman's request that her partner use a condom was met with accusations of infidelity and threats to her life. She reported that it "was easier to engage in unprotected sex" with her husband than to insist on condom use, despite knowing that he used drugs and suspecting that he had concurrent sexual partners. Another woman, who was already living with HIV, described how her boyfriend had interfered with her treatment, flushing her medication down the toilet while saying, "You're going to die anyway."[565]

Despite the remarkable developments in treatment of HIV since the 1980s, these women's testimonies speak to the reality that as the threat of contracting HIV has remained, the onus of prevention still frequently falls to women, even when the power is against them and even when the delivery systems are designed for men.[566]

The testimonies also highlight the ongoing challenges women have faced in obtaining access to regular care. The new drugs were only as effective in managing HIV as people's ability to

[565] The identities of the women mentioned in the report were anonymised. Jane K. Stoever, "Stories Absent from the Courtroom: Responding to Domestic Violence in the Context of HIV and AIDS," *North Carolina Law Review*, 87 N.C.L. Rev. 1157 (May 2009): 1170, 1175.

[566] Following the introduction of highly active antiretroviral therapy, AIDS diagnoses and deaths declined substantially from 1995 to 1998 and remained stable from 1999 to 2008, at an average of 38,279 AIDS diagnoses and 17,489 deaths per year, respectively. CDC, "HIV Surveillance—United States, 1981-2008," *MMWR* 60, no. 21 (June 3, 2011): 689. For more on the estimated number of AIDS diagnoses and deaths, and estimated number of persons living with AIDS diagnosis, and living with diagnosed or undiagnosed HIV infection, see the graph on page 691.

take them, and one of the main challenges women face in managing HIV as a chronic condition is compliance with therapeutic regimens. Moreover, if someone takes HIV medication inconsistently, the virus may come back adapted to that medication, meaning it may not work again. In addition to the potential threat of partner interference, taking antiretroviral drugs regularly is particularly challenging for women who frequently experience severe side effects as recommendations for dosages are still based on clinical trials that predominantly involved men. Certain HIV medications are six to eight times more likely to cause an adverse drug reaction in women, and HIV medicines can interfere with a woman's hormonal birth control.[567]

The fact that the medical community's understanding of the safety and effectiveness of HIV medicine is still based on research done on men speaks to the persistent, historical gender bias in biomedical research.[568] The clinical trial GRACE, which stands for Gender, Race, and Clinical Experience, was the first trial specifically designed to determine differences in HIV drug effectiveness, safety, and side effects between men and women and it did not begin until 2006—more than three decades into the epidemic. In 1993, following pressure from activists and advocates, the US government passed the National Institute of Health Revitalization Act that made it illegal not to include women and racial and ethnic minorities in federally funded clinical trials.[569] Despite changes in regulation, factors ranging from distrust of the medical establishment to a lack of support meant that researchers failed to recruit many women in subsequent HIV studies. A 2016 study found that the exclusion of women in US HIV

[567] Heather P. Whitley and Wesley Lindsey, "Sex-Based Differences in Drug Activity," *American Family Physician* 80, no. 11 (December 2009): 1254-8, accessed February 2020, available at: https://www.aafp.org/afp/2009/1201/p1254.html; Anna Medaris Miller, "What It's Like to Be a Woman With HIV," *U.S. News*, March 10, 2015, accessed February 2020, https://health.usnews.com/health-news/patient-advice/articles/2015/03/10/what-its-like-to-be-a-woman-with-hiv
[568] Perez, *Invisible Women*, 201.
[569] Katherine A. Liu and Natalie A. Dipietro Mager, "Women's involvement in clinical trials: historical perspective and future implications," *Pharmacy Practice* 14, no. 1 (2016): 708, accessed February 2020, available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4800017/

research is such that women make up only 19.2 percent of participants in antiretroviral studies, 38.1 percent in vaccination studies, and 11.1 percent in studies to find a cure.[570] As a result of the chronic under-representation of women in HIV research, doctors still know less about how HIV and HIV drugs act differently in women's bodies and the issues that might affect women's interest in or ability to adhere to medication.[571]

Gendered problems similarly persisted in the research and development for new prevention treatments. In the mid-1990s, following the escalating evidence of women's vulnerability to HIV—both biologically and socially—activists from the fields of women's health, contraceptive research and development, and HIV/AIDS called for prevention options that would remove the onus of condom negotiation for women.[572] Despite the medical community's initial enthusiasm for a woman-controlled and initiated prevention tool, no such product has come to market. As scientists intended for the woman-initiated product to be as cheap as possible and used only before sex, drug manufacturing companies believed it had less potential to make profit than pills taken daily. As a result, private investors were less interested in underwriting the medical research, meaning that promising products have stalled due to a lack of corporate money to take them forward.

---

[570] Lisa Rapaport, "Women are missing from HIV drug trials," *Reuters*, October 2, 2015, accessed February 2020, https://in.reuters.com/article/us-health-hiv-women-idINKCN0RW2E520151002; Henry J. Kaiser Family Foundation, "Women and HIV/AIDS in the United States," March 6, 2014, accessed February 2020, https://www.kff.org/hivaids/fact-sheet/women-and-hivaids-in-the-united-states/

[571] For more information on the GRACE trial and the reasons why so few women participate in trials in general see, The Well Project, "Lessons from GRACE: A US Study Focused on Women Living with HIV," March 20, 2019, accessed February 2020, https://www.thewellproject.org/hiv-information/lessons-grace-us-study-focused-women-living-hiv

[572] Steve Sternberg, "Methods of Preventing AIDS," *Miami Times*, August 23, 2006. Biological factors that make women more susceptible to heterosexual transmission of the virus include the concentration of vulnerable cells in the cervix, prolonged exposure to semen during intercourse, and the presence of asymptomatic STDs. Women are twice as likely to acquire HIV during heterosexual vaginal intercourse without condoms than their male partners, and young women (10-24 years old) are twice as likely to acquire HIV as young men the same age. Social factors that make women more vulnerable to infection include unfaithful partners, being forced into sex, and reliance on sex work for income. See CDC, "HIV Risk Behaviors," last updated 13 November 2019, accessed February 2020, https://www.cdc.gov/hiv/pdf/risk/estimates/cdc-hiv-risk-behaviors.pdf; Avert, "Women and Girls, HIV and AIDS," last updated October 10, 2019, accessed February 2020, https://www.avert.org/professionals/hiv-social-issues/key-affected-populations/women#footnote2_r14af4d

The prevention tools that did make it to market were new treatments, but with old problems. Women were under-represented in the medical research and development for the new drugs, and the cultural messaging around their promotion gave the impression that researchers had designed them solely for men. Compounding the research and advertising that associated the new prevention tools with male sexuality and health, the recent efforts on the part of the Trump administration to repeal the Obama-era Patient Protection and Affordable Care Act (ACA) and the political right to close the not-for-profit health spaces that women receive information and regular, preventative treatment from, put available prevention options further beyond the reach of women with real public health effects.

The first section of this chapter begins in the mid-1990s, examining the efforts of women's health advocates to bring to market a woman-controlled and initiated prevention tool. In section two, I show that as these products have stalled due to a lack of money to take them forward, advocates have instead worked to prepare women for the tools that did make it to market, but whose design and advertising implied they were for men. In section three, I explore how government efforts to reverse ACA and reform the Title X programme put available prevention options further beyond the reach of women; a situation which is compounded by the particularities of US health and regulation. Section four addresses how a range of activists are currently seeking to confront those particularities for the sake of widening people's access to life-saving treatment.

The efforts on the part of feminist scientists and health advocates to put women's healthcare needs on the HIV prevention agenda in the twenty-first century is in many ways women's response to the AIDS epidemic as seen through the previous generation, only now, the target

is different, and the medical context for women's activism has shifted. Not struggling to change the actions of a particular group or individual, women have more recently addressed the persistent economic and power issues in a changed treatment situation. Specifically, building on the efforts of the feminist healthcare movement that sought to make healthcare more equitable and earlier AIDS activism that sought to broaden access to treatment and services, women have addressed the challenge of women not being able to afford drugs because of the deregulated pharmaceutical industry, and women not having control because the health delivery systems are not made for them.[573] Their efforts to do so does not comprise a concerted campaign but involves many different voices, offering a different perspective on how activism works.

In the Hands of Women

The mood at the 11th International AIDS Conference in Vancouver in 1996 felt hopeful for the first time in a long time. Since the inaugural meeting in Atlanta in 1985, the AIDS conference has served as the major international forum for exchanging scientific information about HIV/AIDS, providing a setting for activists and members of the public health community to address the latest challenges that the epidemic posed to people's health and rights. After years of searching for a vaccine, cure, or any way to prolong the lives of people infected with HIV, in 1996 scientists at the Vancouver conference reported on the breakthrough news that combinations of new drugs, called protease inhibitors, had allowed

[573] For more on earlier AIDS healthcare activism, especially over drug testing and widening access to the healthcare system for persons with HIV and AIDS, see Epstein, *Impure Science*, esp. chap. 6, 208-235; Peter Cohen, "Acting UP: AIDS and the Politics of Class" in *Love and Anger: Essays on AIDS, Activism, and Politics* (New York: Routledge, c. 1993, 2013), 28-43; France, *How to Survive a Plague*, 325-326, 344; Hobson, *Lavender and Red*, esp. chap. 6, 155-187; Bell, "Rethinking the 'Straight State,'" *Journal of American History*, 931-952; Bell, "Between Public and Private" *Journal of American Studies*, 159-183. For more on the aims of the feminist healthcare movement, see Jane Pincus and Joan Ditzion, "Preface/Introduction to 1984 Edition," in *New Our Bodies, Ourselves*, ed. BWHBC, 13-16; Rosen, *The World Split Open*, 175-181; Morgen, *Into Our Own Hands*; Kline, *Bodies of Knowledge*.

people with HIV to leave their sickbeds and for the first time return to their pre-diagnosis lives.[574] With the advent of protease inhibitors in the mid-1990s, tackling HIV increasingly became about the prevention of a chronic, manageable illness.

The optimism felt at the Vancouver meeting did not last into the next conference in Geneva two years later. Several scientists spoke of disappointing results of tests of once promising vaccines.[575] Developing an effective vaccine was so challenging because the HIV virus mutates frequently and replicates as soon as it enters the body—up to 1,000 times as fast as a typical influenza virus.[576] Adding to the dampened mood, some experts explained that even though protease inhibitors offered hope, it was hope beyond the reach of the vast majority of people infected with HIV who could not afford the treatment. The combination of therapies could cost up to $20,000 a year in the United States alone. Dr Toye H. Brewer of the University of Washington in Seattle summed up his disappointment in knowing that "just a minority of people around the world are going to benefit" from the promise of new drugs.[577] The repeated failures in vaccine research and the high cost of HIV medicine led the medical community to put prevention at the centre of the efforts to contain the epidemic as it entered its third decade.[578] As one journalist writing in 2006 put it, "if care and treatment were the buzzwords of the first 25 years of the pandemic, prevention is decidedly the key player of the

[574] Rupa Chinai, "Cocktail of drugs' yields positive results on HIV," *Times of India*, August 3, 1996, 13.
[575] Up to twenty percent of the participants in some of the vaccine trials dropped out because they could no longer stand the nausea, headaches, and need to swallow up to two dozen pills a day. Medics said that the drugs also affected the blood system by causing anaemia and loss of blood cells. They are toxic to the liver and kidneys. Medics did not know whether the drugs would partially or completely restore the immune system. Chinai, "Cocktail of drugs' yields positive results on HIV," 13.
[576] Kounteya Sinha, "Bid to Keep Out HIV During Sex," *Times of India*, November 30, 2006.
[577] David W. Dunlap, "From AIDS Conference, Talk of Life, Not Death," *New York Times*, July 15, 1996.
[578] Lawrence K. Altman, "AIDS Meeting Ends with Little Hope of Breakthrough: Emphasis on Prevention," *New York Times*, July 5, 1998. In 1984, then secretary of health and human services, Margaret Heckler, reassured people that scientists would develop a vaccine in two or three years. Claudia Dreifus, "A Conversation with Zeda Rosenberg; Agency Seeks a Virus-Killer for Women to Help Control the Spread of AIDS," *New York Times*, July 29, 2003.

next 25."[579] The CDC reiterated the need to prevent new HIV infections in their 2000 surveillance report as the number of people newly infected with the virus in the United States began to climb for the first time following the introduction of protease inhibitors in 1996.[580]

The fact that the rise in new HIV infections happened more rapidly among women than men in many parts of the world made the need for new prevention tools by and for women particularly urgent.[581] In 1990, South African epidemiologist and advocate Zena Stein put the demand for women-controlled prevention options on the scientific agenda when she published in the *American Journal of Public Health* the first journal article calling for prevention tools for women.[582] Women's health advocates at the US National Conference on Women and HIV Infection in 1991—the second ever conference on women and HIV in the country—took up Stein's call, insisting that the formal conference recommendations include a demand for HIV prevention "methods which are woman-controlled and may be used without detection by their sexual partners."[583] In the United States, feminist scientists such as Sharon Hillier, a professor of obstetrics-gynaecology and reproductive services at the University of Pittsburgh and Zeda Fran Rosenberg, then a senior scientist for HIV prevention at the NIH in Washington, D.C., similarly took up Stein's call to develop alternatives to the male condom and re-directed their energies toward developing methods for preventing HIV

[579] Bachi Karkaria, "Bedfellows for the Condom: Global strategists help find new prevention tools for AIDS," *Times of India*, November 4, 2006.
[580] The CDC attributed the slowing in rates of decline in AIDS incidence and deaths to reaching the limits of therapy in extending survival; failing therapies due to treatment-resistant viral strains; late HIV testing; inadequate access to and adherence to treatment in some populations; recent increases in HIV incidence in some risk groups. CDC, "HIV/AIDS Surveillance Report: U.S. HIV and AIDS cases reported through June 2000," *MMWR* 12, no. 1 (June 2000): 3.
[581] Denis McClean, "£30m AIDS fund contribution praised: Denis McClean reports from the 15th International AIDS Conference in Bangkok," *Irish Times*, July 13, 2004.
[582] Zena Stein, "HIV prevention: the need for methods women can use," *American Journal of Public Health* 80 no. 4, (1990): 460-62, box 139, fol. 11, BWHBC records, Schlesinger Library.
[583] Stein, "HIV prevention," 460-62. The first ever National Women and HIV Conference took place in Washington, D.C., in December 1990. The conference took place as a direct result of activist pressure through protests such as Storm the NIH in May and the International AIDS Conference in San Francisco in July 1990. Murray, "An Activist Perspective on the First National Women and HIV Conference," 8-10.

in women in the early 1990s.[584] At the turn of the twenty-first century, many in the scientific and AIDS advocacy communities argued that not only was it possible to develop a safe and effective woman-controlled prevention tool, but that they could make such a product publicly available well before an HIV vaccine, with the potential to prevent millions of new infections over the course of a few years.[585]

Microbicides, advocates believed, had the potential to be woman-initiated, cheap, easy to use, undetectable during sex, ideally come in both contraceptive and non-contraceptive forms, and used only at the time of sex. Microbicides are substances containing drugs that come in the form of gels, films, sponges, foams, creams or a ring that women can discreetly apply inside their vagina before sex to block sexually transmitted diseases, including HIV. Instead of having to negotiate with a partner about wearing a condom every time they have sex, vaginal microbicides allow women to control their own protection. For advocates such as Megan Gottemoeller of the Center for Health and Gender Equality (CHANGE), "microbicides are an essential component of an overall approach to prevention that takes into account the contexts in which women are struggling to protect themselves."[586] Others similarly hoped that microbicides could become the first publicly available form of protection that women could use without men knowing. The ability to protect oneself without having to rely on the willingness of a sexual partner to use contraception is particularly important for women given the gendered power imbalance in condom negotiation. Although scientists had proven the effectiveness of correct use of male condoms in preventing HIV infection, many men refuse,

[584] Dinsa Sachan, "Zeda Rosenberg: determined to empower women to prevent HIV infection," *The BMJ* (October 2, 2017): 359:j4424, accessed February 2020, available at: https://doi.org/10.1136/bmj.j4424
[585] Peter Piot, "Plenary Address Delivered at Microbicide 2000," March 13, 2000; Kounteya Sinha, "Ahead of World AIDS Day, Hope Rides on Push for Prevention & Drug Dole: Bid to keep out HIV during sex," *Times of India*, November 30, 2006.
[586] Megan Gottemoeller, "Empowering Women to Prevent HIV: The Microbicide Advocacy Agenda," *Agenda: Empowering Women for Gender Equality* 44, AIDS: Global Concerns for Women (2000): 36.

sometimes violently, to wear condoms when having sex with their partner, including in acts of sexual violence such as "stealthing".[587] Women also cannot hide their use of the female condom—the only woman-initiated and controlled HIV prevention method that the FDA approved in 1993—from sexual partners.[588] The fact that widespread sexual violence and poverty increased the risk of infection in women, coupled with the fact that the available prevention methods were outside the control of most, underscored the need for an affordable method that women could use without needing male consent.[589]

The first microbicide study began in 1989, when researchers tested the efficacy of nonoxynol-9 (N-9), a contraceptive gel, against HIV among women sex workers in Kenya. Scientists who worked on the Joint United Nations Program on HIV/AIDS (UNAIDS) study announced the results eleven years later to expectant participants of the 13th International AIDS conference in Durban, South Africa, in 2000. Much to their disappointment, attendees learned that the trial had failed.[590] Instead of protecting women, the compound actually increased their chance of infection because it irritated vaginal tissues, enhancing the ability of

[587] Stealthing is the act of removing a condom during sex without a partners' consent. Donald McNeil, "New Lines of Attack in H.I.V. Prevention," *New York Times*, November 9, 2010; World Health Organization (WHO), Violence Against Women and HIV/AIDS: Critical Intersections. Intimate Partner Violence and HIV/AIDS, no. 1, 2004, 2-3, accessed February 2020, https://www.who.int/hac/techguidance/pht/InfoBulletinIntimatePartnerViolenceFinal.pdf

[588] Jim Pickett and Mitchell Warren, "Men & Women Demand Rectal Microbicides," *Achieve* 5, no. 4 (2013): 11.

[589] Avert, "Women and Girls, HIV and AIDS," last updated October 10, 2019, accessed February 2020, https://www.avert.org/professionals/hiv-social-issues/key-affected-populations/women#footnote2_r14af4d; Fernando Notario-Pérez et al., "Historical Development of Vaginal Microbicides to Prevent Sexual Transmission of HIV in Women" *Drug Design, Development and Therapy* 11 (June 15, 2017): 1767-1787, accessed February 2020, available at: https://doi.org/10.2147/DDDT.S133170. Scientists writing for *The Lancet* in 2007 noted that "the development of efficient, widely available, and low-cost microbicides to prevent sexually transmitted HIV infections should be given high priority, see Jan Balzarini and Lut Van Damme, "Microbicide drug candidates to prevent HIV infection," *The Lancet* 369, no. 9563 (February 14, 2007): 787, accessed February 2020, available at: https://doi.org/10.1016/S0140-6736(07)60202-5.

[590] The International AIDS conference in Durban was the first held in a country with widespread poverty. Speakers directly attributed the magnitude of the epidemic to the failure to advocate protective measures and to provide effective treatments to vast populations in Africa and elsewhere. Lawrence K. Altman, "Talking about AIDS, With All the World Watching," *New York Times*, August 8, 2006, F1; Sharon Hillier et al., "In vitro and in vivo: the story of nonoxynol 9," *Journal of Acquired Immunodeficiency Syndrome* 39, no. 1 (1 May 2005): 1-8, accessed February 2020, available at: https://doi.org/10.1097/01.qai.0000159671.25950.74

HIV to infect the cells.[591] Highlighting the gap in knowledge over how women's unique physiology put them at risk of infection, for decades women had used products containing nonoxynol-9 as contraceptives alone or in combination with diaphragms or cervical caps.[592] It was also an ingredient in lubricants on some condoms. The prevalence of nonoxynol-9 meant that a number of the contraceptive products women were already using to protect themselves sexually were in fact making them more vulnerable to HIV infection.[593]

After the failed N-9 trial, setbacks continued to define the "flip flop world of microbicide research."[594] Researchers across the world nevertheless persisted and continued to trial several different substances hoping to "give women the power in the anti-AIDS war."[595] Similar to N-9, researchers found that gels using other chemicals in advanced stages of research increased the risk of HIV transmission among the women who used them. Researchers had to pull these and other trials for safety reasons.[596] Further trials found that other gels had no effect.[597] In the early 2000s, over twenty microbicides were involved in clinical trials. According to microbicide advocates, the biggest barrier to researching and developing a safe and effective product was a lack of resources.

[591] "New Drugs is Said to Offer Hope for Vaginal Gel to Block H.I.V.," *New York Times*, October 15, 2004, A23.
[592] Gottemoeller, "Empowering Women to Prevent HIV," 32.
[593] Joseph Perriens of UNAIDS concluded that condoms were likely to remain the primary means of protection against HIV for most people for the foreseeable future. Penny J. Hitchcock, chief of research on sexually transmitted diseases at the National Institute of Allergy and Infectious diseases also commented that, "if this holds, we have to be very careful about how women use these products or say not to use them at all." Susan Okie, "AIDS Study Prompts New Look at Prevention," *Washington Post*, August 14, 2000, A3.
[594] Malathy Iyer, "City scientists may crack AIDS code: Lead Research in the Development of Microbicide Gels to Kill HIV," *Times of India*, February 3, 2007.
[595] Iyer, "City scientists may crack AIDS code."
[596] Lawrence K. Altman, "Tests to Begin on New Drugs to Protect Women from Contracting H.I.V.," *New York Times*, July 14, 2004.
[597] Donald McNeil, "AIDS Prevention Gel Fails in Trial, Researchers Say," *New York Times*, December 15, 2009.

More specifically, the enthusiasm of microbicide researchers for these products failed to attract investment from wealthy pharmaceutical companies that typically fund drug development.[598] The primary goal of pharmaceutical companies is to invest in the scientific development of a product that will earn a profit. Several studies published in the early 2000s, including a 2002 report from the Rockefeller Foundation, predicted that while a microbicide product would eventually tap a large annual market worldwide, sales of the first generation of microbicides would not cover a companies' cost of investing in their development.[599] The lack of profit potential was a huge disincentive for pharmaceutical companies to invest. Pharmaceutical companies already made high profits from birth control tools such as the contraceptive pill because women had to use it daily. Unlike the pill, women would only need to use a microbicide sporadically, each time they had sex, limiting its profit potential.

The task of research and development consequently fell to non-profit foundations and academic institutions without the necessary capital to finance large-scale clinical trials.[600] In contrast to treatment and vaccine research, which was largely in the domain of large pharmaceutical companies, progress in the field of prevention technologies depended primarily on public funding from the governments of the United States and the European Union.[601] Pharmaceutical companies planned to withhold investment in the first generation of microbicide products and enter the market only once non-profit research institutions had established that such a market existed.

[598] According to Dr Peter Piot, the executive director of the UN AIDS programme, attracting the interest of the pharmaceutical industry posed the main challenge to microbicide development. Lerner, "Product to Protect Women from H.I.V. Is Elusive," *New York Times*, July 3, 2001, F6.
[599] Jordan Lite, "New Push for Woman-Controlled AIDS Prevention," *Women's Enews*, May 19, 2002, accessed February 2020, https://womensenews.org/2002/05/new-push-woman-controlled-aids-prevention/
[600] Gottemoeller, "Empowering Women to Prevent HIV," 33.
[601] HIV Prevention Research & Development Investments, 2000-2015. Investment priorities to fund innovation in a challenging global health landscape, October 2016, 5-7, accessed February 2020, http://www.hivresourcetracking.org/wp-content/uploads/2016/12/Resource_Tracking_Report_2015.pdf

Without significant investment from major pharmaceutical companies, funds available for clinical trials often fell short of the amount needed and promising microbicide products stalled for lack of money to take them forward.[602] Of the US $1.8 billion invested in AIDS research by the NIH in 1999, around $28 million went to microbicide research and development, compared to around $180 million for vaccine research.[603] Each clinical trial lasted a minimum of five years and cost between $50 to $100 million to run, and researchers and advocates argued that the field of microbicide research and development needed $100 million annually to become available to women as quickly as possible.[604]

In the absence of pharmaceutical support, women's health advocates organised to raise awareness of, and public demand for, woman-initiated HIV prevention tools themselves. At the 12th International AIDS Conference in Geneva in 1998, a group of women's health and AIDS advocates from around the world launched the Global Campaign for STI/HIV Prevention Alternatives for Women, also known as the Global Campaign for Microbicides (GCM), an organisation demanding greater public commitment to making women-controlled prevention methods like microbicides and the female condom available. Over fifty organisations from around the world co-sponsored the GCM in order to raise the profile of microbicides among public health and research communities as well as among potential users.[605]

[602] Lite, "New Push for Woman-Controlled AIDS Prevention."
[603] Anna Forbes et al., "In Our Own Hands: A case study on mobilizing demand for HIV prevention for women," 2013, 16, accessed February 2020, https://path.azureedge.net/media/documents/APP_gcm_hiv_cs.pdf; Gottemoeller, "Empowering Women to Prevent HIV," 33.
[604] Gottemoeller, "Empowering Women to Prevent HIV," 33.
[605] For more on the history of the Global Campaign for Microbicides, see Forbes et al., "In Our Own Hands," 10-12.

In March 2000, GCM co-sponsors worked in collaboration with Congresswomen Connie Morella (R-MD) and Nancy Pelosi (D-CA) to introduce the Microbicide Development Act (MDA), a bill in the US House of Representatives authorising $50-100 million annual investment in microbicides.[606] That same year, members of the GCM also held the first international conference on the topic, Microbicides 2000, in Washington, D.C., to raise funds and awareness in the field. Representatives introduced the MDA in Congress six times between 1999 and 2008 and, although the bill never passed, the government implemented two of its key provisions. Specifically, in 2007, the NIH set up a dedicated microbicide research and development unit. Federal funding for microbicides also increased steadily between 2000 and 2010, tripling from $28 million in 1999 to $92 million in 2004.[607] This public funding was essential as the pharmaceutical industry had not committed substantial financial resources to microbicide research and development.[608]

GCM was part of a larger grassroots effort to apply political pressure, with the aim to increase government and non-profit funding for microbicide research and development. In 2002, microbiologist and epidemiologist Zeda Rosenberg resigned from her job as scientific director for the HIV Prevention Trials Network (HPTN) at Family Health International (FHI) in North Carolina to start her own non-profit organisation dedicated to developing and making available microbicides to women around the world, the International Partnership for Microbicides (IPM). Supported by the Rockefeller Foundation, the Bill and Melinda Gates Foundation, and a series of other organisations, she established IPM in order to push for increased investment in microbicide research.[609] Rosenberg also believed that inventing an

[606] Gottemoeller, "Empowering Women to Prevent HIV," 34.
[607] Forbes et al., "In Our Own Hands," 15.
[608] Forbes et al., "In Our Own Hands,"16.
[609] International Partnership for Microbicides, "Our Donors," accessed February 2020, https://www.ipmglobal.org/about-ipm/donors

effective medicine was only half the battle and that "nearly as important as whether it kills HIV is whether a microbicide feels acceptable, whether it can be used discretely if necessary and how it is packaged and promoted."[610] Before researchers had invented the product's active ingredient, the IPM spent years determining how to get women in a variety of cultures to use it.[611] Meanwhile, in 2004, the GCM began a search for donors that it called "Looking for Mrs. McCormick," a reference to Katharine Dexter McCormick, a leader in the suffrage movement and the League of Women Voters, who donated the majority of the financial resources for the research and development of the first birth control pill when a private drug company pulled its support.[612] Two years later, in 2006, Susan Hillier started the Microbicide Trials Network (MTN), a group of organisations that the NIH set up to monitor clinical trials on a new wave of microbicide products. The Rockefeller Foundation also launched a Microbicide Initiative and the Bill and Melinda Gates Foundation similarly contributed millions to trials that aimed to bring these "invisible condoms" to the market.[613]

Rosenberg attributed the pharmaceutical industry's lack of enthusiasm for microbicide development in part to the fact that "a vaccine is a powerful symbol of the triumph of science" compared to the "less glamorous microbicide."[614] She also believed that the lack of enthusiasm resulted from the fact that microbicide scientists were developing a product that women needed, but that was not necessarily profitable. Her organisation, the IPM, developed products primarily with funding from grants and therefore "unlike commercial pharmaceutical companies, IPM is not seeking to set a price designed to recoup investments

[610] Tina Rosenberg, "When a Pill is Not Enough," *New York Times*, August 6, 2006.
[611] Bachi Karkaria, "Science and Ethics Can Be Served in Clinical Trials," *Times of India*, March 7, 2008, 14.
[612] Armond Fields, *Katharine Dexter McCormick: Pioneer for Women's Rights* (Westport: Praeger Publishers, 2003), xi.
[613] Lawrence Altman, "A Familiar Pair Urge Greater Attention for AIDS," *New York Times*, August 15, 2006; Lawrence Altman, "Tests of Drugs to Block HIV Infection Are Halted Over Safety," *New York Times*, February 1, 2007.
[614] Karkaria, "Science and Ethics Can Be Served in Clinical Trials," 14.

in R&D [research and development]."[615] Researchers knew that they needed to make a microbicide product as inexpensive as possible due to the gendered elements of poverty and in order to "put prevention in the hands of the most biologically and socially disadvantaged party, namely, women."[616] That meant that a microbicide product needed to cost much less than a pill and ideally be available without a prescription in chemists, kiosks, and shops.[617] One of the ways in which scientists sought to keep the cost of a microbicide down for women was to design a product for women to use only at the time of sex. As a result of the design, the products were unlikely to earn as much profit as pills requiring a daily regimen.

In addition to the question of profit, Rosenberg also attributed the lack of significant investment on the part of major pharmaceutical companies to a reluctance to develop a product that promoted women's sexual autonomy. She claimed that because:

> This anti-AIDS strategy involves a product that needs to be used vaginally and is associated with sex, it has problems gaining acceptance. When you think about an HIV vaccine, you don't think about sex. It's a vaccine, like the one for influenza. When you think of a vaginal microbicide there's no way you can't think about sex. That makes some people very uncomfortable.[618]

What Rosenberg saw as a reluctance on the part of the pharmaceutical industry to fund a product that was explicitly tied to women's sexuality spoke to a wider challenge that women had faced in asserting their right to sexual self-determination throughout the epidemic. As

[615] International Partnership for Microbicides, "Preparing for Access to Microbicides and the Dapivirine Ring for HIV Prevention," current as of May 2011, 26, accessed February 2020, https://assets.publishing.service.gov.uk/media/57a08af0ed915d3cfd000a20/IPMAccessStrategy.pdf
[616] Bachi Karkaria, "Science and Ethics Can Be Served in Clinical Trials," *Times of India*, March 7, 2008, 14.
[617] Lerner, "Product to Protect Women from H.I.V. Is Elusive," *New York Times*, July 3, 2001, F6.
[618] Dreifus, "A Conversation with Zeda Rosenberg."

was the case in previous prevention initiatives, women's sexual empowerment and safety were also at the heart of the microbicide effort. Rosenberg and other advocates wanted to develop a microbicide that could do for HIV prevention what the pill did for contraception—give women the ability to protect themselves sexually without having to rely on a partner. They expressed this aim through the slogans on promotional materials such as, "With condoms, safer sex is his decision. We want to make it yours."[619] This message contrasted with the CDC and other public health agencies' often tone-deaf safer sex publicity from the 1980s that sought to give women verbal strategies to encourage men to engage in safer sex in the wake of AIDS, but that still put the burden of responsibility on them, such as, "If he doesn't have a condom, you just have to take a deep breath and tell him to go and get one."[620] The desire on the part of feminist scientists and advocates, in contrast, was to develop a product that gave women the ability to protect themselves sexually without having to rely on the willingness of a partner. Their efforts to do so came up against not only the profit motive of drug companies reluctant to take a risk on a potentially unprofitable treatment that would primarily serve women, but a political agenda hostile to reproductive rights.

The enthusiasm of microbicide researchers for these products failed to attract significant investment from pharmaceutical companies who did not see the products as enough of a commercial opportunity. The case of microbicides therefore proved member of the BWHBC Lucy Candib's argument made more than three decades earlier in the first version of *Our Bodies, Ourselve*s, entitled *Women and Their Bodies: a course* (1970), that "we have not had the power to determine medical priorities; they are determined by the corporate medical

[619] Forbes et al., "In Our Own Hands,"14.
[620] Atlanta, GA.: Centers for Disease Control. 1983. National Library of Medicine, accessed February 2020, https://stacks.cdc.gov/view/cdc/34804

industry (including drug companies)."[621] The criticism that the US healthcare system puts the profit motive of drug companies before the health of those in need is one that feminists had levelled against the industry for decades.[622] From the late 1990s onwards, microbicide advocates saw this critique made concrete when drug companies decided not to take on the risk and cost of research and development for HIV prevention technologies which could particularly benefit women.

Over the course of the next decade, the field of HIV prevention shifted away from microbicide research and toward the development of a pill that taken once a day reduces the risk of contracting HIV through sex. Women were initially under-represented in the clinical trials for this drug and researchers knew little of women's interest in or ability to adhere to the medication. Similar to the healthcare delivery systems in women's prisons that were designed for men, this gap in knowledge was another consequence of what Perez argued happens when designers default to men and forget to accommodate women's specific needs.[623] As Perez noted, while researchers may not have "deliberately set out to exclude women," they did not "think to consider if women's needs might be different" either.[624] Concerned that women would again get left behind in the roll-out of the latest HIV treatment to come to market, women who were already involved in microbicide advocacy turned their attention towards helping women to prepare for the new medicine.

[621] BWHBC, *Women and Their Bodies: a course*, 1970, 6, accessed February 2020, https://www.ourbodiesourselves.org/cms/assets/uploads/2014/04/Women-and-Their-Bodies-1970.pdf
[622] Morgen, *Into Our Own Hands*, 72-73; Musser, "From Our Body to Yourselves," 93, 96, 97.
[623] Perez, *Invisible Women*, 313
[624] Perez, *Invisible Women*, 32.

Preparing Women for the Prevention Agenda

After more than a decade of failed clinical trials, a breakthrough in the field of microbicide research finally came in 2008. A research team funded through the NIH reported that women could safely use a topical gel made with the antiretroviral drug tenofovir.[625] The California-based pharmaceutical company Gilead Sciences Inc. made and sold the drug tenofovir under the brand name Viread. It was the first potential microbicide to use a licensed antiretroviral drug. After proving that the tenofovir gel was safe for women to use, researchers now had to prove its effectiveness in preventing HIV transmission.[626] This breakthrough came in July 2010, when researchers carrying out the clinical trial CAPRISA 004 in South Africa confirmed that inserting a vaginal-gel version of the antiretroviral drug tenofovir reduced HIV incidence in women by up to 39 percent.[627]

A few months after the success of the CAPRISA 004 trial, a global trial in gay men and a small number of transgender women who have sex with men confirmed that the pill version of tenofovir could reduce new HIV infections when taken once a day—a strategy called PrEP (pre-exposure prophylaxis)—by 92 percent.[628] The inclusion of transgender women and the exclusion of cisgender women in the trial implied that pharmaceutical companies still put trans women in the biological category of "men." Gilead Sciences Inc. also sold the pill version of tenofovir disoproxil fumarate (TDF) in combination with the drug emtricitabine

[625] A topical gel is a medication that is applied to a particular place on or in the body.
[626] "Finally, a safe gel to protect women from AIDS! The gel uses the drug tenofovir and is quite acceptable to women," *Times of India*, February 27, 2008.
[627] Researchers announced the results at the 18th International AIDS Conference in Vienna. Quarraisha Abdool Karim et al., "Effectiveness and safety of tenofovir gel, an antiretroviral microbicide, for the prevention of HIV infection in women," *Science* 329, no. 5996 (September 3, 2010): 1168-74, accessed February 2020, available at: https://dx.doi.org/10.1126%2Fscience.1193748; Henry J Kaiser Family Foundation, AIDS 2010: Study Finds Microbicide Containing HIV Drug Lowers Infection Risk in Women by 39%, July 20, 2010, accessed February 2020, https://www.kff.org/news-summary/aids-2010-study-finds-microbicide-containing-hiv-drug-lowers-infection-risk-in-women-by-39/
[628] Pickett and Warren, "Men & Women Demand Rectal Microbicides," 11.

under the brand name Truvada. In March 2012, the FDA approved Gilead's proposal to sell the combination pill Truvada as an HIV prevention strategy. The FDA had first approved Truvada for HIV treatment back in 2004. In 2012, it became the first drug that the FDA approved for the prevention of HIV and has dominated the field of prevention in the years since.

The rise of PrEP marked the decline of microbicides. Regulatory authorities approved Truvada for PrEP faster than a gel because researchers had proven them safe and effective for treatment more quickly.[629] Researchers struggled to duplicate the success of the CAPRISA 004 trial in part because of the persistent lack of funding from major drug companies and a reduction in funding from non-profit foundations.[630] Studies that did secure funding failed to repeat the success of CAPRISA 004. Participants found it hard to stick to the daily regimen of applying the gel because women were not always in a situation where they could do so discreetly.[631] Understanding why women's health advocates still preferred microbicides to pills largely came down to a question of access. As women are more reliant on public health insurance than men, and women of colour more reliant than white women, a cheap gel that did not require a prescription had more chance of reaching the racial and minority ethnic women most impacted in the epidemic and with less access to uninterrupted health insurance.[632] As pharmaceutical companies could set and raise their prices as much as they

[629] Donald G. McNeil Jr. "New Lines of Attack in HIV Prevention," *New York Times*, November 9, 2010.
[630] Henry J Kaiser Family Foundation, AIDS 2010: Study Finds Microbicide Containing HIV Drug Lowers Infection Risk in Women by 39%, July 20, 2010, accessed February 2020, https://www.kff.org/news-summary/aids-2010-study-finds-microbicide-containing-hiv-drug-lowers-infection-risk-in-women-by-39/
[631] Gus Cairns, "VOICE trial: Microbicide gel may have stopped two out of three HIV infections—in the women who used it," *aidsmap*, February 9, 2019, accessed February 2020, http://www.aidsmap.com/VOICE-trial-Microbicide-gel-may-have-stopped-two-out-of-three-HIV-infections-in-the-women-who-used-it/page/2943410/
[632] Institute of Medicine (US) Committee on the Ryan White CARE Act: Data for Resource Allocation, Planning, and Evaluation, "Measuring What Matters: Allocation, Planning, and Quality Assessment for the Ryan White CARE Act," (Washington, D.C.,: National Academies Press, 2004), accessed February 2020, available at: https://www.ncbi.nlm.nih.gov/books/NBK216136/

wanted, pills, in contrast, were enormously expensive. As a prescription drug requiring quarterly doctor visits to check for kidney function and bone density—an additional cost—Truvada is hard to obtain without a doctor. Moreover, a gel that came in both contraceptive and non-contraceptive forms also enabled women to protect themselves from HIV and other sexually transmitted diseases while maintaining their reproductive autonomy. Only protecting the part of the body that needed protection, short-acting, and designed for women to use only at the time of sex, a local gel also had fewer adverse side effects. Despite these benefits, an additional blow came when the GCM, an organisation pivotal to the development of prevention tools for women, announced that it did not have enough money to stay open and closed its doors in July 2012.[633]

These setbacks drove feminist health advocates to turn their attention towards helping women to navigate Truvada for PrEP. In March 2012, shortly after the FDA's approval of the drug, a group of women started the Women and PrEP Working Group, a national coalition of women focused on HIV and PrEP. Founders of the group included long-time AIDS activist and creator of Sister Love, Inc., the programme for women living with HIV in Atlanta, Dázon Dixon Diallo, and women's health consultant and former member of the GCM, Anna Forbes.[634] Both Diallo and Forbes wanted to chart a safe path for PrEP use among women in the United States and determine whether PrEP could empower women in the same way that they hoped a microbicide might. Where Forbes had hoped that microbicides would give women an alternative when men refused to use a condom, she now wanted to ensure that if women used PrEP, it would not again relieve men of the responsibility of taking precautions during sex.[635]

[633] Forbes et al., "In Our Own Hands," 38.
[634] Nelson, *More Than Medicine*, 157-168.
[635] Olivia G. Ford, "How to Make PrEP Work for Women in the U.S.?" *TheBody*, October 15, 2013, accessed January 2020, https://www.thebody.com/article/how-to-make-prep-work-for-women-in-the-us

Women like Forbes had started the working group, concerned that without their intervention the roll out of PrEP among women could repeat the mistakes of the roll out of the female condom two decades earlier.[636] First approved for sale in the United States in May 1993, the female condom promised to give women more control in protecting against pregnancy and sexually transmitted diseases.[637] In 1993, women like Cynthia A. Pearson of the National Women's Health Network had celebrated the female condom as "the first product like this on the market. For the first time, this will give women control over exposure to sexually transmitted diseases."[638] Unfortunately, the initial optimism Pearson had expressed about the product did not translate into sales. Companies did not properly promote it or educate providers so that they could in turn inform their patients.[639] Moreover, some journalists derided the product for its look and feel.[640] The poor introduction resulted in low use both in the US and internationally which resulted in female condoms selling at a much higher price than the male alternative.[641] An intervention that advocates once saw as a bold step forward for reproductive health therefore missed decades of potential effectiveness. Women's health advocates now worried that, without proper implementation, Truvada for PrEP could be another missed opportunity in giving women more ways to protect their sexual health.

An early blow to the women's confidence in Truvada came just a few months after the announcement that the drug reduced the HIV infection rate in HIV-negative gay men.[642]

---

[636] Ford, "How to Make PrEP Work for Women in the U.S.?" *TheBody*, October 15, 2013.
[637] Donald McNeil Jr, "Redesigning a Condom So Women Will Use It," *New York Times*, November 13, 2007.
[638] Warren E. Leary, "Female Condom for Market," *New York Times*, May 11, 1993.
[639] John Schwartz, "Sale of Female Condom Is Approved," *Washington Post*, May 11, 1993.
[640] Laura Blumenfeld, "Style Plus: The New Sexual 'Reality' Now, A Condom for Women," *Washington Post*, March 9, 1992, B5.
[641] William Kremer, "The return of the female condom?" *BBC World Service*, December 15, 2013, accessed February 2020, https://www.bbc.co.uk/news/magazine-25348410.
[642] Robert M. Grant et al., "Uptake of pre-exposure prophylaxis, sexual practices, and HIV incidence in men and transgender women who have sex with men: a cohort study," *The Lancet* 14, no. 9 (22 July 2014): 820-829, accessed February 2020, available at: https://doi.org/10.1016/S1473-3099(14)70847-3

FEM-PrEP, the first large-scale clinical trial of PrEP in women from Kenya, Tanzania, and South Africa showed that Truvada was ineffective in preventing HIV in women.[643] The researchers speculated that the drug had an unexpected interaction with women's contraception and that side-effects among women taking Truvada, especially nausea, might have led to poor adherence. The findings confirmed that antiretroviral drugs have different levels of effective prevention between men and women. They also reiterated the limitations of doing clinical research solely or largely on men and extrapolating the results to women.

Two subsequent international studies published in the summer of 2012 confirmed that Truvada did work to prevent HIV transmission in women.[644] However, researchers in the United States had still not carried out any clinical trials on the efficacy of PrEP in women in the country. In 2012 the CDC proposed a PrEP trial involving cisgender women in the United States. Such a study did not begin for another three years because it struggled to secure full funding. For members of the Working Group, the NIH's reluctance to fund a trial solely involving women proved that the agency did not see women's health as a priority on the HIV prevention agenda.[645] HIV-positive women in the United Kingdom levelled similar criticism against the National Health Service (NHS) when in December 2016, after NHS England announced funding for a large-scale PrEP trial, the eligibility criteria included no cisgender women. AIDS advocate Yasmin argued that the criteria proved that "the entire concept of understanding heterosexual risk was beyond us."[646] In July 2014, the CDC issued guidance

[643] Ford, "How to Make PrEP Work for Women in the U.S.?" *TheBody*, 15 October 2013.
[644] Jared M. Baeten, et al., "Antiretroviral Prophylaxis for HIV Prevention in Heterosexual Men and Women," *New England Journal of Medicine* (August 2, 2012): 367:399-410, accessed February 2020, available at: https://www.nejm.org/doi/full/10.1056/NEJMoa1108524; Michael C. Thigpen et al., "Antiretroviral Preexposure Prophylaxis for Heterosexual HIV Transmission in Botswana," *New England Journal of Medicine* (August 2, 2012): 367:423-434, accessed February 2020, available at: https://www.nejm.org/doi/full/10.1056/NEJMoa1110711
[645] Ford, "How to Make PrEP Work for Women in the U.S.?" *TheBody*, 15 October 2013.
[646] My PrEP Story: Yasmin (part 1), August 8, 2018, accessed February 2020, https://prepster.info/2018/08/prep-story-yasmin-part-1/

for clinicians to provide PrEP to women "at substantial risk of HIV acquisition."[647] One year later, the Working Group and other PrEP advocacy organisations secured enough funding from the CDC and its partners to launch the Sustainable Health Center Implementation PrEP Pilot Study (SHIPP)—the first PrEP study enrolling cisgender women in the United States.[648]

Global and domestic policies that undermined women's health compounded the underrepresentation of women in international medical research. In 2017, President Donald Trump reinstated a global version of the gag rule introduced three decades earlier by President Ronald Reagan in 1984. Otherwise known as the Mexico City Policy, it withheld global health funding for organisations that "perform or actively promote abortion" abroad. The policy also denied funding to non-government organisations that provided contraception and forced clinics and community centres to choose between restricting their services or forgoing US government funding. Illustrating the partisan nature of public health policy, every Republican president since Reagan has enacted some form of the rule, and every Democratic president has reversed it.[649] Trump expanded the Mexico City Policy and applied it to HIV-funding through the President's Emergency Plan for AIDS Relief (PEPFAR), the largest US global health programme. Since PEPFAR-funded HIV programmes had historically been exempt from the policy, advocates cannot predict the full impact of the expanded gag rule for PEPFAR on implementing partner programmes. Research on prior iterations of the policy has noted that it diverted funds from trusted sexual and reproductive

[647] Cicatelli Associates Inc. (CAI), African American Women and PrEP, 1, accessed February 2020, https://docs.wixstatic.com/ugd/68e4cb_8748d15a45cb453c91ff1d31ad368a65.pdf
[648] Anna Forbes, "Women Deserve to Know About HIV Prevention Medication Too," *Rewire.News*, March 10, 2015, accessed February 2020, https://rewire.news/article/2015/03/10/women-deserve-know-hiv-prevention-medication/
[649] Nurith Aizenman, "Will Trump Reinstate Reagan's Abortion Rule for International Charities?" *wbur news*, December 6, 2016, accessed February 2020, https://www.wbur.org/npr/503187530/will-trump-bring-back-the-reagan-rule-about-abortions.

health providers, resulting in clinic closures and decreased access to contraceptives.[650] Reductions in contraceptive coverage in turn contributed to increased rates of abortion and unintended pregnancy.[651] As contraception coverage is a known contributor of HIV prevention, researchers estimate that even a small change in the availability of contraception in regions that receive PEPFAR funding and which have high HIV prevalence, such as Sub-Saharan Africa, will have serious consequences for new HIV infections and women's health.[652] Both the domestic and global version of the gag rule speak to the Trump administration's intent to further an ideological agenda and to not prevent new HIV infections or protect women's reproductive health.[653]

Such recent global and domestic policy practices that have side-lined women's health are especially troubling given the latest statistics and knowledge of the transmission of the virus. Women, globally, make up more than half of all people living with HIV.[654] In the United States, women comprise one in four new HIV diagnoses.[655] Black women account for over 60 percent of women with new HIV diagnoses, and one in 48 black women are expected to

[650] Center For Health and Gender Equity (CHANGE), "Global Gag Rule Fact Sheet," July 2018, 1-2, accessed July 2019, http://www.genderhealth.org/files/uploads/change/publications/CHANGE_GGR_fact_sheet.pdf; amfAR, "The Effect of the Expanded Mexico City Policy on HIV/AIDS Programming: Evidence from the PEPFAR Implementing Partners Survey," January 2019, 1-2, accessed July 2019, https://www.amfar.org/uploadedFiles/_amfarorg/Articles/On_The_Hill/2019/IB-1-31-19a.pdf

[651] Kelly M. Jones of the International Food Policy Research Institute, "Evaluating the Mexico City Policy: How US Foreign Policy Affects Fertility Outcomes and Child Health in Ghana" (December 2011), v, accessed January 2020, https://www.poppov.org/~/media/PopPov/Documents/events/6thAnnConf/jones-2011-mexico-city-fertility.pdf

[652] Jon Welch, "Opinion: Trump's Reinstated 'Global Gag Rule' On Abortion is Cruellest to the Poorest," *wbur news*, January 26, 2017, accessed February 2020, https://www.wbur.org/commonhealth/2017/01/26/new-mother-die-gag-rule

[653] Jason Beaubien, "Praise for the Global HIV Program That Trump Wants to Cut," *npr*, July 25, 2018, accessed February 2020, https://www.npr.org/sections/goatsandsoda/2018/07/25/632395250/praise-for-the-u-s-hiv-program-that-trump-wants-to-cut

[654] UNAIDS, "Women and HIV: A Spotlight on Adolescent Girls and Young Women," (2019), 12, accessed February 2020, https://www.unaids.org/sites/default/files/media_asset/2019_women-and-hiv_en.pdf; Anne-Claire Guichard, "On International Women's Day, UNAIDS calls for greater action to protect young women and adolescent girls," UNAIDS Press Statement, March 8, 2019, accessed February 2020, https://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2019/march/20190308_iwd

[655] CDC Fact Sheet, "Today's HIV/AIDS Epidemic," August 2016, https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/todaysepidemic-508.pdf; http://files.kff.org/attachment/Infographic-Medicaids-Role-for-Individuals-with-HIV

contract HIV in their lifetime.[656] PrEP use is still largely limited to white gay men aged 25 and older. Women have an overall low level of awareness of the medication, but once informed, have expressed a willingness to consider its use.[657] Gilead showed an almost fourfold increase in PrEP uptake between 2014 and 2015 among women; however, the overall numbers of women taking PrEP has declined since 2012.[658] In New York, black and Latina women represented 90 percent of the overall number of women diagnosed with HIV in 2017, and only 34 percent were aware of PrEP. In the first half of 2018, only 1,300 women were prescribed PrEP in the city, compared to 16,000 men.[659] According to a 2016 CDC study, women comprised 19 percent of all new HIV diagnoses, but they made up only seven percent of all PrEP users.[660] With the power imbalance in condom negotiation and the fact that women are twice as likely to acquire HIV during heterosexual vaginal intercourse without condoms than are their male partners, access to effective HIV prevention, including the option of PrEP, is crucial for women.[661]

Similar to the Women and PrEP Working Group, other advocates have organised to raise awareness of PrEP among women. Members of the Working Group critiqued the male-

[656] Erika Aaron et al., "Optimizing Delivery of HIV Preexposure Prophylaxis for Women in the United States," *AIDS Patient Care and STDs* 32, no. 1 (January 1, 2018): 16-23, accessed February 2020, available at: https://doi.org/10.1089/apc.2017.0201; CDC Fact Sheet, "HIV Among African Americans," undated, 1, accessed February 2020, https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/cdc-hiv-aa-508.pdf
[657] Judith Auerbach et al., "Knowledge, attitudes, and likelihood of pre-exposure prophylaxis (PrEP) use among US women at risk of acquiring HIV," *AIDS Patient Care STDS* 29, no. 2 (February 1, 2015): 102-110, accessed February 2020, available at: https://doi.org/10.1089/apc.2014.0142
[658] Bianca S. Hill et al., "Leveraging Social Media to Explore Black Women's Perspectives on HIV Pre-exposure Prophylaxis," *Journal of Associated Nurses AIDS Care*, 29, no. 1 (January-February 2018): 107-114, accessed February 2020, available at: https://doi.org/10.1016/j.jana.2017.06.010; A 2017 study showed that men constituted 94 percent of Truvada users. See AIDSVu, "Overview of 2017 PrEP Update," 2, accessed February 2020, https://aidsvu.org/wp-content/uploads/2018/11/2017-PrEP-Data-Update-Overview-1.pdf
[659] Kenyon Farrow, "New Campaign, Toolkit Gets Providers PrEP'd for Women," *TheBodyPro*, May 10, 2019, accessed February 2020, https://www.thebodypro.com/article/new-campaign-toolkit-gets-providers-prep-for-women
[660] AIDSVu, "Mapping PrEP: First Ever Data on PrEP Users Across the U.S.," accessed February 2020, https://aidsvu.org/prep/
[661] CDC, "HIV Risk Behaviors," https://www.cdc.gov/hiv/pdf/risk/estimates/cdc-hiv-risk-behaviors.pdf

centric media campaigns that targeted men.[662] In 2015, Gilead Sciences launched a televised advertising campaign promoting public awareness of HIV prevention. In one advert, the viewer watches a young white man dancing topless in a club before he meets and begins kissing another white man. "I like to party, and I like to be safe," he says before taking a Truvada pill.[663] In July 2016, the Women's Collective, a non-profit organisation based in Washington, D.C., launched PrEP for Her, a campaign designed to increase knowledge of PrEP among black women. The Collective partnered with the D.C. Health Department and secured funding from the CDC and the MAC AIDS Foundation. Dr Travis Gayles, Chief Medical Office at the D.C. Department of Health, noted the importance of introducing a prevention effort that targets women. Ashlee Wimberly, PrEP for Women Project Coordinator, critiqued the absence of women in existing initiatives and Martha Cameron, the Director of Prevention at the Collective, concurred that "there has hardly been any campaign, social media strategies, even images out there that have targeted women in general and especially women of color with regard to PrEP."[664] The initiative therefore sought to increase knowledge and PrEP awareness through social media and marketing campaigns, creating posters picturing women next to such tag lines as: "Dominate your sex life: PrEP is a safe, daily pill that helps prevent HIV."[665] Because women need to adhere to PrEP to make the medication beneficial, the group also addressed women's barriers to sustained care, such as

[662] Forbes, "Women Deserve to Know About HIV Prevention Medication Too," *Rewire.News*, March 10, 2015.
[663] Gilead Sciences, Inc. "I Like to Party" video, November 4, 2015, accessed February 2020, available at: https://www.youtube.com/watch?v=FXZcoBsoGBY
[664] Mehroz Baig, "PrEP for Her: Bringing Women into the HIV Prevention Conversation," *HuffPost*, August 16, 2017, accessed February 2020, https://www.huffpost.com/entry/prep-for-her-bringing-wom_b_11527650?guccounter=1&guce_referrer=aHR0cHM6Ly93d3cuZ29vZ2xlLmNvbS8&guce_referrer_sig=AQAAAG011WuPhOuwT-yzbB_rgPUFZr1QTIrp5QPY6akHKS2mg0eSvuRGZkE_i8H4kf03SIvpbuniAEIEjqAPMbIfwzOuShCZoTIoHOhXJUXUDBiD6U-owyfMRrCfeey0WNAIrKdD84_Bqcy1pPHi31C1q6oOMgFoMvLRTIf5QW01BXnp
[665] Washington, D.C. PrEP Awareness Campaign for all Women, accessed February 2020, available at: https://sexualbeing.org/get-involved/prep-for-her/

financial instability, being in violent relationships, and limited access to not-for-profit treatment spaces.[666]

Other advocacy groups similarly organised to raise awareness of PrEP as well as the need for better media coverage regarding women's risk of HIV. On a poster that hangs inside a Planned Parenthood clinic, a young Black woman with long braids is pictured sitting in front of a graffitied wall, looking directly into the camera. Written above her is the sentence, "I PrEP because: I'm Black girl magic." This and similar versions of the poster hang in clinics, health departments, universities, and faith institutions across the United States. Other posters display women next to the tag line: "Take Control. PrEP is a daily pill that can prevent HIV." Fatima Hyacinthe who leads the Black AIDS Institute's PrEP campaign similarly created the "I PrEP Because" and "Take Control" poster series as part of a marketing campaign to promote PrEP use among Black women and as alternatives to the available visuals and information that drove the perception that Truvada is predominantly for men.[667]

The problems involved with PrEP, the global gag rule, and getting women treated are part of a larger problem with the gutting of Title X and Planned Parenthood. The efforts on the part of the Trump administration and the political right to defund not-for-profit health centres means stopping them from receiving Medicaid reimbursement for the other preventative health services they provide, including hormone replacement therapy (HRT) for transgender patients, birth control, pregnancy care, cancer screenings and, since the 1980s, HIV testing,

[666] A trial in Europe has provided strong evidence that PrEP can be taken only at times of risk, as opposed to daily dosing, and still be effective. This was the case for men who have sex with men: the researchers do not test whether intermittent PrEP worked for women (or for heterosexual men). See PrEP in Europe, "Intermittent PrEP: Do you have to take it every day?" accessed February 2020, http://www.prepineurope.org/en/faqs/does-prep-work/intermittent-prep/

[667] Black Women and PrEP Toolkit Posters, accessed February 2020, available at: https://blackaids.org/black-women-and-prep/; See also Demetria Mosley, "With Black Women at High Risk for HIV, Why Are So Few Taking the Prevention Pill?" *Rewire.News*, November 30, 2018, accessed February 2020, https://rewire.news/article/2018/11/30/black-women-hiv-few-taking-prevention/

treatment, and education services. Efforts to defund Planned Parenthood and other non-profit treatment spaces are particularly harmful for the women who, due to the convergence of racism, sexism, homophobia, and other systemic barriers contributing to income inequality cannot afford private insurance. The preventative, persistent care offered at these not-for-profit family planning centres can be the difference between life and death.

Saving Title X in the Fight to End AIDS

Guests staying at the Trump International Hotel in New York City on 9th May 2017 who looked out of their windows and onto Central Park West Street would have seen hundreds of women marching with signs that read "Died of AIDS" and "Died from Unsafe Abortion."[668] Cognizant of the overlaps between reproductive health services and HIV/AIDS treatment, the women were protesting the House of Representatives' recent vote to advance President Donald Trump's political agenda in repealing ACA and blocking patients from accessing health services at Planned Parenthood centres. The political assault on women's reproductive health services did not cease when the Senate blocked the repeal in July. Instead, the most recent strategy conservatives have deployed in their ever-shifting attack on women's reproductive rights, including access to HIV/AIDS services, comes in the form of gutting Title X.

Established in 1970, Title X of the Public Health Service Act is a federal grant programme that distributes funding to family planning health centres. Title X-funded health centres provide regular, preventative health care, including affordable birth control and reproductive

[668] Michelle Chen, "Trump's Global Gag Rule Is Making It Harder to Fight the AIDS Crisis," *The Nation*, March 25, 2019, accessed February 2020, https://www.thenation.com/article/archive/global-gag-rule-trump-hiv-aids/

healthcare services to people who are uninsured, on low-income, or seeking confidential services. They offer gynaecological exams, contraception, cancer, and HIV/AIDS screening. Crucially, Title X providers refuse no-one based on their inability to pay.[669] These health sites are many women's only health care option.[670]

The Trump administration's proposed Title X rule will cut the access of Planned Parenthood and other abortion providers to Title X funding unless they physically and financially separate abortion from the other services that they provide. It also bans doctors in the Title X programme from referring patients to abortion providers, even when patients request such referrals. Barring doctors from telling women how they could safely and legally access abortion elsewhere prohibits them from giving women full information about all of their sexual and reproductive healthcare options.[671]

As Title X is a federal programme that pays for reproductive health services for low-income women, the Trump Administration's new Title X policy is particularly burdensome to low-income women and women of colour, who, as a result of decades of policies that have

[669] Kiersten Gillette-Pierce and Jamila Taylor, "The Threat to Title X Family Planning: Why It Matters and What's at Stake for Women," *Center for American Progress*, February 9, 2017, accessed February 2020, https://www.americanprogress.org/issues/women/reports/2017/02/09/414773/the-threat-to-title-x-family-planning/

[670] More than sixty percent of women of reproductive age report that a family planning site is their usually source of reproductive and general health care services. 41 percent say it is their only source of care. See See Vanessa A. White and Christine Brazell, "Family Planning Provides Key in Fight Against HIV," *HIV.gov*, undated, accessed February 2020, https://www.hiv.gov/blog/family-planning-providers-key-in-fight-against-hiv. For more on the potential impact of defunding non-profit clinics on women's health, see also, Jennifer J. Frost et al., "Specialized Family Planning Clinics in the United States: Why Women Choose Them and Their Role in Meeting Women's Health Care Needs," *Women's Health Issues* 22, no. 6 (November 2012): 1-22, accessed February 2020, https://www.guttmacher.org/sites/default/files/pdfs/pubs/journals/j.whi.2012.09.002.pdf; Planned Parenthood, "The Impact of Defunding Planned Parenthood," accessed February 2020, https://www.istandwithpp.org/defund-defined/impact-defunding-planned-parenthood

[671] Under Trump's new rules, clinics that receive funds from the federal family-planning grant programme will no longer be able to perform abortions in the same space where they see other patients. Abortion and other health-care services will be required to be physically and financially separate entities. Title X participants will no longer be able to refer patients to abortion providers. Julie Wittes Schlack, "The Title X 'Gag Rule' Plays Politics by Attacking Women's Health," *wbur news*, March 1, 2019, accessed February 2020, https://www.wbur.org/cognoscenti/2019/03/01/title-x-gag-rule-julie-wittes-schlack

undermined their bodily autonomy and quality health care, already have worse health outcomes than white women with the means to afford private insurance. HIV/AIDS is one such health disparity between women, with black and Latina women constituting over eighty percent of women living with the virus.[672] Title X sites provide an important entry point for reaching low-income, uninsured, and underinsured women at risk of and living with HIV, offering on-site testing and immediate connection to care.[673] Most of the insured patients who visit a Title X provider have coverage through Medicaid, the largest insurer for people living with HIV. Of the more than four million people who relied on Title X providers to access preventative healthcare and treatment in 2017, more than half identified as either black, Latina, Hispanic, or Native American.[674]

According to the White House, the Trump administration's proposed Title X rule is "an effort to ensure that taxpayers do not fund the abortion industry."[675] Similar to other policies that politicians have proposed to undermine legal abortion since the 1970s, Trump's Title X policy is grounded more in ideology than epidemiological or social reality. The 1976 Hyde Amendment already prohibits women enrolled in Medicaid from using their insurance to pay for abortion care, and since its enactment in 1970, Title X has similarly specified that federal

[672] Planned Parenthood, "Medicaid and Reproductive Health," accessed February 2020, https://www.plannedparenthoodaction.org/issues/health-care-equity/medicaid-and-reproductive-health; Kaiser Foundation, "Women's Health Insurance Coverage," January 24, 2020, accessed February 2020, https://www.kff.org/womens-health-policy/fact-sheet/womens-health-insurance-coverage-fact-sheet/
[673] White and Brazell, "Family Planning Provides Key in Fight Against HIV," undated, *HIV.gov*.
[674] C. I. Fowler et al. *Family Planning Annual Report: 2017 national summary* (August 2018), ES-2, accessed February 2020, available at: https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2017-national-summary.pdf; Approximately 30 percent of Black women and 24 percent of Latina women ages 15 to 44 are enrolled in Medicaid, compared to approximately 14 percent of White women. Kaiser Family Foundation, "Women of Color More Likely to be Uninsured or Covered by Medicaid, 2012," November 12, 2013, accessed February 2020, https://www.kff.org/womens-health-policy/slide/women-of-color-more-likely-to-be-uninsured-or-covered-by-medicaid-2012/; Heather D. Boonstra, "Abortion in the Lives of Women Struggling Financially: Why Insurance Coverage Matters," *Guttamcher Institute* Vol. 19, July 14, 2016, accessed February 2020, https://www.guttmacher.org/gpr/2016/07/abortion-lives-women-struggling-financially-why-insurance-coverage-matters
[675] White House, "Support for Trump Administration's Proposed Title Rule," issued on May 22, 2018, accessed February 2020, https://www.whitehouse.gov/briefings-statements/support-trump-administrations-proposed-title-x-rule/

funding cannot be used for abortions.[676] Moreover, according to the CDC, the incidence of abortion is currently at an historic low, calling into question the need for new policies that address the issue.[677] In contrast to Koop's pragmatic public health approach, ideology is driving the Trump administration's policies. Whereas Koop advocated for prevention to help women prevent unwanted pregnancies—the best way to avoid needing an abortion—Republican conservatives such as Ohio governor Mike DeWine (R-OH) are instead slashing public financing for Planned Parenthood clinics in the state that similarly offer women prevention options. DeWine's efforts have led to the closure of two clinics in Ohio already, neither of which provided abortions.[678]

The strategy of targeting vulnerable women, including women from immigrant and refugee communities, adolescents, patients who are homeless, and women without comprehensive insurance coverage and the means to travel for their care, endure longer waiting times, and take more time off work has been replicated from earlier anti-abortion initiatives, such as the Hyde Amendment. As Congresswoman Katie Porter (D-CA) has highlighted, the gendered aspects of poverty, such as the unpaid care work that women and girls predominantly carry out, often leaves women unable to afford adequate medical care.[679] Moreover, single mothers are more likely to be uninsured than women in two-parent households.[680] The new Title X policy therefore puts preventative health services, such as screenings for the detection and treatment of sexually transmitted diseases and reproductive cancers, further beyond the reach

[676] Margaret Talbot, "How the Trump Administration is Stigmatizing Abortion," *New Yorker*, August 24, 2019, accessed https://www.newyorker.com/news/daily-comment/how-the-trump-administration-is-stigmatizing-abortion
[677] Alejandro De La Garza, "Number of U.S. Abortions Hits Lowest Rate Since Roe. Wade, CDC," *Time Magazine*, November 21, 2018, accessed February 2020, https://time.com/5461616/abortions-lowest-rate-cdc/
[678] "The G.O.P's War on Women's Health Gets Results," *New York Times*, September 9, 2019.
[679] Caroline Kelly, "Freshman Democrat presses JPMorgan CEO Jamie Dimon over pay disparity," *CNN*, April 11, 2019, accessed February 2020, https://edition.cnn.com/2019/04/10/politics/katie-porter-jamie-dimon-bank-employees/index.html
[680] Kaiser Family Foundation, "Women' Health Insurance Coverage," January 24, 2020, accessed February 2020, https://www.kff.org/womens-health-policy/fact-sheet/womens-health-insurance-coverage-fact-sheet/

of women who, as a result of myriad systemic and policy factors, from a lack of access to adequate housing to inadequate or no insurance coverage, already face delayed health diagnoses, higher rates of and increased mortality rates for cervical cancer, HIV, and breast cancer.[681]

The twenty-year assault on Planned Parenthood has forced a number of health clinics to close to the detriment of women's health.[682] Between 2011 and 2013, Texas Republicans rejected millions of dollars in federal Medicaid funding to undermine Planned Parenthood and other abortion providers that mostly low-income and women of colour relied on for care. As a result, 82 of the state's health clinics closed, about a third of them belonging to Planned Parenthood. Over the course of the next three years, nearly 50,000 fewer women received reproductive health care through the new state-run programme. Maternal mortality rates in Texas spiked, with black women being three times more likely to die from complications of childbirth than white or Latina women.[683] When under the direction of Governor Mike Pence, the Indiana state government slashed various sources of funding to Planned Parenthood in 2011 causing five different clinics to close across the state, none of which offered abortion

[681] Maria Gallucci, "Black women are dying of cervical cancer at twice the rate of white women, study shows," *Mashable UK*, January 23, 2017, accessed February 2020, https://mashable.com/2017/01/23/cervical-cancer-study-racial-disparity/?europe=true; Zahra Barnes, "8 Health Conditions that Disproportionately Affect Black Women," *Self*, March 30, 2017, accessed February 2020, https://www.self.com/story/black-women-health-conditions; Erika Stallings, "This is How the American Healthcare System Is Failing Black Women," *The Oprah Magazine*, August 1, 2018, accessed February 2020, https://www.oprahmag.com/life/health/a23100351/racial-bias-in-healthcare-black-women/

[682] After Kansas removed Planned Parenthood from the state's Title X programme in 2014, the organisation closed a health centre in the city of Hays. Similarly, in Iowa, rates of sexually transmitted diseases spiked when their health centres were forced to close. Hannah Levintova, "Iowa Just Gutted Planned Parenthood and the Results for Women are Brutal," *Mother Jones*, September/October 2017, accessed February 2020, https://www.motherjones.com/politics/2017/07/iowa-just-gutted-planned-parenthood-and-the-results-for-women-are-brutal/; Olga Khazan, "The Biggest Consequences of Trump's New Abortion Rule Won't Be for Abortion," *The Atlantic*, March 5, 2019, accessed February 2020, https://www.theatlantic.com/health/archive/2019/03/trumps-title-x-rule-change-planned-parenthood/584005/; Reay Earhart, "The Disastrous Consequences of Defunding Planned Parenthood," *Advocate*, April 14, 2017, accessed February 2020, https://www.advocate.com/commentary/2017/4/14/disastrous-consequences-defunding-planned-parenthood

[683] Mattie Quinn, "Why Texas Is the Most Dangerous U.S. State to Have a Baby," *Governing*, May 2017, accessed February 2020, https://www.governing.com/topics/health-human-services/gov-maternal-infant-mortality-pregnant-women-texas.html

services, its residents were left without anywhere to receive HIV testing. Similar to other rural counties in the country, high unemployment and poverty rates already limited people's access to healthcare. The closure of Scott County's Planned Parenthood resulted in the worst HIV outbreak in Indianan history.[684]

In the wake of funding cuts that have forced non-profit family planning sites specialising in women's health to close around the country, private retail companies such as CVS, Walgreens, Rite Aid, and Target have set up alternative treatment sites within their drug shops, also known as "Minute Clinics," to fill the gap. Like prison sick-calls, Minute Clinics are designed to provide one-off services and are ill-equipped in dealing with chronic health problems. Moreover, Minute Clinics are not set up to offer preventative and regular, constant care for chronic conditions that are more common in women than men.[685] They do not, for example, offer the regular gynaecological exams that doctors recommend for women living with HIV. And, just as with women in prison whose access to medical care was reliant on prison guards taking their complaints seriously, Minute Clinics also remove women's agency, leaving their ability to access primary care in the hands of individuals making a value judgement about their bodies.[686] However, unlike prisons with state oversight, CVS and other private drug stores leave pharmacists and sales associates free to refuse treatment based on

[684] Planned Parenthood, "The Effects of Defunding: Texas and Indiana," accessed February 2020, https://www.plannedparenthood.org/uploads/filer_public/9e/71/9e713a00-4844-43aa-adf6-3cc9e6cf30e0/the_effects_of_defunding_texas_and_indiana.pdf; Caitlin Conrad et al., "Community Outbreak of HIV Infection Linked to Injection Drug Use of Oxymorphone—Indiana, 2015," *MMWR Weekly* 64, no. 1624 (May 1, 2015): 443-444.

[685] A 2015 study found that thirty-eight percent of women suffer from one or more chronic diseases, compared to thirty percent of men. See Kristine Goodwin, "Improving Women's Health: State Policy Options," National Conference on State Legislatures, December 2015, 1, accessed February 2020, https://www.ncsl.org/Portals/1/Documents/Health/WHchecklist12-15.pdf

[686] In 2004, the Minnesota chapter of the National Organization for Women (NOW) began to picket CVS stores in Minneapolis because the company would not guarantee in-store access to contraceptives, including emergency contraceptives. Erin Matson, "Dear CVS: A Real 'Health-Care Company' Guarantees In-Store Access to Birth Control," *Re.Wire News*, February 27, 2014, accessed February 2020, https://rewire.news/article/2014/02/27/dear-cvs-real-health-care-company-guarantees-store-access-birth-control/

ideological grounds.[687] Approximately forty percent of the roughly 67,000 pharmacies in the United States are private retail corporations with no legal obligation to offer reproductive health services.[688] Because of the refusal of corporate leaders to make emergency and all other forms of contraception available in every store, regardless of individual employees who object to it, Minute Clinics put women trying to access primary care at the whim of the ideology of individual pharmacists.

The gutting of Title X, Planned Parenthood, and the Trump administration's attempts to reverse ACA are the culmination of the political rights' twenty-year effort to make healthcare more private and ideological. The consequences of privatised healthcare disproportionately affect women with chronic ailments, especially poor women of colour with HIV. Moreover, the deregulation of the pharmaceutical industry further compounds the challenge for women navigating an increasingly ideological healthcare system, a situation that activists are currently working hard to resist.

Taking on Big Pharma

On 8th May 2019, at Gilead Sciences Inc.'s annual shareholder meeting in San Francisco, a young woman named Emily Sanderson stood up in front of a panel of suited men and demanded that the company stop obstructing access to Truvada for PrEP. Sanderson, who is the national organiser of the international advocacy organisation Health GAP's Student Global AIDS Campaign, told the panel that she was "disgusted by the fact that you would put

[687] Matson, "Dear CVS," *Rewire.News*, February 27, 2014. According to the ACLU, "a pharmacy's or pharmacists' refusal to sell birth control does not violate a woman's federal constitutional rights." ACLU, "Religious Refusals and Reproductive Rights: Accessing Birth Control at the Pharmacy," 2007, 1, accessed February 2020, https://www.aclu.org/files/images/asset_upload_file119_29548.pdf
[688] Dima Mazen Qato et al., "The availability of pharmacies in the United States: 2007-2015," *PLoS ONE* 12, no. 8 (August 16, 2017), accessed February 2020, available at: https://doi.org/10.1371/journal.pone.0183172

profiteering ahead of the lives of people like me," and asked what the manufacturer's plan was to make sure that every single person in the United States can access PrEP when they need it.[689] Sanderson's protest did not mark the first time that the drug company had come under fire over the prices it set for its HIV medicine. In 2013, after ACT UP San Francisco got back together following years of stagnation, the group held a street action protesting the high price of Gilead's new drug, Stribild.[690] Six years later, Sanderson again highlighted the need for widespread access to Gilead's available prevention medication, noting that it cost substantially more money to treat HIV than to prevent it.[691] She also argued that if Americans could access low cost generic drugs at a price comparable to what is available on the international market, the total cost of a year's worth of PrEP clinical care would amount to less than the average price of a 30-day supply of Truvada at current prices.[692] When the panellists pointed to their programmes that defray co-pay costs as evidence of the company's efforts to make their drugs affordable, Sanderson asked why, if Gilead's programmes were effective, had rates of new HIV infections in the United States remained static since 2013.[693] The CDC similarly suggested that the decline in rates of new HIV infections had plateaued since 2013 as a result of effective HIV prevention and treatment not reaching those who could benefit most.[694]

---

[689] Health GAP, "AIDS Activists Disrupt Gilead Shareholder Meeting," May 8, 2019, available at: https://www.facebook.com/healthgap/videos/373025566641540/?v=373025566641540

[690] Matt Sharp, "Three Decades of Treatment Activism," *Achieve* 5, no. 4 (2013): 4.

[691] In the United States, each prevented HIV infection saves approximately $400,000 in lifetime medical costs. In the UK, it costs approximately £15,000 a year to treat a patient with HIV. PrEP, which is not available on the NHS, would cost it £5,000 a year. Nancy Bernstein and Christine Campbell, "Ending Homelessness to End HIV," *Achieve* 5, no. 4 (2013): 6. "Governor Cuomo Announces Plan to End the AIDS Epidemic in New York State," June 29, 2014, *ny.gov*, accessed February 2020, https://www.governor.ny.gov/news/governor-cuomo-announces-plan-end-aids-epidemic-new-york-state

[692] Generic means that the patent protection, afforded to a drug's original inventor and developer, has expired. Once a patent has expired, other drug companies are able to make generic copies of the drug and price it lower than their competitors. The PREP4ALL Collaboration, "A National Action Plan for Universal Access to HIV Pre-Exposure Prophylaxis (PrEP) in the United States," (July 2018): 33, accessed February 2020, https://www.poz.com/pdfs/national-action-plan-prep-2018.pdf

[693] Health GAP, "AIDS Activists Disrupt Gilead Shareholder Meeting," https://www.facebook.com/healthgap/videos/373025566641540/?v=373025566641540

[694] CDC, "U.S. Statistics," last updated January 16, 2020, accessed February 2020, https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics

Despite the drug's potential to drastically curb the spread of infection, approximately 167,000 people in the country are currently taking PrEP—only ten percent of those it is estimated could benefit.[695] Moreover, Truvada has largely failed to reach women at risk of new infections. Activists largely attribute the relatively low access to the drug to its high cost, which results from Gilead Sciences, Inc.'s ability to set and raise its price as high as it wants. Activists for cheaper medicines cite high drug prices as the reason why the majority of people diagnosed with an HIV infection in the United States do not have the virus under control, or that fewer than half of HIV-positive individuals, including HIV-positive women, are engaged in ongoing care, and that just over a half are virally suppressed.[696]

Gilead has set the price of Truvada at approximately $2,000 per month in the United States, while generic versions available outside the country are sold monthly for as little as $6. When the FDA first approved Truvada for HIV treatment in 2004, Gilead charged $800 for a one-month supply. Since the FDA approved Truvada for HIV prevention in 2012, Gilead has steadily raised the drug's price, despite the medicine not undergoing any therapeutic changes.[697] Gilead earned $3 billion from sales of the drug in 2018 alone, and since 2004, the company has recorded approximately $36 billion in revenue from the medicine.[698]

---

[695] Asia Russell, "AIDS Activists Disrupt Gilead Shareholder Meeting Over Access," *Health Gap Global Access Project*, May 8, 2019, accessed February 2020, https://healthgap.org/press/aids-activists-disrupt-gilead-shareholder-meeting-over-access-to-hiv-prevention-medicine/

[696] CDC Fact Sheet, "Today's HIV/AIDS Epidemic," August 2016, 2, accessed February 2020, https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/todaysepidemic-508.pdf ; CDC, "HIV in the United States and Dependent Areas," December 2019, 2, accessed February 2020, https://www.cdc.gov/hiv/pdf/statistics/overview/cdc-hiv-us-ataglance.pdf

[697] Donna Young, "Gilead CEO defends HIV drug Truvada's price, insists CDC patents invalid," *S&P Global*, May 16, 2019, accessed February 2020, https://www.spglobal.com/marketintelligence/en/news-insights/latest-news-headlines/51879834

[698] Ned Pagilarulo, "Gilead CEO pressured on PrEP pricing at House hearing," *Biopharmadive*, May 17, 2019, accessed February 2020, https://www.biopharmadive.com/news/gilead-ceo-house-hearing-prep-hiv-drug-pricing/555028/

Truvada's high US cost, which puts the drug beyond the reach of many, is a consequence of the particularities of the United States health care market and regulation.[699] The question of how to maintain medical innovation while making medicines available, affordable, and accessible to those who need them is at the heart of the historic struggle over healthcare in the United States. The nature of that struggle in the United States differs from the struggle over healthcare in other countries with a nationalised healthcare system in that many see healthcare as a privilege and not a right.[700] This departure in values is not inevitable but a consequence of a series of political choices, especially the patent process and lack of bulk buying.

Unlike countries with a national healthcare system, the United States has no government panel that either regulates or negotiates drug prices. Instead, each of the thousands of health insurance plans across the country have to negotiate their own prices with drug-makers separately. Because Americans are fragmented across these different health insurers, plans have much less bargaining power to demand lower prices. Other countries are instead able to buy drugs in bulk and negotiate lower prices from providers. A law passed in the Republican controlled House and Senate in 2003 expressly prohibited the federal government from negotiating cheaper prices for prescription medicines available through the insurance plan Medicare Part D.[701] As negotiation is a key counterweight against excessive pricing during

[699] In 2015, the CDC estimated that more than 1.1 million people in the US are at high enough risk to warrant PrEP, but fewer than 150,000 have ever received it. Despite the medical advancement Truvada represented, the rate of new HIV infections dipped only slightly from 2012 to 2016, eventually plateauing at around 40,000 new infections per year. Moreover, fewer than half people living with HIV in the US are virally suppressed. Sony Salzman, "Trump Touted Gilead's Donation of HIV-Prevention Medication, But Doctors Want Generics—Not Charity," *Rewire.News*, May 23, 2019, accessed February 2020, https://rewire.news/article/2019/05/23/trump-touted-gileads-donation-of-hiv-prevention-medication-but-doctors-want-generics-not-charity/

[700] For more on the differences between European and US approaches to the patent process and healthcare, see Jean-Paul Gaudillière, "How pharmaceuticals became patentable: the production and appropriation of drugs in the twentieth century," *History and Technology* 24 no. 2 (2008): 100-101.

[701] Stuart Silverstein, "This is Why Your Prescriptions Cost So Damn Much," *Mother Jones*, October 21, 2016, accessed February 2020, https://www.motherjones.com/politics/2016/10/drug-industry-pharmaceutical-lobbyists-medicare-part-d-prices/

market exclusivity, the lack of government negotiation is one of the main reasons why Americans pay the highest prescription costs of anyone in the world.[702] Even with bulk buying, in encouraging monopoly practices, the patent protection process keeps prices artificially high in the United States.

Patents usually last twenty-years before a drug becomes generic. The creation of new and better medications requires investment in research. Patents are intended to encourage pharmaceutical companies to invest their time and money in a drug they can profit from without the threat of competition. A twenty-year patent incentivises companies to make huge financial and temporal investments in pharmaceutical innovations. While the drug industry acknowledges that, at least in the short term, federal intervention in the marketplace could lower drug prices, they also argue that such a step would kill incentives to develop new medicines.[703] The idea behind the patent process, then, is to give drug companies the freedom to invent and invest in new and improved prescriptions.

While pharmaceutical companies argue that government regulation of drug pricing would stunt innovation, activists point out that too little regulation also restricts people's access to medication. As patent-protected drugs face no price caps or competitors for about twenty-years, patent holders have market exclusivity.[704] Market exclusivity means that patent protection effectively grants the pharmaceutical industry a monopoly on drugs, regardless of the human cost. In 1984, Congress passed the Hatch-Waxman Act, otherwise known as the

[702] Aaron S. Kesselheim et al., "The High Cost of Prescription Drugs in the United States," *JAMA* 316, no. 8 (August 23/30, 2016): 861, accessed February 2020, available at: https://jamanetwork.com/journals/jama/article-abstract/2545691
[703] Silverstein, "This is Why Your Prescriptions Cost So Damn Much."
[704] Tahir Amin, "The problem with high drug prices isn't 'foreign freeloading,' it's the patent system," *CNBC*, June 27, 2018, accessed February 2020, https://www.cnbc.com/2018/06/25/high-drug-prices-caused-by-us-patent-system.html

"Price Competition and Patent Term Restoration Act" in order to make it easier for generic drugs to enter the market, bring drug prices down, and increase public access. According to law professor Robin Feldman, while this measure worked for a while, drug companies developed a series of business and legal strategies to prevent cheaper drugs from entering the market.[705] Several pharmaceutical companies began adding secondary patents to drugs that already existed by making minor medical modifications to the dosage or the delivery system. The changes had little therapeutic effect and worked instead to extend a companies' monopoly.[706] Moreover, professor of medicine Aaron S. Kesselheim found no link between research and development costs and prices. He argued that prescription drugs are instead priced primarily on what the market will bear.[707] Critics of the drug pricing system therefore argue that market exclusivity, protected by monopoly rights awarded through FDA approval and patents, primarily serves drug manufacturers at the expense of individuals.[708]

While patents and corporate profits are often protected politically, the proactive role that the government took in implementing the polio vaccine in the 1950s proves that the current government could do more to make HIV medicines available to anyone who needs them, regardless of their means to pay.[709] In the 1950s, Jonas Salk did not patent the polio vaccine, a decision that enabled five separate pharmaceutical companies to simultaneously manufacture the vaccine, allowing them to produce it in both great quantity and at low cost.

---

[705] Robin Feldman, *Drug Wars: How Big Pharma Raises Prices and Keeps Generics Off the Market* (Cambridge: Cambridge University Press, 2017), 22-24. For more on the Hatch Waxman Act, including a series of scandals following the implementation of the act, see Jeremy A. Greene, *Generic: The Unbranding of Modern Medicine* (Baltimore: John Hopkins University Press, 2014), 3-4.
[706] Joe Nocera, "Why Big Pharma Is Winning the Drug Price Wars," *Bloomberg*, April 8, 2019, accessed February 2020, https://www.bloomberg.com/opinion/articles/2019-04-08/why-drug-prices-keep-rising-despite-congress-s-efforts
[707] Kesselheim et al., "The High Cost of Prescription Drugs in the United States," 858.
[708] Elle Mahdavi, "Patents and the Pharmaceutical Industry," *BerkeleyHaas*, May 26, 2017, accessed February 2020, https://cmr.berkeley.edu/blog/2017/5/patents-and-pharmaceuticals/
[709] Mahdavi, "Patents and the Pharmaceutical Industry," *BerkeleyHaas*, May 26, 2017, accessed February 2020, https://cmr.berkeley.edu/blog/2017/5/patents-and-pharmaceuticals/

The decision not to patent the vaccine was not Salk's alone—the National Foundation and the University of Pittsburgh had also contributed to the research and development of the product.[710] President Eisenhower then directed Congress to appropriate $28 million to ensure that no-one was "denied vaccination by reason of its cost."[711] As a result, the number of new polio cases in the country dropped by more than 92 percent within six years, and two decades later, in 1979, the CDC had declared the polio virus eliminated from the United States.[712] This precedent has inspired AIDS activists.

In July 2018, the PrEP4ALL Collaboration, an advocacy organisation that Emily Sanderson had co-founded earlier that year, released a 40-page call to action entitled "A National Action Plan for Universal Access to HIV Pre-Exposure Prophylaxis (PrEP) in the United States." In it, the Collaboration argued that "America's success in fighting polio proves what is possible when our society dedicates itself to fighting for better health for all."[713] They outlined the steps that the current government could take to cancel the patent on the drug that enables Gilead's monopoly on Truvada and therefore end the HIV epidemic without a vaccine. Under the bipartisan Bayh-Dole Act of 1980, a provision in American law called march-in rights means that if a drug was developed using federally funded research, the government can take the patent away from a company if it is not available at a reasonable price and assign it to somebody else.[714] A report published in the *Washington Post* in March 2019 revealed that the federal government had issued $50 million in grants to researchers developing Truvada as

[710] David M. Oshinsky, *Polio: An American Story*, 211.
[711] James C. Hagerty, Press Secretary to the President, Press Release Statement by the President About the Polio Vaccine Situation, May 31, 1955, 3, accessed February 2020, https://www.eisenhowerlibrary.gov/sites/default/files/research/online-documents/salk/salk-g.pdf
[712] J Hamborsky et al., Epidemiology and Prevention of Vaccine Preventable Diseases, 13th edition, April 2015, 308, accessed February 2020, https://www.cdc.gov/vaccines/pubs/pinkbook/downloads/polio.pdf
[713] The PREP4ALL Collaboration, "A National Action Plan for Universal Access to HIV Pre-Exposure Prophylaxis (PrEP) in the United States," 4.
[714] The PREP4ALL Collaboration, "A National Action Plan for Universal Access to HIV Pre-Exposure Prophylaxis (PrEP) in the United States," 36-40.

PrEP.[715] This means that US taxpayers paid for Truvada through the NIH and, according the PrEP4ALL, still retain the relevant intellectual property rights to break Gilead's patent on the drug.[716]

The NIH responded to the *Washington Post* report stating that it is not within its purview to control the price of drugs. However, besides the example of polio vaccination, a more recent precedent for the government taking a patent licence away from pharmaceutical companies in the wake of national health emergencies exists.[717] One week after the 9/11 attacks on the United States in 2001, fears of an anthrax epidemic swept the country. Bayer, the same company that makes aspirin, held the patent on the most prominent anti-anthrax drug, ciprofloxacin, and charged $13 a pill. When the government wanted 200 million pills for its stockpile, they asked Bayer to lower the price and threatened to take away their patent on Cipro if they refused. Bayer agreed and lowered the price to $1.50 a pill.[718] For advocacy groups like PrEP4ALL, the government's refusal to take the same steps to lower the price of Truvada for PrEP undermines any serious political commitment on the part of the Trump administration to halt the spread of HIV.

On 9th May 2019, the day after Gilead's shareholder meeting in San Francisco, the CEO of Gilead Sciences Inc., Daniel O'Day, announced that the company had brokered a deal with the DHHS to give a free supply of Truvada to approximately 200,000 uninsured patients a year through 2030. Gilead also announced its decision to let a generic version of Truvada

[715] Christopher Rowland, "An HIV treatment cost taxpayers millions. The government patented it. But a pharma giant is making billions," *Washington Post*, March 26, 2019, https://www.washingtonpost.com/business/economy/pharma-giant-profits-from-hiv-treatment-funded-by-taxpayers-and-patented-by-the-government/2019/03/26/cee5afb4-40fc-11e9-9361-301ffb5bd5e6_story.html
[716] #BreakThePatent Campaign, accessed February 2020, available at: https://breakthepatent.org
[717] Trenton Straube, "Here's How We Can Get Universal Access to PrEP," *POZ*, July 25, 2018, accessed February 2020, https://www.poz.com/article/universal-access-prep-hiv-prevention
[718] Heather Stewart et al., "Bayer bows to pressure on anthrax antidote," *The Guardian*, October 23, 2001, accessed February 2020, https://www.theguardian.com/business/2001/oct/23/anthrax.businessofresearch

come to the market in September 2020, a year earlier than it had agreed to under a patent settlement deal with the drug company Teva Pharmaceutical Industries Ltd., which won FDA approval of the lower-cost version in 2014.[719]

Gilead's announcement demonstrated the activists' ability to move drug companies to act, but news of the charitable donation and the introduction of an early generic on the market failed to fully placate their concerns. Aaron S. Lord, a member of PrEP4ALL and physician at New York University School of Medicine, asked what was to stop Gilead—other than a desire for profit margins—from releasing the rights to Truvada immediately.[720] Dr Michael Saag, an HIV researcher at the University of Alabama and a member of the Presidential Advisory Council on HIV/AIDS, similarly noted that while Gilead's donation was a "nice gesture," what most providers and patients wanted were reasonably and affordably priced drugs, not charity.[721] Industry-controlled charity still relies on the benevolence of private companies and removes agency from the individuals who need medicine. Critics noted that providing 200,000 people with medicine did not go far enough as an estimated 1.2 million people at risk of HIV needed access to PrEP now.[722] Moreover, charity care perpetuates tropes of who is deserving and who is not deserving in welfare politics, tropes that have historically perpetuated value judgements about women's behaviour.

[719] In the 1990s, drug companies did not want to lower their HIV drug prices for people affected by AIDS in Africa. As a result of public outcry, they decided to distribute a certain number of free or heavily discounted drugs in the market. If you can give enough free drugs in the market, you dry up the demand, and there is no incentive for generic makers to get into it. See the example of South Africa. Sharp, "Three Decades of Treatment Activism," 4.
[720] David Artavia, "Meet the Organizers from PrEP4ALL," *hivplusmag*, May 14, 2019, accessed February 2020, https://www.hivplusmag.com/uu/2019/5/14/meet-organizers-prep4all
[721] Salzman, "Trump Touted Gilead's Donation of HIV-Prevention Medication, But Doctors Want Generics—Not Charity."
[722] Artavia, "Meet the Organizers from PrEP4ALL," *hivplusmag*, May 14, 2019.

Within a week of Gilead's announcement and after meeting with activists, members of the House Oversight and Reform Committee called Daniel O'Day to a hearing before Congress to justify recent Truvada price hikes. Congresswoman Alexandria Ocasio-Cortez (D-NY) questioned O'Day about the disproportionately high cost of the US drug, asking why Gilead sold Truvada for PrEP in generic forms for less than $8 in countries such as Australia and South Africa but for $2,000 a month in the United States. O'Day explained that unlike in other parts of the world where the drug is generic, Gilead still has the patent on Truvada in the United States, allowing the company to legally set and raise prices as high as they wanted them to be.[723]

The hearing was not the first time that a head of a pharmaceutical company had received criticism for the price tags they have attached to life-saving AIDS medication. Patent protections famously enabled the CEO of Turing Pharmaceuticals, Martin Shkreli, to inflate the price of the drug Daraprim from $13.50 to $750 a pill virtually overnight in 2015. Shkreli bought the rights to Daraprim, a generic drug used to treat HIV and cancer, with the aim to sell it at an extreme mark-up to maximise profit.[724] Shkreli's approach to drug pricing, while controversial, was legal and aligned with free market advocates who believe that the forces of supply and demand should set prices for healthcare goods and services and that charity should provide care for those without insurance. Shkreli's attempts to increase the affordability of Daraprim through a co-payment assistance programme for people with private insurance and donation programmes to help those who are deemed eligible made

[723] Andrew Buncombe, "AOC asks pharma CEO why $2,000 HIV drug costs just $8 in Australia: 'People are dying for no reason,'" *The Independent*, May 17, 2019, accessed February 2020, https://www.independent.co.uk/news/world/americas/us-politics/aoc-hiv-drug-cost-us-australia-ceo-gilead-video-a8919316.html. In 2018 the UK high court overturned Gilead's patent extension on Truvada, meaning that unbranded versions of the drug can be legally prescribed. National AIDS Trust (NAT), "PrEP Drug Patent Overturned in UK—NAT Respond," Tuesday 18, 2018, accessed February 2020, https://www.nat.org.uk/press-release/prep-drug-patent-overturned-uk-nat-respond

[724] Anonymous, "The People v. Martin Shkreli," *Wall Street Journal*, December 19, 2015.

people reliant on charity and assistance programmes. Charity healthcare undermines the notion that everyone should have equal access to universal care and removes people's autonomy, making their health and well-being dependent on the benevolence of an individual or organisation.[725] As with privately owned Minute Clinics, charity care places a particularly heavy burden on women, as their ability to access primary care is left in the hands of individuals and organisations free to make value judgments about their bodies. Women's fight for healthcare access is about equality, not charity. Even with special programmes or insurance mitigating the cost for users, someone still ends up paying more because of a private companies' desire for profit.[726]

The same week that O'Day appeared before Congress, nine activists for cheaper medicines—Brenda Emily Goodrow, Peter Staley, Steve Fuller, Gregg S. Gonsalves, Andrew R. Spieldenner, Robert J. Vazquez, Jason Walker, Michael Warner, and Jacob Zydonis—launched a class action antitrust lawsuit filed by 140 patients from 31 states against Gilead Sciences Inc. and several other manufacturers of HIV drugs.[727] These include some of the nation's largest pharmaceutical companies, including Bristol-Myers Squibb Company and the Johnson & Johnson subsidiary Janssen R&D Ireland. The lawsuit, *Peter Staley, et al. v. Gilead Sciences, Inc., et al.,* represents activists' most recent effort to widen access to affordable HIV medicines, and the trial date is set for February 2022.[728] The case, filed in the United States District Court for the Northern District of California, alleges that the drug manufacturers illegally conspired to keep prices artificially high on some of the most

[725] Salzman, "Trump Touted Gilead's Donation of HIV-Prevention Medication, But Doctors Want Generics—Not Charity."
[726] Nia Lyn, "Condemn Martin Shkreli's price increase of AIDS medication," *University Wire*, April 5, 2016.
[727] The plaintiffs are seeking damages and injunctive relief (a legal remedy that may be sought in a civil lawsuit, in addition to, or in place of, monetary damages.) Rather than offering money as payment for a wrong in a civil action, injunctive relief is a court order for the defendant to stop a specified act or behaviour.
[728] Liz Highleyman, "Drug Company Antitrust Trial Gets 2022 Court Date," *Poz*, January 23, 2020, accessed February 2020, https://www.poz.com/article/drug-company-antitrust-trial-gets-2022-court-date

important and widely used medicines for the treatment and prevention of HIV in the United States.[729] The complaint alleges that:

> Through an array of anticompetitive practices Gilead has acquired and maintained a monopoly in the market for drugs that comprise the modern HIV treatment regimen known as 'combination antiretroviral therapy' ('cART'). The scheme has enabled Gilead and its co-conspirators to unlawfully extend patent protection for their drugs, impair entry by would-be generic competitors, and charge exorbitant, supracompetitive prices for the drugs that people living with HIV need to survive.[730]

According to the complaint, in making agreements with partner companies requiring them to use their HIV medicine tenofovir disoproxil (TDF) in their fixed-dose-combination pills even when a much cheaper generic version of the compound was available, Gilead violated the Sherman Antitrust Act—a law introduced in 1890 to regulate competition. In exchange, Gilead agreed not to market pills that competed with BMS and Janssen's HIV drugs after the patents had expired. In blocking generic competition, Gilead could keep the prices for its own HIV-drugs at an inflated level.[731] More than eighty percent of patients starting an HIV regimen in the United States and over eighty percent of continuing patients take one or more of Gilead's products every day, demonstrating how in controlling the market for tenofovir, Gilead dominates the market for cART.[732]

---

[729] Eric Sagonowsky, "Gilead tries—and fails—to dodge lawsuit claiming it delayed safer HIV meds," *FiercePharma*, May 14, 2019, accessed February 2020, https://www.fiercepharma.com/pharma/gilead-fails-to-convince-judge-to-toss-hiv-drug-case

[730] Peter Staley, et al. Plaintiffs v. Gilead Sciences, Inc., et al. Defendants, Case No. 3:19-cv-2573 (May 5, 2019): 3, accessed February 2020, available at: https://drive.google.com/file/d/0B4BdaKgM6bo7VWhMdXlnMUNWc24wRzVNZXNIeDBRcjlUeVZr/view

[731] Charleston Lim, "Lawsuit Accuses Gilead Sciences of propping up cost of lifesaving HIV treatments by blocking generic competition," *CNBC*, May 14, 2019, https://www.cnbc.com/2019/05/14/lawsuit-alleges-gilead-propped-up-cost-of-hiv-drug.html

[732] Staley, et al. Plaintiffs v. Gilead Sciences, Inc., et al. Defendants, Case No. 3:19-cv-2573, 3.

The complaint also alleges that Gilead withheld safer HIV drugs for years in order to protect its TDF monopoly. Activist Brenda Goodrow is one of the six lead plaintiffs claiming that for years, major drug firms have intentionally blocked a cheaper, generic version of HIV treatment from coming to market.[733] In April 2019, Gilead submitted a new drug application requesting FDA approval of its Descovy combination pill for PrEP. Descovy contains tenofovir alafenamide (TAF)—an updated formulation of tenofovir that is easier on the kidneys and bones—and emtricitabine. In a clinical trial that included some transgender but no cisgender women—the implication again being that pharmaceutical companies still treat trans women as biological men—researchers showed that Descovy worked as well as and was better for bones and kidneys than the Truvada pill containing TDF. According to the complaint, Gilead withheld drugs containing tenofovir alafenamide fumarate (TAF) in 2004 in order to keep out competition, despite knowing the TAF-based medicines were safer. The FDA approved Descovy in October 2019, before the generic version of Truvada became available. As a result, activists worry that instead of improving access to the generic medicine, many will choose to switch to the safer, high-cost drug Descovy.[734] For women, Descovy is another new medicine with old problems. The FDA did not approve its use for women, as no women were included in the clinical trials needed to bring it to market.[735]

[733] Goodrow has worked with the CDC on various ACT Against AIDS Initiatives including the *Let's Stop HIV Together* anti-stigma campaign, where she appears on one of their posters alongside the tagline "She's not my friend with HIV. She's my friend." CDC, *Lets Stop HIV Together* Campaign Resources, accessed February 2020, https://www.cdc.gov/stophivtogether/campaigns/index.html

[734] Trenton Straube, "Generic PrEP to Arrive in September 2020, but Will Big Savings Follow?" *POZ*, May 9, 2019, accessed February 2020, https://www.poz.com/article/generic-prep-arrive-september-2020-will-big-savings-follow

[735] Anna Forbes, "HIV Affects Millions of Women. So Why Isn't a New PrEP Drug Approved for Their Use?" December 2, 2019, accessed February 2020, https://rewire.news/article/2019/12/02/hiv-truvada-descovy-women/

Despite the success of the ACA in providing those at risk from and living with HIV and AIDS with greater access to coverage and care, the power of the pharmaceutical industry to set and raise drug prices free from government regulation continues to curb people's access to life-saving medication. The cost of prescription drugs has become a contentious political issue over the past two decades as prices have continually climbed. As seen throughout the forty-year history of the epidemic, women have repeatedly suffered as a consequence of financial considerations, whether from a reluctance on the part of the federal bureaucracy to expand its welfare programmes to HIV-positive women in the 1980s, from prison authorities failing to provide its women prisoners access to treatment for reproductive and chronic illnesses and, more recently, as an unintended consequence of the profiteering of the pharmaceutical industry.

The pharmaceutical industry cannot stop HIV with antiretroviral therapy and PrEP alone. As historian Allen Brandt put it in 1985, drugs are rarely "magic bullets."[736] Without a shift in either the healthcare system or the patent process, PrEP will continue to be beyond the reach of many, a reality which will continue to harm women.

Conclusion

Just as the introduction of vaccines and cures did not automatically signal the end of other infectious diseases, the remarkable success of medical advances in transforming an HIV infection from a "death sentence" to a chronic and manageable condition by the close of the twentieth century should not give the impression that HIV has become a problem of the past in the modern United States. Women, people of colour, people living with multiple

[736] Brandt, *No Magic Bullet.*

disabilities, people detained in prison, and people living in poverty continue to bear the heaviest burden of the epidemic.

Ending the HIV epidemic requires not only scientific breakthroughs but political choices. The government could break Gilead's patent using its march-in rights. They could also broaden healthcare access, including Medicaid expansion in all fifty states and US territories, and seek to structurally address the social determinants of health including poverty, education, housing, and exposure to violence. Bringing the AIDS epidemic under control as it enters its fifth decade requires protecting the civil liberties and dignity of all people, including women.

Historians, nor society at large, do not know how the latest plans to end the AIDS epidemic will play out. The fact that the history of HIV is one in motion requires historians to make sense of events as they happen without the assistance of an institutional archive. Manuscript collections cannot yet reveal whether activists for cheaper medicines will succeed in their attempts to hold drug companies accountable for the high cost of medication, or how effective the Trump administration's new Title X rule will prove in restricting women's access to non-profit treatment spaces. Nor can the existing historical record tell us whether feminist scientists will finally realise their decades long goal of bringing a woman-initiated and controlled prevention tool to market and, if they do, whether it will empower women or, similar to the female condom, be relegated to relative obscurity.

What we do know is that throughout the forty-year history of the AIDS epidemic women, with varying degrees of power, in diverse settings, and against different odds have fought both for recognition for treatment and to protect their autonomy against those seeking to use AIDS as a wedge to claim greater control over their bodies and lives. A younger generation

of women at the centre of the activism to end HIV now continue the work of women who confronted HIV while taking on entrenched power in the first decades of the epidemic, just as those activists built on the legacies of women fighting for medical equality and bodily autonomy in the feminist healthcare movement of the 1960s and 1970s.

Conclusion

New Beginnings

President Donald Trump had only been in office five months when, in June 2017, six members of the Presidential Advisory Council on HIV/AIDS (PACHA) quit. Founded by President Bill Clinton in 1995, PACHA is a president-appointed group of experts tasked with advising the secretary of the Department of Health and Human Services (DHHS) and, ultimately, the president, on how to promote the most effective HIV treatment and prevention strategies. The six members who quit did so out of frustration over Trump's policies on healthcare, which he had designed without consulting them. The members were particularly concerned about the potentially devastating impact of the Trump administration's proposed American Health Care Act (AHCA) for people living with HIV. A bill that sought to repeal the Obama-era Affordable Care Act (ACA), AHCA would make healthcare access for people with pre-existing conditions more difficult and prevent many people living with HIV from receiving proper treatment. Although the Senate blocked the bill, the members who quit the council also worried about Trump's new Title X rule, which prevents clinics that receive federal funds for family planning services from performing abortions or making abortion referrals in the same space where they see other patients. The courts have consistently upheld the new rule, which took effect in March 2020. Moreover, Trump's ongoing efforts to gut Medicaid funding have raised concerns that his administration will halt, or reverse, important gains made in the treatment and prevention of HIV.[737]

[737] Alice Park, "6 Resigned from Trump's HIV/AIDS Advisory Board. Here's Why One Doctor Stayed," *Time Magazine*, June 20, 2017, accessed February 2020, https://time.com/4824456/trump-hiv-aids-council-resign/; Michael Hiltzik, "Trump makes his most aggressive move yet to gut Medicaid," January 30, 2020, accessed February 2020, https://www.latimes.com/business/story/2020-01-30/trump-moves-to-gut-medicaid

President Trump's response to the HIV epidemic is an example of the disconnect between the promises the president makes in public and the policies he introduces that, in practice, accomplish the opposite. In his 2019 State of the Union address, Trump surprised many when he pledged to put the United States at the forefront of a bold goal to end the HIV epidemic worldwide by 2030. The statement jarred with the hostile actions his administration had taken toward women and other people living with and at risk of HIV infection throughout his tenure.[738] Trump reiterated his pledge to end HIV by 2030 and doubled down on his statements about healthcare in his 2020 State of the Union address, to which long-time women's health and HIV advocate Nancy Pelosi (D-CA) responded by ripping up his speech.[739] As the Trump administration works to undermine women's health through domestic and global policy practices, references to their autonomy are also being erased in the public sphere. An image of the 2017 Women's March that took place on 21st January, the day after Trump's inauguration, is featured in an upcoming exhibition celebrating the centennial of women's suffrage at the National Archives in Washington, D.C. Ostensibly wishing to avoid engaging in political controversy or causing offence, the archivists blurred posters that showed messages criticising Trump and expressing women's autonomy, sometimes explicitly, in the photograph.[740]

2020 is a seismic year for women's health. With the upcoming presidential election in November, much of what will happen in women's health, and the health of women with HIV

[738] James Hamblin, "Stopping HIV Would Require an Entirely Different Trump," *The Atlantic*, February 6, 2019, accessed February 2020, https://www.theatlantic.com/health/archive/2019/02/trump-state-of-the-union-hiv/582076/

[739] Ian Millhiser, "The Biggest lie in Trump's State of the Union Speech," February 4, 2020, accessed February 2020, https://www.vox.com/2020/2/4/21123495/biggest-lie-trump-state-of-the-union-2020-preexisting-conditions; Julia Belluz, "Trump called for an end to AIDS in the US by 2030. That's totally realistic," February 4, 2020, accessed February 2020, https://www.vox.com/2019/2/5/18210455/state-of-the-union-2020-trump-aids-hiv-health

[740] Joe Heim, "National Archives exhibit blurs images critical of President Trump," *Washington Post*, January 17, 2020, accessed February 2020, https://www.washingtonpost.com/local/national-archives-exhibit-blurs-images-critical-of-president-trump/2020/01/17/71d8e80c-37e3-11ea-9541-9107303481a4_story.html

and AIDS specifically, will depend on what happens next politically. In this conclusion, I will first consider the politics of our current moment in order to offer four lessons that help historians to better understand the changes and continuities in the politics of women's health, and particularly the health of women with AIDS, over the forty-year period that this thesis has charted. I will then summarise the main arguments of the thesis and conclude with two stories that illustrate the new and historic challenges facing women living with HIV today.

Four Lessons

First, the fact that the future of Planned Parenthood is under threat speaks to how far coercion and ideology have replaced pragmatism and compassion in the political approach to women's health since the end of the Reagan era. Since the 1980s, the anti-abortion movement has tried to amend Title X regulations so that recipients must separate their Title X-funded prevention services from their abortion activities funded through other sources. But, whereas in chapter two, Surgeon General Koop built the most unlikely of alliances with Faye Wattleton and Planned Parenthood with the effect of blocking efforts to limit women's access to legal abortion, chapter five addressed the consequences of a twenty-year assault on Planned Parenthood on the part of the political right since. In August 2019, Planned Parenthood withdrew from the Title X programme. Alexis McGill Johnson, the acting President of Planned Parenthood, along with Marcia Degeer, President of Maine Family Planning (MFP), and other clinic leaders, decided to forgo Title X funding in order to keep offering women full reproductive health services, including providing and referring patients for abortion.[741] Without Title X funding, many of these clinics will not have the resources to reduce the fees

[741] Sarah McCammon, "Planned Parenthood Withdraws From Title X Program Over Trump Abortion Rule," *npr*, August 19, 2019, accessed February 2020, https://www.npr.org/2019/08/19/752438119/planned-parenthood-out-of-title-x-over-trump-rule

for non-abortion medical procedures for uninsured women, possibly forcing them to close.[742] The requirement that Title X services are physically and financially separate from non-Title X services, including both abortion and abortion referrals, may prove too financially and logistically burdensome, especially for small community clinics. The 2011 HIV outbreak in Indiana and the simultaneous spike in maternal mortality rates in Texas have already shown the harmful consequences of clinic closures.

Second, uncertainties in the future of microbicide research also reveal that the same challenge of putting and keeping women's needs on the male-oriented health agenda that existed in the 1980s persists today. In November 2018, the NIH announced their plans to discontinue funding for research into local microbicides after 2020. Instead, the institute will fund research into solutions that can protect a person no matter where in the body they are exposed to the virus, such as implants and injections of long-acting HIV prevention drugs now in development. While an intravaginal ring is one of the four long-acting HIV prevention tools that the NIAID is researching, feminist scientists still believe that a microbicide gel is a crucial tool to empower women in the fight to end AIDS. Methods such as injectable PrEP affect the entire body, likely requiring up to six clinic visits per year, a financial burden for women without access to uninterrupted public health insurance. As the US public sector has been the strongest funder of microbicide research and development worldwide to date and, as scientists cannot rely on corporate investment to fill this gap, advocates worry that the NIH's decision will effectively defund local microbicide research altogether.[743] The NIH's decision

[742] Alice Miranda Ollstein and Rachel Roubein, "Trump administration begins enforcing abortion 'gag rule,'" *Politico*, July 16, 2019, accessed February 2020, https://www.politico.com/story/2019/07/16/trump-administration-abortion-gag-rule-1593665

[743] Anna Forbes, "Vital Microbicides May Soon Be Out of Reach," *Rewire.News*, November 9, 2017, accessed February 2020, https://rewire.news/article/2017/11/09/vital-microbicides-may-soon-reach/; Resource Tracking for HIV Prevention Research & Development, *HIV Prevention Research & Development Investments, 2000-2015: Investment priorities to fund innovation in a challenging global health landscape* (October 2016): 29-30, accessed February 2020, http://www.hivresourcetracking.org/wp-content/uploads/2016/12/Resource_Tracking_Report_2015.pdf

therefore threatens almost three decades of work to bring to market a gel that is available without a prescription, and is cheap, easy to use, and has few side effects.

Third, the contemporary debate over the future direction of the US healthcare system reveals how precarious the medical situation still is for those dependent on publicly funded healthcare. If the presumptive Democratic presidential nominee, Joe Biden, beats President Trump in the November election, he has the potential to play a central role both in influencing the future of Planned Parenthood and microbicide research and to create a single, federal, universal health insurance programme otherwise known as Medicare-for-All. The new system would replace most existing public and private health insurance with a new federal programme guaranteeing health coverage for all or nearly all US residents. As well as noting the benefits of extending coverage for some Medicaid services to more Americans, the political debate has largely ignored the potential consequences of Medicare-for-All for people reliant on the Medicaid programme. Forty percent of people living with HIV currently rely on Medicaid. Moreover, women are more reliant on Medicaid than men, and women of colour more reliant than white women. At present, it is unclear how Medicare-for-All proposals would affect coverage, benefits, out of pocket costs, and access to care for the low-income and vulnerable populations currently reliant on the Medicaid programme.[744]

Fourth, the fight over women's health continues to extend beyond the executive branch of government. Since the 2018 midterm elections, the Republican-controlled Senate has repeatedly stonewalled the reform efforts of the activist House of Representatives. In 2019, the Senate blocked bills that House Democrats passed that focused on healthcare, including

[744] Jennifer Tolbert et al., "How Will Medicare-for-all Proposals Affect Medicaid?," *Kaiser Family Foundation*, September 12, 2019, accessed February 2020, https://www.kff.org/medicaid/issue-brief/how-will-medicare-for-all-proposals-affect-medicaid/

those seeking to lower prescription drug prices, to protect pre-existing conditions, and condemn the Trump administration's campaign to reverse ACA. Many of the bills that have passed in the House are sitting in the Senate. Instead of taking up major policy issues, Senate Majority Leader Mitch McConnell (R-KY) has focused more on confirming nominations to the judiciary and Trump's Cabinet. Many of these nominees are conservative and hold views that are hostile to reproductive health and rights. As life-time positions, these federal judges will be a key part of Trump's legacy, potentially restricting women's ability to access healthcare for decades to come.[745]

Despite not knowing the outcome of the upcoming presidential election, this thesis demonstrates that structural issues have persisted in women's health, and the health of women with HIV specifically, over the past forty years regardless of who was in power. It has shown that across time and place, women fighting to stay alive in the context of HIV and AIDS in the United States have also sought to reform a healthcare system that frequently failed to address their reproductive and chronic illnesses, often putting their ability to access care at the whim of individuals making value judgements about their bodies. Women have also taken on a deregulated pharmaceutical industry that frequently puts profiteering before their health needs. Moreover, they have worked to help women navigate health delivery systems that researchers have developed using the male model of health as described in this thesis while confronting the persistent gender bias in medical research. In an uncertain future, historians will surely continue to find women struggling against structural issues while fighting for medical equality, autonomy, and rights.

[745] Planned Parenthood, "Courting Disaster: Trump's Judicial Nominees," accessed February 2020, https://www.plannedparenthoodaction.org/issues/trump-judicial-nominations

Summary of the Main Arguments in this Thesis

Speculating on the future trajectory of the history of women's health and examining its past, this thesis shows that gender acts as a discriminatory vector in US politics. Time and again, the women in this thesis came second to men in terms of AIDS policy making, receiving healthcare, and accessing new health technologies. Women especially found it more difficult to access equal treatment and care when their race, class, sexual identity, and legal status—identities and statuses which often overlapped—meant they could not or did not place their arguments within a respectability politics framework. Yet, because of their marginalisation, these women were best placed to see the impact of inequality and to demand political change and justice. They had the language and the desire to address disparities in economics, crime, and public health.

Although the women AIDS activists in this thesis often found themselves in an adverse political environment, they were nevertheless able to achieve some of their goals. Speaking to the politicisation of children and the unborn in the 1980s, the state often responded more proactively to women's needs when they involved infants and children. The pattern of the state recognising women first as mothers played out in the early medical and political response to HIV, as diagnosticians and doctors first realised that women could contract the virus when their children became sick, and subsequently that women needed access to public health measures such as clinical trials in order to prevent perinatal transmission. Furthermore, state authorities supported residential programmes that different advocacy groups set up to protect the needs of abandoned infants with HIV and AIDS. Although women such as Barbara Bush played an active role in supporting these new institutions, the focus on children effectively erased HIV-positive women from the story.

In contrast, government authorities were less receptive—and often responded more punitively—to women who were childless, or who foregrounded actual sexual activity and practice instead of their childbearing potential. Conservative politicians worked to censor the explicit educational materials of women who had sex with women. Queer women struggled for recognition as a group that required inclusion in surveillance, research, and treatment protocols. Women—such as those in prison—whom the state did not deem important enough to spend money on also suffered from a lack of financial support.

A large part of the ability of the women in this thesis to gain political traction therefore depended on them leveraging their childbearing capacity as opposed to their own sexual agency. This pattern speaks to a longer history of government regulation of non-procreative sexual acts. While women are often treated as secondary to men in histories exploring the relationship between sexuality and the state, this thesis shows that women's ability to make a set of collective claims and demands on the political process was still closely tied to reproduction, and a concern for the health and well-being of children in the late twentieth and early twenty-first century.[746] Although women AIDS activists had a language to articulate their rights, receiving state support was still closely tied to the function of respectability politics.

Women's relative ability to achieve their goals depended on the different types of activism available to different groups of people based on their legal status, race, and class. Activist success was often tied to the power of the people being targeted. For women in prison with

[746] For example, Canaday's field defining study, *The Straight State*, only dedicated one chapter to lesbian women.

limited resources, connecting to groups with existing activist networks and deep fundraising histories, and therefore greater means to take up their cause, was central to their ability to launch a class action lawsuit against the state of California. Equally, their inability to fundamentally improve the health services at their facilities spoke to the stark power imbalance that existed between women prisoners and a carceral state that was expanding in increasingly punitive ways in this period.

While the egregious conditions of incarceration brought many women prisoners into activism for the first time, a number of other women in this thesis—such as those involved in the Boston Women's Health Book Collective, the Lesbian Avengers, the ACT UP Women's Caucus, and the ACE programme at Bedford Hills—came to AIDS activism from other causes, enabling them to mobilise effectively against the health crisis of AIDS. Many who fought to centre women in AIDS policy making and education and to broaden women's access to healthcare continued the work of the feminist and LGBTQ health movements of the 1960s and 1970s.[747] Specifically, the health networks that were forged and the experience gained in creating sex manuals and LGBT guides, coupled with the sentiment that communities should become their own health advocates provided a model for addressing the new health crisis of AIDS from the 1980s onwards. Women's previous experience with feminist and LGBTQ healthcare therefore put them at the centre of the fight against HIV and AIDS in the following decades.

The function of the public-private healthcare system in the United States—compounded by the growing influence of the pharmaceutical industry in this period—has impacted how

[747] Katie Batza, "From Sperm Runners to Sperm Banks: Lesbians, Assisted Conception, and Challenging the Fertility Industry, 1971-1983," *Journal of Women's History*, Vol. 23 no. 2 (2016): 82-102; Wendy Kline, *Coming Home: How Midwives Changed Birth* (Oxford: Oxford University Press, 2019).

American women have experienced the AIDS epidemic based on their race and class. Unlike countries with a single payer healthcare system, health insurance in the United States is closely tied to employment. The gender gap in employment in the United States means that, as women experience higher rates of unemployment than men, they are more likely to be uninsured or underinsured and reliant on public health coverage.[748] The convergence of longstanding structural inequalities has made securing jobs with decent wages especially difficult for women of colour, who are less likely to have coverage afforded by an employer compared to white women.[749] The fact that women of colour disproportionately rely on public coverage means that the political assault on public healthcare and women's non-profit treatment spaces detailed in this thesis—seen most recently in President Trump's attempt to limit the scope of ACA and reform the Title X programme—impacts women of colour particularly negatively. Affording medications is harder for those without health coverage. The ability of the pharmaceutical industry to set and raise drug prices free from government regulation has also put life-saving HIV prevention and treatment medicine beyond the reach of many. The persistently high rates of HIV among black and Latina women since the 1980s reveal how inequities in the healthcare system continue to result in disproportionately adverse health access and outcomes for women of colour. The class and racial divide in healthcare access, facilitated by a hybrid public-private health system and a politically powerful pharmaceutical industry, tell a distinctly American story about gender relations, race, and political culture.

[748] According to the International Labour Organization, the labour force participation rate in the USA is 55.7% for women and 68.3% for men. "The gender gap in employment: What's holding women back?" *International Labour Organization*, published December 2017, updated March 2018, accessed May 2020, https://www.ilo.org/infostories/en-GB/Stories/Employment/barriers-women

[749] "Women's Health Insurance Coverage," *Kaiser Family Foundation*, January 24, 2020, accessed May 2020, https://www.kff.org/womens-health-policy/fact-sheet/womens-health-insurance-coverage-fact-sheet/

The glaring intersectional discrepancies of health inequalities in the United States meant that people with AIDS were not all treated equally, nor were their symptoms recognised equally. Women who were already involved in anti-poverty activism tackled these intersectional oppressions from the outset. For example, Maxine Wolfe of the ACT UP Women's Caucus challenged the white, male-centric approach to HIV in the early 1980s by petitioning the CDC to diagnose woman-specific manifestations of HIV as AIDS so that women would have access to the state services and disability benefits that were originally denied to them because the initial symptoms were based on how HIV manifested in men. In addition to revealing how diverse groups of people can be infected by the same disease but suffer differently because of differential recognition and care, this thesis shows how our understanding of the patient and the context for caregiving is different when we take an intersectional approach. The distinct ways in which people experience HIV care and treatment derives from their position in society, a reality which is evident not only within hospitals but within communities and prisons.

The question of access and the role of the pharmaceutical industry in perpetuating health inequalities based on women's identities and legal and economic statuses speaks to the overall trajectory of the four decades that this thesis has chronicled. Change is perhaps seen most clearly in the radically different treatment options that are available to people today compared to 1980. Change is also evident in the politics of women's health, which has become increasingly ideological and privatised since 1980 and which has in turn limited women's ability to benefit from medical improvements. The history of women and AIDS is marked by continuities in terms of the persistent economic and political challenges facing women living with HIV, and the persistence of women to meet those challenges across different levels of society.

While this thesis has sought to find patterns in women's response to the AIDS epidemic, women are not a homogenous group, and neither is their activism. No single study can encapsulate the entirety of women's diverse experiences of and response to HIV and AIDS in the United States. Although the category of "women" applies to both cisgender and transgender women, biological sex is the principal framework of this thesis. While many of the issues addressed are not unique to cis women, trans women also have distinct political needs and demands that went beyond the scope of this project. Going forward, focusing on trans activism would provide an opportunity to further examine how women whose multiple lived experiences do not fit neatly into prescriptive identity categories engage with the state. As trans rights have become increasingly visible within the media and political debate in recent years, so too has the trans community become subject to discrimination and attack. Historians might examine whether the pattern of vulnerability assisting visibility, and the tension between needing state recognition but resisting state regulation that the women AIDS activists of this thesis have navigated also applies to trans activism.

History has the power to shape not only what we remember but what we forget. There are many reasons why women were marginalised in response to the HIV and AIDS epidemic in the United States at different historical moments and why they have been underrepresented in the historiography since. Yet, often spoken out of silences, the stories of the women chronicled here are critical for understanding the relationship between the state and gender politics in modern America; serving as examples of how and on what terms the government and healthcare providers ignore or discriminate against women, and how and on what terms they become more receptive to women's collective claims and demands. Their activism also speaks to the power of ordinary women organising to secure the right to decide for

themselves about their bodies. The need to tackle systemic barriers to decent health services—whether in the form of economics, politics, or interpersonal relationships—is imperative to this goal.

Two Stories

I will conclude with two stories. The first illustrates how women continue to live with the consequences of some of the earlier perceptions about women and the AIDS epidemic, even as the treatment of HIV has progressed radically since the 1980s. The second addresses the tension between needing to both mark the suffering and loss caused by the AIDS crisis while at the same time supporting those living with HIV now.[750] Both speak to the importance of forgoing easy endings when writing the history of women in the HIV and AIDS epidemic in the United States.

In January 2008, police arrested 37-year-old Cecelia Ann Sliker in her home in Sarasota, Florida on a felony child neglect charge. At the trial later that month, Sliker, originally from New Jersey, pleaded guilty to the charge and Circuit Judge Debra Johnes Riva sentenced her to 15 years in prison. As part of a plea deal approved by her prosecutors, Judge Riva reduced Sliker's sentence to two years' probation in Port Manatee jail.[751] Beginning in the mid-1980s, states such as Florida began implementing HIV-specific criminal exposure laws.[752] Since

[750] Historian Julio Capó has similarly emphasised that HIV was and remains a history in motion. See Brier et. al., "Interchange: HIV/AIDS and U.S. History," *Journal of American History* 104, no. 2, (September 2017): 433.
[751] HIV Justice Network, "US: Florida Woman Guilty of Mother-To-Child HIV Transmission," October, 28 2008, accessed February 2020, http://www.hivjustice.net/case/us-florida-woman-guilty-of-mother-to-child-hiv-transmission/
[752] CDC, "HIV and STD Criminal Laws," accessed February 2020, https://www.cdc.gov/hiv/policies/law/states/exposure.html. Many HIV criminalisation laws were put into place after the 1990 Ryan White Care Act articulated that states would not receive funding unless state laws criminalised knowingly exposing another to HIV. For an overview of HIV criminalisation in the United States, see Positive Justice Project, *Ending and Defending Against HIV Criminalization: A Manual for Advocates* 1,

then, in states where these laws are still on the books, pregnant women have had a legal obligation to disclose their HIV status to a partner, and to seek medical attention for their unborn children.

In this first successful case of a criminal prosecution for mother-to-child transmission of HIV in the United States, authorities charged Sliker on account of her knowing that she was HIV-positive and choosing not to seek available HIV treatment for her unborn son when she learned she was pregnant with him in 2004.[753] Sliker reportedly knew of her HIV-positive status before giving birth to her first son in 2001, when she had followed up with treatment to successfully block transmission of the virus. Three years later, when Sliker became pregnant again, she chose not to seek medical attention. She had kept her HIV-positive status from her second son's father for fear of what he would do to her had he found out. Journalists did not explicitly state that Sliker was in an abusive relationship but her testimony, coupled with the fact she had sought medical care for her first child but not her second, and the prevalent link between gender-based violence and HIV infection, suggests that fear of intimate partner violence was a factor which drove her to not seek medical attention this time. Sliker carried the burden of the earlier panic about pregnant mothers infecting their children with AIDS.

In 2014, Kia Labeija lies on her back on the bedroom floor of her Hell's Kitchen apartment in Manhattan, New York City. She is wearing a red sequin dress and gold strappy heels. Her head is turned toward the camera as she stares frankly out at the viewer. In her arms, she is hugging a framed photograph of her and her mother. The image is called "Kia and Mommy: 24." Her age in the portrait, twenty-four, is also the title of a collection of four self-portraits

First Edition (Fall 2010): 1-214, accessed February 2020, https://hivlawcommission.org/wp-content/uploads/2017/06/Ending-and-Defending-Against-HIV-Criminalization-A-Manual-for-Advocates.pdf

[753] Sliker was prosecuted whereas a woman arrested under similar circumstances in 1998 was not because treatment options for children were now more regimented. Ahmed, "HIV and Women," 38-39.

exploring what it was like growing up as an HIV-positive woman to which this image belongs. The three other images in Kia's self-portrait series similarly address her experience with the US healthcare system. In one, entitled "Mourning Sickness," she lies on her bathroom floor in a floral bathrobe, again staring directly into the camera, her fuchsia lipstick matching her pink headscarf. The portrait addresses the nausea and dizziness that come from taking a combination of three or more antiretroviral drugs every day—violent side effects that make it difficult for people to adhere to the strict regimen of medications.[754] The image is also a play on words to connect the nausea of HIV medication and the nausea in pregnancy with the loss of her mother to AIDS.[755]

Kia Labeija was born Kia Michelle Benbow to an African American father and a Filipino mother in New York City in 1990. Kia's mother, Kwan Bennett, did not get tested for HIV before she became pregnant, and shared the experience of many other women in learning that she was HIV-positive when her child was born with the virus. The first reports of AIDS among infants in 1982 and the discovery that women could transmit HIV during pregnancy and childbirth in 1985 prompted New York State to mandate that doctors offer counselling and voluntary testing for HIV to all pregnant women in 1987.[756] In the late 1980s, the New York State Department of Health also started an anonymous new-born seroprevalence study to track the rates of HIV infection among childbearing women in the state. Doctors tested the blood obtained from all infants born between 1987 and 1990 in order to determine whether a

[754] Simona A. Lacob et al., "Improving the Adherence to Antiretroviral Therapy, a Difficult but Essential Task for a Successful HIV Treatment—Clinical Points of View and Practical Considerations," *Frontiers in Pharmacy* 8, no. 831 (November 2017): 1-3, accessed February 2020, available at: https://doi.org/10.3389/fphar.2017.00831

[755] Amelia Abraham, "Photographing Black, Female, HIV Positive Power," *Refinery 29*, December 8, 2016, accessed February 2020, https://uk.style.yahoo.com/photographing-black-female-hiv-positive-070500970.html

[756] CDC, "Unexplained Immunodeficiency and Opportunistic Infections in Infants—New York, New Jersey, California," *MMWR* 31, no. 49 (December 17, 1982): 665-667; CDC, "Current Trends Recommendations for Assisting in the Prevention of Perinatal Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus and Acquired Immunodeficiency Syndrome," *MMWR* 34, no. 48 (December 06, 1985): 721-6, 731-2.

woman was HIV-positive.[757] Many women with limited access to healthcare services first learned of their positive status when doctors found HIV antibodies in the blood of their new-born infants.[758] The rates of infection in New York were highest in New York City, and researchers estimated that AIDS would orphan thousands of children in the area in the coming decade.[759] In 2004, when Kia was fourteen years old and in the seventh grade, her mother died of AIDS-related complications. That Kia is alive today while her mother is not is a testament to how developments in treatment regimens have led to the experiential shift from dying of AIDS to living with HIV within a generation. Her work is also representative of that of other activists seeking to keep what society perceives as the "end" of the HIV epidemic open.[760]

The women in this thesis have met the persisting challenges that women living with HIV such as Sliker and Labeija have faced with persisting organising. Over the past decade, a new generation of activists have organised to widen women's access to available HIV treatments. Their efforts build on the activism of women who got the government and pharmaceutical industry to recognise women for treatment as women and not just as mothers in the first decade and a half of the epidemic, as well as the lesbian activists who fought for recognition within public health and lesbian communities in the culture wars, and the women in prison who sought structural reform in order to secure adequate care in the carceral state. Activists are similarly drawing on the work of healthcare feminists who in the 1970s critiqued the capitalist organisation of the healthcare system "designed to profit certain groups of individuals or corporations" and who founded not-for-profit medical facilities to provide

[757] Marte and Anastos, "Women—The Missing Persons in the AIDS Epidemic," 11-12.
[758] Carola Marte and Kathryn Anastos, "Women—The Missing Persons in the AIDS Epidemic," 12.
[759] National Research Council, *The Social Impact of AIDS in the United States* (Washington, D.C.: The National Academies Press, 1993, 288, accessed February 2020, available at: https://doi.org/10.17226/1881
[760] Theodore Kerr, "How to Have an AIDS Memorial in an Epidemic," *C Magazine*, no. 142 (Summer 2019), accessed February 2020, https://cmagazine.com/issues/142/how-to-have-an-aids-memorial-in-an-epidemic

accurate, non-judgemental care for themselves and other women.[761] Rooted at the intersection of the feminist healthcare movement and women's AIDS activism, women currently working to get women tested and treated are at the centre of the next evolution in the fight to end AIDS. The fact that women have responded to the AIDS epidemic over the course of its forty-year history by building on earlier feminist organising and directing it into new avenues in order to meet new challenges obliterates the false periodizing of waves that rendered previous forms of feminist thinking and protest obsolete.[762]

The diverse and intersectional efforts of women to resist the AIDS epidemic are important to recount not only in and of themselves. Instead, centring women's underappreciated fight for bodily autonomy and medical equality in the context of the AIDS epidemic in the United States reveals that women in the past, present, and future have and will continue to need recognition free from prescriptions and risk for both. Offering a different chronology to the AIDS epidemic, *Out of the Silence* has shown how, through building community, friendship, and mutual support, women have persisted in their fight for equality and autonomy for the sake of staying alive, even as the political approach to women's healthcare became increasingly punitive, and even when entrenched power was against them.

[761] The Boston Women's Health Collective, *Women and Their Bodies*, 179. Morgen, *Into Our Own Hands*, 70-108.
[762] Philosophy professor Kate Manne has similarly called for a feminist political discourse that emphasises "amendment, addition, and new centers of discussion." Manne, *Down Girl*, xxi.

Illustrations

1. Cathy for *Glamour*. July 1987. Box 139. Fol. 10. Boston Women's Health Book Collective (BWHBC) records. Arthur & Elizabeth Schlesinger Library on the History of Women in America, Boston, MA.

2. Alison Bechdel, *Making it a Woman's Guide to Sex in the Age of AIDS*. Reprinted in *Broadsheet*. March 1989. Box 139. Fol. 13. BWHBC records. Schlesinger Library, Boston, MA.

3. Data on cases of perinatal AIDS in the United States. In CDC "Achievements in Public Health: Reduction in Perinatal Transmission of HIV Infection—United States, 1985-2005," *MMWR* 55, no. 21 (June 2, 2006): 592-597.

4. Gran Fury. Control [Barbara Bush] (Black and white). *The New York Public Library Digital Collections*. 1989. New York Public Library Manuscripts and Archives Division. Used with permission of the NYPL Manuscripts and Archives Division.

5. Political Funeral for Joan Baker. Box 3. Fol. Political Funeral for Joan Baker, October 23, 1993. Lesbian Avengers Records. GLBT Historical Society Archives and Special Collections. Used with permission of the GLBT Archives and Special Collections.

6. Cynthia Madansky and Julie Tolentino Wood. *The Safer Sex Handbook for Lesbians*. 1993. Subject file: AIDS. Lesbian Herstory Archive. Used with permission of the Lesbian Herstory Archive.

7. Cynthia Madansky and Julie Tolentino Wood. *The Safer Sex Handbook for Lesbians*. 1993. Subject file: AIDS. Lesbian Herstory Archive. Used with permission of the Lesbian Herstory Archive.

Bibliography

Primary Sources

Manuscript and Archival Sources

Arthur & Elizabeth Schlesinger Library on the History of Women in America, Boston, MA.

Ann P. Meredith Papers
Boston Women's Health Book Collective Records
Call Off Your Old Tired Ethics Records
Focus on Women Videotapes
Linda J. Laubenstein Papers
Periodicals:
Communiqué: from the frontline. New York: Lesbian Avengers.
LAP notes. Lesbian AIDS Project at GMHC.
Lesbian Health Issues Newsletter. San Francisco, CA: National Center for Lesbian Rights.

GLBT Historical Society Archives and Special Collections, San Francisco, CA.

Donald Montwill Papers
Hank Wilson Papers
Lesbian Avengers Papers
Randy Burns Papers
Wayne T. Corbitt Videotapes

Lesbian Herstory Archive, New York City, NY.

Maxine Wolfe Papers
Subject File: AIDS

LGBT Community Center National Archive, Manhattan, NY.

Coalition for Lesbian and Gay Rights Records
Don Barrington Papers
Gay and Lesbian Youth of New York Records
Judy Greenspan Papers
New York Memorial Quilt Records

Library of Congress, Washington, D.C.

Motion Picture and Television Reading Room:
Ask Dr. Ruth Videotapes
Prints and Photographs Division:
Unprocessed PR 13 CN 1991:022.
Unprocessed PR 13 CN 1992:024.
Unprocessed PR 13 CN 1992:149.
Unprocessed PR 13 CN 1994:060.
Recorded Sound Research Center:

Abortion Debate at the National Press Club. January 1983.

National Library of Medicine Archives & Modern Manuscripts, Bethesda, MD.

C. Everett Koop Papers

New York Public Library Manuscripts and Archives Division, New York City, NY.

Fierce Pussy Collection
Gay Men's Health Crisis (GMHC) Records
Women's Action Coalition (WAC) Records

New York University Library Tamiment Library & Robert F. Wagner Labor Archives, New York City, NY.

Women's Health Action Mobilization (WHAM!) Records

Ronald Reagan Presidential Library and Museum, Simi Valley, CA.

Beryl Sprinkel Files
Dee Jepsen Files
James Warner Files
John Klenk Files
Kae K. Rairdin Files
Kathleen D. Koch Files
Kenneth T. Cribb Files
Nancy Risque Files
Office of White House Correspondence
Richard A. David Files
Robert Sweet Files

San Francisco Public Library James C. Hormel LGBTQIA Center, San Francisco, CA.

Barbara Cameron Papers
LGBTQIA Ephemera Collection

University of California San Francisco Archives and Special Collections, San Francisco, CA.

Nancy E. Stoller Papers

Visual AIDS!, New York City, New York.

Hate Mail Papers
Miscellaneous Papers
Women's Action Papers

Printed Primary Sources

Books and Articles

Banzhaf, Marion, and Cynthia Chris, Kim Christensen, Alexis Danzig, Risa Denenberg, Zoe Leonard, Deb Levine, Rachel Lurie, Monica Pearl, Catherine Saalfield, Polly Thistlethwaite, Judith Walker, and Brigitte Weil. *Women, AIDS, and Activism by the ACT UP/NY Women and AIDS Handbook Group*. Boston: South End Press, 1999.

Boston Women's Health Book Collective. *New Our Bodies, Our Selves: A Book by and for Women*. New York: Simon & Schuster, 1992.

Boudin, Kathy, and Judith Clark, "Community of Women Organize Themselves to Cope with the AIDS Crisis: A Case Study from Bedford Hill Correctional Facility." *Social Justice* 17, no. 2 (40) (Summer 1990): 90-109.

Bush, Barbara. *Barbara Bush: A Memoir*. New York: Simon & Schuster, 1994.

Koop, C. Everett. *The Memoirs of America's Family Doctor*. Grand Rapids, Michigan: Zondervan Publishing House, 1992.

Medical and Psychological Impact of Abortion: Hearing Before the Human Resources and Intergovernmental Relations Subcommittee of the Committee on Government Operations, House of Representatives, One Hundred First Congress, First Session. Vol. 4. March 16, 1989. U.S. Government Printing Office, 1989. Digitized July 10, 2012. Accessed February 2020. http://hdl.handle.net/2027/pur1.32754076877616

Members of the ACE Program at Bedford Hills. *Breaking the Walls of Silence: AIDS and Women in a New York Maximum Security Prison*. New York: Overlook Press, 1998.

Wattleton, Faye. *How to Talk With your Child About Sexuality*. New York: Doubleday, 1986.

Wattleton, Faye. *Life on the Line*. New York: Ballantine Books, 1996.

CDC Surveillance Reports

Accessed online through the CDC Reports Archive:
https://www.cdc.gov/hiv/library/reports/hiv-surveillance-archive.html

CDC. "*Pneumocystis* Pneumonia—Los Angeles." *MMWR* 30, no. 21 (June 5, 1981): 250-252.

CDC. "Current Trends Update on Acquired Immune Deficiency Syndrome (AIDS)—United States." *MMWR* 31, no. 37 (September 24, 1982): 507-508, 513-514.

CDC. "Epidemiologic Notes and Reports Possible Transfusion-Associated Acquired Immune Deficiency Syndrome (AIDS)—California." *MMWR* 31, no. 48 (December 10, 1982): 652-4.

CDC. "Unexplained Immunodeficiency and Opportunistic Infections in Infants—New York, New Jersey, California." *MMWR* 31, no. 49 (December 17, 1982): 665-667.

CDC. "Acquired Immune Deficiency Syndrome (AIDS) in Prison Inmates—New York, New Jersey." *MMWR* 31, no. 52 (January 7, 1983): 700-701.

CDC. "Epidemiologic Notes and Reports Immunodeficiency among Female Sexual Partners of Males with Acquired Immune Deficiency Syndrome (AIDS)—New York." *MMWR* 31, no. 52 (January 7, 1983): 697-8.

CDC. "Provisional Public Health Service Inter-Agency Recommendations for Screening Donated Blood and Plasma for Antibody to the Virus Causing Acquired Immunodeficiency Syndrome." *MMWR* 32, no. 1 (January 11, 1985): 1-16.

CDC. "Current Trends Recommendations for Assisting in the Prevention of Perinatal Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus and Acquired Immunodeficiency Syndrome." *MMWR* 34, no. 48 (December 6, 1985): 721-6, 731-2.

CDC. "Current Trends Update: Acquired Immunodeficiency Syndrome—United States, 1981-1988." *MMWR* 39, no. 14 (April 14, 1989): 229-232, 234-236.

CDC. "1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults." *MMWR* 41, no. RR-17 (December 18, 1992).

CDC. "Impact of the Expanded AIDS Surveillance Case Definition on AIDS Case Reporting—United States, 1993." *MMWR* 43, no. 9 (March 11, 1994): 160-161, 167-170.

CDC. "Recommendations of the U.S. Public Health Service Task Force on the Use of Zidovudine to Reduce Perinatal Transmission of Human Immunodeficiency Virus." *MMWR* 43, no. RR-11 (August 5, 1994): 1-20.

CDC. "HIV/AIDS Surveillance Report: U.S. HIV and AIDS cases reported through June 2000." *MMWR* 12, no. 1 (June 2000): 1-41.

CDC. "HIV and AIDS—United States, 1981-2000." *MMWR* 50, no. 21 (June 1, 2001): 43-434.

CDC. "Achievements in Public Health: Reduction in Perinatal Transmission of HIV Infection—United States, 1985-2005." *MMWR* 55, no. 21 (June 2, 2006): 592-597.

CDC. "HIV Surveillance—United States, 1981-2008." *MMWR* 60, no. 21 (June 3, 2011): 689.

CDC. "Community Outbreak of HIV Infection Linked to Injection Drug Use of Oxymorphone—Indiana, 2015." *MMWR Weekly* 64, no. 1624 (May 1, 2015): 443-444.

Court Cases

Estelle v. Gamble, 429 U.S. 97 (1976): 104-105. Accessed February 2020. http://cdn.loc.gov/service/ll/usrep/usrep429/usrep429097/usrep429097.pdf

Peter Staley v. Gilead Sciences, Inc. Case No. 3:19-cv-2573 (May 5, 2019): 1-136. Accessed February 2020. https://drive.google.com/file/d/0B4BdaKgM6bo7VWhMdXlnMUNWc24wRzVNZXNIeDBRcjlUeVZr/view

Plata v. Davis, 329 F.3d 1101 (9th Cir. 2003): 2-20. Accessed February 2020. https://casetext.com/case/plata-v-davis

Shumate v. Wilson, 95-619, (E.D. Cal. 1995) Accessed February 2020. https://www.clearinghouse.net/detail.php?id=582

Electronic Material

Articles in the United States Congress. Senate. Committee on Labor and Human Resources. "Nomination: hearing before the Committee on Labor and Human Resources, United States Senate, Ninety-seventh Congress, first session, on C. Everett Koop, of Pennsylvania, to be medical director in regular corps and to be surgeon general of the Public." October 1, 1981. Library of Congress. Accessed February 2020. http://hdl.handle.net/2027/pur1.32754076791106

Atlanta, GA.: Centers for Disease Control. 1983. National Library of Medicine. Accessed February 2020. https://stacks.cdc.gov/view/cdc/34804

Atlanta, GA.: Centers for Disease Control. 1990. National Library of Medicine. Accessed February 2020. https://stacks.cdc.gov/view/cdc/34465

Boston Women's Health Collective. *Women and Their Bodies: a course*. 1970. Accessed February 2020. https://www.ourbodiesourselves.org/cms/assets/uploads/2014/04/Women-and-Their-Bodies-1970.pdf

California Coalition for Women Prisoners. Accessed February 2020. http://womenprisoners.org/about/000085.html

Congressional Record 140, no. 103 (August 1, 1994). Accessed February 2020. https://www.gpo.gov/fdsys/pkg/CREC-1994-08-01/html/CREC-1994-08-01-pt1-PgS11.htm

Gilead Sciences, Inc. "I Like to Party" video. November 4, 2015. Accessed February 2020. https://www.youtube.com/watch?v=FXZcoBsoGBY

Hagerty, James C. Press Release Statement by the President About the Polio Vaccine Situation. May 31, 1955. 1-4. Accessed February 2020. https://www.eisenhowerlibrary.gov/sites/default/files/research/online-documents/salk/salk-g.pdf

Health GAP. "AIDS Activists Dsirupt Gilead Shareholder Meeting." May 8, 2019. Accessed February 2020. https://www.facebook.com/healthgap/videos/373025566641540/?v=373025566641540

H.R. 3396—104th Congress: Defense of Marriage Act of 1996. Accessed February 2020. https://www.govtrack.us/congress/bills/104/hr3396

Initiative Petition submitted by the OCA. Oregon History Society Research Library. Accessed February 2020. https://oregonencyclopedia.org/articles/oregon_citizens_alliance/#.WnQ5HFPFKqA

List of Lesbian Avenger Chapters. Accessed February 2020. http://www.lesbianavengers.com/about/chapters.shtml

Presidential Commission on the HIV Epidemic. November 24, 1987. Accessed February 2020. https://www.c-span.org/video/?389-1/aids

Radical Lesbians. "The Woman Identified Woman Manifesto." 1970. Accessed February 2020. https://www.historyisaweapon.com/defcon1/radicalesbianswoman.html

S.296—101st Congress: Women's Health Equality Act of 1990. Accessed February 2020. https://www.congress.gov/bill/101st-congress/senate-bill/2961

S.1—103rd Congress: National Institutes of Health Revitalization Act of 1993. Accessed February 2020. https://www.congress.gov/bill/103rd-congress/senate-bill/1

Oral History

ACT UP Oral History Project. Accessed February 2020. http://www.actuporalhistory.org/index1.html

Voices of Feminism Oral History Project. Sophia Smith Collection. Smith College. Northampton, MA. Accessed February 2020. https://findingaids.smith.edu/repositories/2/resources/657

Medical Journals

Aaron, Erika, and Cori Blum, Dominika Seidman, Mary Jo Hoyt, Joanne Simone, Meg Sullivan and Dawn K. Smith. "Optimizing Delivery of HIV Preexposure Prophylaxis for Women in the United States." *AIDS Patient Care and STDs* 32, no. 1 (January 1, 2018): 16-23. Accessed February 2020. https://doi.org/10.1089/apc.2017.0201

Auerbach, Judith, and Suzanne Kinsky, Gina Brown, and Vignetta Charles. "Knowledge, attitudes, and likelihood of pre-exposure prophylaxis (PrEP) use among US women at risk of acquiring HIV." *AIDS Patient Care STDS* 29, no. 2 (February 1, 2015): 102-110. Accessed February 2020. https://doi.org/10.1089/apc.2014.0142

Baeten, Jared M., and Deborah Donnell, Patrick Ndase, Nelly R. Mugo, James D. Campbell, Jonathan Wangisi, Jordan W. Tappero, Elizabeth A. Bukusi, Craig R. Cohen, Elly Katabira, Allan Ronald, Elioda Tumwesigye, et al., for the Partners PrEP Study Team. "Antiretroviral Prophylaxis for HIV Prevention in Heterosexual Men and Women." *New England Journal of Medicine* (August 2, 2012): 367:399-410. Accessed February 2020. https://www.nejm.org/doi/full/10.1056/NEJMoa1108524

Balzarini, Jan, and Lut Van Damme. "Microbicide drug candidates to prevent HIV infection." *The Lancet* 369, no. 9563 (February 14, 2007): 787-797. Accessed February 2020. https://doi.org/10.1016/S0140-6736(07)60202-5

Bloche, Maxwell G. "Beyond Autonomy: Coercion and Morality in Clinical Relationships." *Health Matrix* 6, no. 229 (1996): 229-304.

Buckles, Kasey S. and Melanie Guldi, and Joseph Price. "Changing the Price of Marriage: Evidence from Blood Test Requirements." *Journal of Human Resources* 46, no. 3 (July 2011): 539-567. Accessed February 2020. http://jhr.uwpress.org/cgi/reprint/46/3/539

Cleary, Paul D., and Michael J. Barry, Kenneth H. Mayer, Allan M. Brandt, Larry Gostin, and Harvey V. Fineberg. "Compulsory Premarital Screening for the Human Immunodeficiency Virus: Technical and Public Health Considerations." *JAMA* 258, no. 13 (October 2, 1987): 1757-1762. Accessed February 2020. https://jamanetwork.com/journals/jama/fullarticle/368468

Grant, Robert M., and Peter L. Anderson, Vanessa McMahan, Albert Liu, K. Rivet Amico, Megha Mehrotra, Sybil Hosek, Carlos Mosquera, Martin Casapia, Orlando Montoa, Susan Buchbinder, Valdilea G. Veloso, Kenneth Mayer, Suwat Chariyalertsak, Linda-Gail Bekker, Esper G. Kallas, Mauro Schechter, Juan Guanira, Lane Bushman, David N. Burns, James F. Rooney, and David V. Glidden. "Uptake of pre-exposure prophylaxis, sexual practices, and HIV incidence in men and transgender women who have sex with men: a cohort study." *The Lancet* 14, no. 9 (22 July 2014): 820-829. Accessed February 2020. https://doi.org/10.1016/S1473-3099(14)70847-3

Haverkos, Harry W., and James W. Curran. "The Current Outbreak of Kaposi's Sarcoma and Opportunistic Infections." *CA: A Cancer Journal for Clinicians* 32, no. 6 (November/December 1982): 330-339. Accessed February 2020. https://doi.org/10.3322/canjclin.32.6.330

Hill, Bianca S., and Viraj V. Patel, Lorlette J. Haughton, and Oni J. Blackstock. "Leveraging Social Media to Explore Black Women's Perspectives on HIV Pre-exposure Prophylaxis." *Journal of Associated Nurses AIDS Care*, 29, no. 1 (January-February 2018): 107-114. Accessed February 2020. https://doi.org/10.1016/j.jana.2017.06.010

Hillier, Sharon, and Thomas Moench, Robin Shattock, Roberta Black, Patricia Reichelderfer, and Fulvia Veronese. "In vitro and in vivo: the story of nonoxynol 9." *Journal of Acquired Immunodeficiency Syndrome* 39, no. 1 (1 May 2005): 1-8. Accessed February 2020. https://doi.org/10.1097/01.qai.0000159671.25950.74

Hymes, Kenneth B., and Jeffrey B. Greene, Aaron Marcus, Daniel C. William, Tony Cheund, Neil S. Prose, Harold Ballard, and Linda J. Laubenstein. "Kaposi's sarcoma in homosexual men—a report of eight cases." *Lancet* 318, no. 8247 (March 1981): 598-600. Accessed February 2020. https://doi.org/10.1016/s0140-6736(81)92740-9

Karim, Quarraisha Abdool, and Salim S. Abdool Karim, Janet A. Frohluch, Anneke C. Grobler, Cheryl Baxter, Leila E. Mansoor, Ayesha B. M. Kharsany, Sengeziwe Sibeko, Koleka P. Mlisana, Zaheen Omar, Tanuja N. Gengiah, Silvia Maarschalk, Natasha Arulappan, Mukelisiwe Mlotshwa, Lynn Morris, and Douglas Taylor. "Effectiveness and

safety of tenofovir gel, an antiretroviral microbicide, for the prevention of HIV infection in women," *Science* 329, no. 5996 (September 3, 2010): 1168-74. Accessed February 2020. https://dx.doi.org/10.1126%2Fscience.1193748

Kesselheim, Aaron S., and Jerry Avorn, and Ameet Sarpatwari. "The High Cost of Prescription Drugs in the United States." *JAMA* 316, no. 8 (August 23/30, 2016): 858-871. Accessed February 2020. https://jamanetwork.com/journals/jama/article-abstract/2545691

Lacob, Simona A., Diana G. Iacob, and Gheorghita Jugulete. "Improving the Adherence to Antiretroviral Therapy, a Difficult but Essential Task for a Successful HIV Treatment—Clinical Points of View and Practical Considerations." *Frontiers in Pharmacy* 8, no. 831 (November 2017): 1-12. Accessed February 2020. https://doi.org/10.3389/fphar.2017.00831

Liu, Katherine A. and Natalie A. Dipietro Mager. "Women's involvement in clinical trials: historical perspective and future implications." *Pharmacy Practice* 14, no. 1 (2016): 708. Accessed February 2020. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4800017/

Nicholas, Stephen W. and Elaine J. Abrams. "Boarder Babies with AIDS in Harlem: Lessons in Applied Public Health." *American Journal of Public Health* 92, no. 2 (February 2002): 163-165. Accessed February 2020. https://dx.doi.org/10.2105%2Fajph.92.2.163

Notario-Pérez, Fernando, and Roberto Ruiz-Caro, and María-Dolores Veiga-Ochoa. "Historical Development of Vaginal Microbicides to Prevent Sexual Transmission of HIV in Women." *Drug Design, Development and Therapy* 11 (June 15, 2017): 1767-1787. Accessed February 2020. https://doi.org/10.2147/DDDT.S133170

Sachan, Dinsa. "Zeda Rosenberg: determined to empower women to prevent HIV infection." *The BMJ* (October 2, 2017): 359: j4424. Accessed February 2020. Available at: https://doi.org/10.1136/bmj.j4424

Smith, Perry F., J. Mikl, B. I. Truman, L. Lessner, J. S. Lehman, R. W. Stevens, E. A. Lord, R. K. Broaddus, and D. L. Morse. "HIV Infection among Women Entering the New York State Correctional System." *American Journal of Public Health* 81, no. Suppl (May 1, 1991): 35-40. Accessed February 2020. https://doi.org/10.2105/AJPH.81.Suppl.35

Thigpen, Michael C., and Poloko M. Kebaabetswa, Lynn A. Paxton, Dawn K. Smith, Charles E. Rose, Tebogo, Segolodi, Faith L. Henderson, Sonal R. Pathak, Fatma A. Soud, Kata L. Chillag, Rodreck Mutanhaurwa, Lovemore Ian Chirwa, et al., for the TDF2 Study Group. "Antiretroviral Preexposure Prophylaxis for Heterosexual HIV Transmission in Botswana." *New England Journal of Medicine* (August 2, 2012): 367:423-434. Accessed February 2020. Available at: https://www.nejm.org/doi/full/10.1056/NEJMoa1110711

Turnock, B. J., and C. J. Kelly. "Mandatory premarital testing for human immunodeficiency virus: The Illinois experience." *Journal of American Medical Association* 261, no. 23, (1989): 3415-3418. Accessed February 2020. https://jamanetwork.com/journals/jama/fullarticle/377684.

Qato, Dima Mazen, and Shannon Zenk, Jocelyn Wilder, Rachel Harrington, Darrell Gaskin, G. Caleb Alexander. "The availability of pharmacies in the United States: 2007-2015." *PLoS*

ONE 12, no. 8 (August 16, 2017). Accessed February 2020. https://doi.org/10.1371/journal.pone.0183172

Westmoreland, Timothy M. "The Affordable Care Act in the United States and HIV Disease: Past, Present, and Future." *Topics in Antiviral Medicine* 24, no. 2 (July-August 2016): 98-102. Accessed February 2020. https://www.ncbi.nlm.nih.gov/pubmed/27841980

Whitley, Heather P., and Wesley Lindsey. "Sex-Based Differences in Drug Activity." *American Family Physician* 80, no. 11 (December 2009): 1254-8. Accessed February 2020. https://www.aafp.org/afp/2009/1201/p1254.html

Periodicals

Boston Globe

Irish Times

Los Angeles Times

National Now Times

New York Amsterdam News

New York Times

Out/Look

Philadelphia Inquirer

Philadelphia Tribune

Richmond Times-Dispatch

San Jose Mercury News

Sinister Wisdom

Times of India

Trouble & Strife

University Wire

Wall Street Journal

Washington Blade

Washington Post

Secondary Material

Printed Secondary Works

Articles

Ahmed, Aziza. "HIV and Women: Incongruent Policies, Criminal Consequences." *Yale Journal of International Affairs* 6, no. 1 (Winter 2011): 32-42.

Batza, Katie. "From Sperm Runners to Sperm Banks: Lesbians, Assisted Conception, and Challenging the Fertility Industry, 1971-1983." *Journal of Women's History* 23, no. 2 (2016): 82-102.

Bell, Jonathan. "Rethinking the 'Straight State': Welfare Politics, Health Care, and Public Policy in the Shadow of AIDS." *Journal of American History* 104, no. 4 (March 2018): 931-952.

Bell, Jonathan. "Between Private and Public: AIDS, Health Care Capitalism, and the Politics of Respectability in 1980s America." *Journal of American Studies* 54, no. 1 (February 2020): 159-183.

Booth, Karen M. '"Just Testing': Race, Sex, and the Media in New York's 'Baby AIDS' Debate.'" *Gender and Society* 14, no. 5 (October 2000): 644-661.

Braukman, Stacy. "'Nothing Else Matters but Sex': Cold War Narratives of Deviance and the Search for Lesbian Teachers in Florida, 1959-1963." *Feminist Studies* 27, no. 3 (Autumn, 2001): 553-575.

Brier, Jennifer, and Jonathan Bell, Julio Capó, Jih-Fei Cheng, Daniel M. Fox, Christina Hanhardt, Emily K. Hobson, Dan Royles. "Interchange: HIV/AIDS and U.S. History." *Journal of American History* 104, Issue 2 (September 2017): 431-460.

Chauncey, George. "'What Gay Studies Taught the Court': The Historians' Amicus Brief in *Lawrence V. Texas*." *GLQ: A Journal of Lesbian and Gay Studies* 10, no. 3 (2004): 509-538.

Christiansen, Adrienne E. and Jeremy J. Hanson, "Comedy as Cure for Tragedy: ACT UP and the Rhetoric of AIDS." *Quarterly Journal of Speech* 82, no. 2 (1996): 157-170.

Cohen, Peter F. '"All They Needed': AIDS, Consumption, and the Politics of Class." *Journal of the History of Sexuality* 8, no. 1 (July 1997): 86-115.

Davis, Angela, and Cassandra Shaylor. "Race, Gender, and the Prison Industrial Complex: California and Beyond." *Meridians* 2, no. 1 (2001): 1-25.

Freedman, Estelle B. "The Prison Lesbian: Race, Class and the Construction of the Aggressive Female Homosexual, 1915-1965." *Feminist Studies* 22, no. 2 (Summer 1996): 397-415.

Gaudillière, Jean-Paul. "How pharmaceuticals became patentable: the production and appropriation of drugs in the twentieth century." *History and Technology* 24 no. 2 (2008): 99-106.

Gilman, Sander L. "AIDS and Syphilis: The Iconography of Disease." *October* 43 (Winter 1987): 87-107.

Gottemoeller, Megan. "Empowering Women to Prevent HIV: The Microbicide Advocacy Agenda." *Agenda: Empowering Women for Gender Equality* 44. AIDS: Global Concerns for Women (2000): 32-36.

Greenspan, Judy. "Struggle for Compassion: The Fight for Quality Care for Women with AIDS at Central California Women's Facility." *Yale Journal of Law & Feminism* 6 Issue. 2 (1993): 393-395.

Gross, Kali N. "African American Women, Mass Incarceration, and the Politics of Protection." *Journal of American History* 102, no. 1 (June 2015): 25-33.

Hammonds, Evelynn. "Race, sex, AIDS the construction of 'Other.'" *Radical America* 20, no. 6 (September 1987): 28-39.

Hill, Amy Pétre. "Death Through Administrative Indifference: The Prison Litigation Reform Act Allows Women to Die in California's Substandard Prison Health Care System." *Hastings Women's Law Journal* 13, no. 2 (Summer 2002): 231-260.

Jeffries, Charlie. "Adolescent Women and the Antiabortion Politics in the Reagan Administration." *Journal of American Studies* 52, no. 1 (2018): 193-213.

Mumford, Kevin. "The Trouble with Gay Rights: Race and the Politics of Sexual Orientation in Philadelphia." *Journal of American History* 98, no. 1 (June 2011): 49-72.

Musser, Amber Jamilla. "From Our Body to Yourselves: The Boston Women's Health Book Collective and Changing Notions of Subjectivity, 1969-1973." *Women's Studies Quarterly* 35, no. 1/2 (Spring-Summer, 2007): 93-109.

O'Connor, John. "Us Social Welfare Policy: The Reagan Record and Legacy." *Journal of Social Policy* 7 no.1 (1998): 37-61.

Rousseau, Christina. "Wages Due Lesbians: Visibility and Feminist Organizing in 1970s Canada." *Gender, Work & Organization* 22, no. 4 (July 2015): 364-374

Rich, Adrienne. "Compulsory Heterosexuality and Lesbian Existence." *Signs* 5, no. 4 (Summer 1980): 631-660.

Shotwell, Alexis. "'Women Don't Get AIDS, They Just Die From It': Memory, Classification, and the Campaign to Change the Definition of AIDS." *Hypatia* 29, no. 2 (Spring 2014): 509-525.

Stoever, Jane K. "Stories Absent from the Courtroom: Responding to Domestic Violence in the Context of HIV and AIDS." *North Carolina Law Review* 87 N.C.L. Rev. 1157 (May 2009): 1157-1229.

Thompson, Heather Ann. "Why Mass Incarceration Matters: Rethinking Crisis, Decline, and Transformation in Postwar American History." *Journal of American History* 97, no. 3 (December 1, 2010): 703-734.

Tietz, Daniel, and Janet Weinberg. "AIDS Activism." *Achieve* 5, no. 4 (2013): 1-23.

Treichler, Paula A. "AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification." *October* 43 (Winter 1987): 31-70.

Turner, William B. "'Adolph Reagan?' Ronald Reagan, AIDS, and Lesbian/Gay Civil Rights." (July 13, 2009): 15-16. Available at SSRN: https://ssrn.com/abstract=1433567

Ziegler, Mary. "The Framing of a Right to Choose: Roe v. Wade and the Changing Debate on Abortion Law." *Law and History Review* 27, no. 2 (Summer 2009): 281-330

Books

Alexander, Michelle. *The New Jim Crow: Mass Incarceration in the Age of Colorblindness.* New York: New Press, 2012.

Ball, Carlos A. *The Right to Be Parents: LGBT Families and the Transformation of Parenthood*. New York: New York University Press, 2012.

Batza, Katie. *Before AIDS: Gay Health Politics in the 1970s*. Philadelphia: University of Pennsylvania Press, 2018.

Berman, William C. *America's right turn: from Nixon to Clinton*. Baltimore, Md.: Johns Hopkins University Press, 1998.

Brandt, Allan M. *No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880*. New York: Oxford University Press, c.1985, 1987.

Brier, Jennifer. *Infectious Ideas: U.S. Political Responses to the AIDS Crisis*. Chapel Hill: University of North Carolina Press, 2009.

Brownlee, W. Elliot, and Hugh David Graham. *The Reagan Presidency: Pragmatic Conservatism and Its Legacies*. Lawrence: University Press of Kansas, 2003.

Canaday, Margot. *The Straight State: Sexuality and Citizenship in Twentieth-Century America.* Princeton, N.J.: Princeton University Press, 2009.

Carroll, Tamar W. *Mobilizing New York: AIDS, Antipoverty, and Feminist Activism.* Chapel Hill: University of North Carolina Press, 2015.

Castiglia, Christopher, and Christopher Reed. *If Memory Serves: Gay Men, AIDS, and the Promise of the Queer Past.* Minneapolis: University of Minnesota Press, 2012.

Chauncey, George. *Gay New York: The Making of the Gay Male World*. New York: Basic Books, 1994.

Chemaly, Soraya. *Rage Becomes Her: The Power of Women's Anger.* New York: Atria Books, 2018.

Clendinen, Dudley, and Adam Nagourney. *Out for Good: The Struggle to Build a Gay Rights Movement in America.* New York: Simon & Schuster, 1999.

Cogswell, Kelly. *Eating Fire: My Life as a Lesbian Avenger.* Minneapolis: University of Minnesota Press, 2014.

Cohen, Cathy J. *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*. Chicago: University of Chicago Press, 1999.

Cohen, Peter F. *Love and Anger: Essays on AIDS, Activism, and Politics*. New York: Routledge, c. 1993, 2013.

Colter, Ephen G. *Policing Public Sex: Queer Politics and the Future of AIDS Activism*. Boston: South End Press, 1996.

Corea, Gena. *The Invisible Epidemic: The Story of Women with AIDS.* New York: HarperCollins, 1992.

Crimp, Douglas. *Melancholia and Moralism: Essays on AIDS and Queer Politics*. Cambridge: MIT Press, 2002.

Critchlow, Donald T. *Phyllis Schlafly and Grassroots Conservatism.* Princeton, N.J.: Princeton University Press, 2005.

Cvetkovich, Ann. *An Archive of Feelings: Trauma, Sexuality, and Lesbian Public Cultures*. Durham: Duke University Press, 2003.

D'Emilio, John, and Estelle B. Freedman. *Intimate Matters: A History of Sexuality in America*. Chicago: University of Chicago Press, c.1988, 1997, 2012.

D'Emilio, John, and William B. Turner. *Creating Change: Sexuality, Public Policy, and Civil Rights*. New York: St. Martin's Press, 2000.

Dubow, Sara. *Ourselves Unborn: A History of the Fetus in Modern America*. New York: Oxford University Press, 2011.

Dunn, Thomas. R. *Queerly Remembered: Rhetorics for Representing the GLBTQ Past.* Columbia, South Carolina: University of South Carolina Press, 2016.

Edelman, Lee. *No Future: Queer Theory and the Death Drive.* Durham: Duke University Press, 2004.

Engel, Jonathan. *Poor People's Medicine: Medicaid and American Charity Care Since 1965*. Durham: Duke University Press, 2006.

Engs, Ruth C. *The Progressive Era's Health Reform Movement: A Historical Dictionary*. Westport, CT: Praeger, 2003.

Epstein, Steven. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press, 1996.

Evans, Sara M. *Tidal Wave: How Women Changed America at Century's End.* New York: The Free Press, 2003.

Faderman, Lillian. *Surpassing the Love of Men: Romantic Friendship and Love Between Women from the Renaissance to the Present.* New York: Morrow, 1981.

Faderman, Lillian. *Odd Girls and Twilight Lovers: A History of Lesbian Life in 20th-Century America*. New York: Columbia University Press, 1991.

Fateman Johanna, and Amy Scholder. *Last Days at Hot Slit: The Radical Feminism of Andrea Dworkin.* California: MIT Press, 2019.

Fejes, Fred. *Gay Rights and Moral Panic: The Origins of America's Debate on Homosexuality*. New York: Palgrave Macmillan, 2008.

Feldman, Robin. *Drug Wars: How Big Pharma Raises Prices and Keeps Generics Off the Market*. Cambridge: Cambridge University Press, 2017.

Fields, Armond. *Katharine Dexter McCormick: Pioneer for Women's Rights*. Westport, CT.: Greenwood Publishing Group, 2003.

Finkelstein, Avram. *After Silence: A History of AIDS Through Its Images*. Berkeley: University of California Press, 2017.

Foege, William H. *House on Fire: The Fight to Eradicate Smallpox*. Berkeley: University of California Press, 2011.

Foucault, Michel. *The Will to Knowledge: The History of Sexuality: Volume One*. London, c. 1976, 1998.

France, David. *How to Survive a Plague: The Inside Story of How Citizens and Science Tamed AIDS.* New York: Alfred A. Knopf, 2016.

Frank, Miriam. *Out in the Union: A Labor History of Queer America.* Philadelphia: Temple University Press, 2014.

Gabriel, Joseph M. *Medical Monopoly: Intellectual Property Rights and the Origins of the Modern Pharmaceutical Industry*. Chicago: University of Chicago Press, 2014.

Gerhard, Jane. *Desiring Revolution: Second Wave Feminism and the Rewriting of American Sexual Thought, 1920 to 1982*. New York: Columbia University Press, 2001.

Ghaziani, Amin. *The Dividends of Dissent: How Conflict and Culture Work in Lesbian and Gay Marches on Washington.* Chicago: University of Chicago Press, 2008.

Gibson, Dawn-Marie. *The Nation of Islam, Louis Farrakhan, and the Men Who Follow Him*. New York: Palgrave Macmillan, 2016.

Gilmore, Ruth W. *Golden Gulag: Prisons, Surplus, Crisis, and Opposition In Globalizing California.* Berkeley: University of California Press, 2006.

Goldstein, Nancy, and Jennifer L. Manlowe. *The Gender Politics of HIV/AIDS in Women.* New York: New York University Press, 1997.

Gordon, Linda. *Pitied but Not Entitled: Single Mothers and the History of Welfare.* New York: Free Press, 1994.

Gottleib, Martin. *The Foundling: The Story of the New York Foundling Hospital*. New York: Lantern Books, 2002.

Gould, Deborah B. *Moving Politics: Emotion and ACT UP's Fight Against AIDS*. Chicago: University of Chicago Press, 2009.

Greene, Jeremy A. *Generic: The Unbranding of Modern Medicine*. Baltimore: Johns Hopkins University Press, 2014.

Halberstam, Jack. *Gaga Feminism: Sex, Gender, and the End of Normal.* Boston, Mass.: Beacon Press, 2012.

Hansen, Randall, and Desmond King. *Sterilized by the State: Eugenics: Race, and the Population Scare in Twentieth-Century North America*. Cambridge: Cambridge University Press, 2013.

Healy, Dan. *Russian Homophobia from Stalin to Sochi*. London: Bloomsbury Academic, 2017.

Herzog, Dagmar. *Sex in Crisis: The New Sexual Revolution and the Future of American Politics*. New York: Basic Books, 2008.

Hewitt, Nancy. *A Companion to American Women's History*. Malden, Mass.: Blackwell Publishing, 2002.

Hinton, Elizabeth. *From the War on Poverty to the War on Crime*. Cambridge, MA.: Harvard University Press, 2016.

Hobson, Emily. *Lavender and Red: Liberation and Solidarity in the Gay and Lesbian Left.* Berkeley: University of California Press, 2016.

Hollibaugh, Amber L. *My Dangerous Desires: A Queer Girl Dreaming Her Way Home*. Durham: Duke University Press, 2000.

Irvine, Janet M. *Talk About Sex: The Battles Over Sex Education in the United States*. Berkeley: University of California Press, 2002.

Johns, Andrew L. *A Companion to Ronald Reagan*. Malden, MA.: Wiley Blackwell, 2015.

Johnson, Haynes. *Sleepwalking Through History: America in the Reagan Years*. New York: W. W. Norton and Company, 2003.

Johnston, Jill. *Lesbian Nation: The Feminist Solution*. New York: Bantam, 1973.

Jonsen, A.R., and J. Stryker. *The Social Impact of AIDS in the United States*. Washington, D.C.: National Academies Press, 1993. Available at: https://doi.org/10.17226/1881

Jordan, June. *Some of Us Did Not Die: New and Selected Essays*. New York: Basic Books, 2002.

Kalman, Laura. *Right Star Rising*: *A New Politics, 1974-1980*. New York: W. W. Norton & Company, Inc., 2010.

Kennedy, Elizabeth Lapovsky, and Madeline D. Davis. *Books of Leather, Slippers of Gold: The History of a Lesbian Community*. New York: Routledge, c. 1993, 2014.

Kline, Wendy. *Bodies of Knowledge: Sexuality, Reproduction, and Women's Health in the Second Wave.* Chicago: University of Chicago Press, 2010.

Kline, Wendy. *Coming Home: How Midwives Changed Birth*. Oxford: Oxford University Press, 2019.

Kunzel, Regina. *Criminal Intimacy: Prison and the Uneven History of Modern American Sexuality.* Chicago: University of Chicago Press, 2008.

Law, Victoria. *Resistance Behind Bars: The Struggles of Incarcerated Women.* Oakland: PM Press, 2009.

Lorde, Audre. *Sister Outsider: Essays and Speeches.* Berkeley: Crossing Press, c. 1984, 2007.

Manne, Kate. *Down Girl: The Logic of Misogyny*. New York: Oxford University Press, 2018.

Martin, William. *With God on Our Side: The Rise of the Religious Right in America*. New York: Broadway Books, 1996.

Mason, Robert. *The Republican Party and American Politics from Hoover to Reagan*. Cambridge: Cambridge University Press, 2011.

McAndrews, Lawrence J. *What They Wished For: American Catholics and American Presidents, 1960-2004*. Athens, Georgia: University of Georgia Press, 2014.

McGirr, Lisa. *Suburban Warriors: The Origins of the New American Right*. Princeton, N.J.: Princeton University Press, c. 2001, 2015.

McGuire, Danielle L. *At The Dark End of the Street: Black Women, Rape, and Resistance—A New History of the Civil Rights Movement from Rosa Parks to the Rise of Black Power*. New York: Alfred A. Knopf, 2010.

McKay, Richard A. *Patient Zero and the Making of the AIDS Epidemic.* Chicago: University of Chicago Press, 2017.

Miley, William M. *The Psychology of Well Being*. Westport, CT: Greenwood Publishing Group, 1999.

Millwood, Gareth. *Vaccinating Britain: Mass Vaccination and the Public Since the Second World War*. Manchester: Manchester University Press, 2019.

Moraga, Chierríe, and Gloria Anzaldúa. *This Bridge Called My Back: Writings by Radical Women of Color*. Albany: State University of New York Press, c.1981, 2015.

Morgen, Sandra. *Into Our Own Hands: The Women's Health Movement in the United States, 1969-1990*. New Brunswick: Rutgers University Press, 2002.

Morris, Charles E. *Remembering the AIDS Quilt*. East Lansing, Michigan: Michigan State University Press, 2011.

Mukherjee, Siddhartha. *The Emperor of all Maladies: A Biography of Cancer*. London: Fourth Estate, 2011.

Muñoz, José. *Cruising Utopia: The Then and There of Queer Futurity*. New York: NYU Press, 2009.

Murakawa, Naomi. *The First Civil Right: How Liberals Built Prison America*. Oxford: Oxford University Press, 2014.

Nelson, Jennifer M. *Women of Color and the Reproductive Rights Movement*. New York: New York University Press, 2003.

Nelson, Jennifer M. *More Than Medicine: A History of the Feminist Women's Health Movement*. New York: New York University Press, 2015.

Noe, V. *Fag Hags, Divas and Moms: The Legacy of Straight Women in the AIDS Community*. Chicago: King Company Publishing, 2019.

Oshinsky, David M. *Polio: An American Story*. New York: Oxford University Press, 2005.

Patterson, James T. *Restless Giant: The United States from Watergate to Bush v. Gore*. New York: Oxford University Press, 2005.

Patton, Cindy. *Last Served?: Gendering the HIV Pandemic*. London: Taylor & Francis, 1994.

Perez, Caroline C. *Invisible Women: Exposing Data Bias in a World Designed for Men.* London: Chatto & Windus, 2018.

Petro, Anthony M. *After the Wrath of God: AIDS, Sexuality, and American Religion*. New York: Oxford University Press, 2015.

Quashie, Kevin. *The Sovereignty of Quiet: Beyond Resistance in Black Culture*. New Brunswick, N.J.: Rutgers University Press, 2012.

Reagan, Leslie J. *Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America*. Berkeley: University of California Press, 2010.

Rich, Adrienne. *Driving into the Wreck: Poems 1971-1972*. New York: W. W. Norton & Company, Inc. c.1973, 2013.

Richie, Beth E. *Arrested Justice: Black Women, Violence, and America's Prison Nation*. New York: New York University Press, 2012.

Rimmerman, Craig A. *From Identity to Politics: The Lesbian and Gay Movements in the United States*. Philadelphia: Temple University Press, 2002.

Roberts, Dorothy E. *Killing The Black Body: Race, Reproduction and the Meaning of Liberty.* New York: Vintage Books, 1999.

Rosen, Ruth, *The World Split Open: How the Modern Women's Movement Changed America*. New York: Penguin, 2000.

Rosenberg, Charles. *The Care of Strangers: The Rise of America's Hospital System.* New York: Basic Books, 1987.

Rossinow, Doug. *The Reagan Era: A History of the 1980s.* New York: Oxford University Press, 2015.

Roth, Nancy L., and Katie Hogan. *Gendered Epidemic: Representations of Women in the Age of AIDS*. New York: Routledge, 1998.

Ruzek, Sheryl B. *The Women's Health Movement: Feminist Alternatives to Medical Control*. New York: Praeger, 1978.

Sacks, Tina K. *Invisible Visits: Black Middle-Class Women in the American Healthcare System*. New York: Oxford University Press, 2019.

Schaller, Michael. *Right Turn: American Life in the Reagan-Bush Era, 1980-1992*. New York: Oxford University Press, 2007.

Scheffler, Judith A. *Wall Tappings: An International Anthology of Women's Prison Writings, 200 to the Present*. New York: Feminist Press at CUNY, 2002.

Schneider, Beth E., and Nancy E. Stoller, *Women Resisting AIDS: Feminist Strategies of Empowerment*. Philadelphia: Temple University Press, 1995.

Shilts, Randy. *And the Band Played On: Politics, People, and the AIDS Epidemic*. New York: Penguin, 1988.

Skocpol, Theda. *Protecting Soldiers and Mothers: The Political Origins of Social Policy in the United States*. Cambridge, MA.: Belknap Press of Harvard University Press, 1992.

Solinger, Rickie. *Abortion Wars: A Half Century of Struggle, 1950-2000*. Berkeley: University of California Press, 1998.

Solinger, Rickie. *Pregnancy and Power: A Short History of Reproductive Politics in America*. New York: New York University Press, c. 2005, 2019.

Solnit, Rebecca. *The Mother of All Questions: Further Feminisms*. London: Granta Publications, 2017.

Sontag, Susan. *Illness as Metaphor and AIDS and its Metaphors*. London: Penguin, 2000.

Stoller, Nancy E. *Lessons from The Damned: Queers, Whores, and Junkies Respond to AIDS*. Routledge: New York, 1998.

Sturken, Marita. *Tangled Memories: The Vietnam War, the AIDS Epidemic, and The Politics of Remembering*. Berkeley: University of California Press, 1997.

Talvi, Silja J. A. *Women Behind Bars: The Crisis of Women in the U.S. Prison System*. Seattle: Sea Press, 2007.

Thompson, Heather Ann. *Blood in the Water: The Attica Prison Uprising of 1971 and Its Legacy*. New York: Pantheon Books, 2016.

Tomes, Nancy. *Remaking the American Patient: How Madison Avenue and Modern Medicine Turned Patients into Consumers*. Chapel Hill: University of North Carolina Press, 2016.

Traister, Rebecca. *Good and Mad: The Revolutionary Power of Women's Anger*. New York: Simon & Schuster, 2018.

Treichler, Paula A. *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS.* Durham: Duke University Press, 1999.

Washington, Harriet. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonia Times to the Present*. New York: Doubleday, 2006.

Weil, Brian. *Every Seventeen Seconds: A Global Perspective on the AIDS Crisis*. Aperture: New York, 1992.

Wilentz, Sean. *The Age of Reagan: A History, 1974-2008*. New York: HarperCollins, 2008.

Wright, Paul, and Tara Herivel. *Prison Nation: The Warehousing of America's Poor*. New York: Routledge: 2003.

Young, Neil J. *We Gather Together: The Religious Right and the Problem of Interfatih Politics*. New York: Oxford University Press, 2016.

Ziegler, Mary. *After Roe: The Lost History of the Abortion Debate*. Cambridge, Mass.: Harvard University Press, 2015.

Zimmerman, Jonathan. *Whose America? Culture Wars in the Public Schools*. Cambridge, Mass.: Harvard University Press, 2002.

Websites

Abraham, Amelia. "Photographing Black, Female, HIV Positive Power." *Refinery 29*. December 8, 2016. Accessed February 2020. https://uk.style.yahoo.com/photographing-black-female-hiv-positive-070500970.html

ACLU National Prison Project. Accessed February 2020. https://www.aclu.org/other/aclu-national-prison-project

ACLU. "Religious Refusals and Reproductive Rights: Accessing Birth Control at the Pharmacy." 2007. 1-4. Accessed February 2020. https://www.aclu.org/files/images/asset_upload_file119_29548.pdf

AIDSVu. "Mapping PrEP: First Ever Data on PrEP Users Across the U.S." Accessed February 2020. https://aidsvu.org/prep/

AIDSVu. "Overview of 2017 PrEP Update." 1-3. Accessed February 2020. https://aidsvu.org/wp-content/uploads/2018/11/2017-PrEP-Data-Update-Overview-1.pdf

AmfAR. "The Effect of the Expanded Mexico City Policy on HIV/AIDS Programming: Evidence from the PEPFAR Implementing Partners Survey." January 2019, 1-2. Accessed July 2019. https://www.amfar.org/uploadedFiles/_amfarorg/Articles/On_The_Hill/2019/IB-1-31-19a.pdf

Amin, Tahir. "The problem with high drug prices isn't 'foreign freeloading,' it's the patent system." *CNBC*. June 27, 2018. Accessed February 2020. https://www.cnbc.com/2018/06/25/high-drug-prices-caused-by-us-patent-system.html

Avert. "History of HIV and AIDS Overview." Last updated October 10, 2019. Accessed February 2020. https://www.avert.org/professionals/history-hiv-aids/overview#footnote5_ig9n74j

Avert. "Women and Girls, HIV and AIDS." Last updated October 10, 2019. Accessed February 2020. https://www.avert.org/professionals/hiv-social-issues/key-affected-populations/women#footnote2_r14af4d

Baig, Mehroz. "PrEP for Her: Bringing Women into the HIV Prevention Conversation." *HuffPost*. August 16, 2017. Accessed February 2020. https://www.huffpost.com/entry/prep-for-her-bringing-wom_b_11527650?guccounter=1&guce_referrer=aHR0cHM6Ly93d3cuZ29vZ2xlLmNvbS8&guce_referrer_sig=AQAAAG011WuPhOuwT-

yzbB_rgPUFZr1QTIrp5QPY6akHKS2mg0eSvuRGZkE_i8H4kf03SIvpbuniAEIEjqAPMbIfwzOuShCZoTIoHOhXJUXUDBiD6U-owyfMRrCfeey0WNAIrKdD84_Bqcy1pPHi31C1q6oOMgFoMvLRTIf5QW01BXnp

Barnes, Zahra. "8 Health Conditions that Disproportionately Affect Black Women." *Self*. March 30, 2017. Accessed February 2020. https://www.self.com/story/black-women-health-conditions;

Beaubien, Jason. "Praise for the Global HIV Program That Trump Wants to Cut." *npr*. July 25, 2018. Accessed February 2020. https://www.npr.org/sections/goatsandsoda/2018/07/25/632395250/praise-for-the-u-s-hiv-program-that-trump-wants-to-cut

Belluz, Julia. "Trump called for an end to AIDS in the US by 2030. That's totally realistic." February 4, 2020. Accessed February 2020. https://www.vox.com/2019/2/5/18210455/state-of-the-union-2020-trump-aids-hiv-health

Black Women and PrEP Toolkit Posters. Accessed February 2020. Available at: https://blackaids.org/black-women-and-prep/

Boonstra, Heather D. "Abortion in the Lives of Women Struggling Financially: Why Insurance Coverage Matters." *Guttamcher Institute* Vol. 19. July 14, 2016. Accessed February 2020. https://www.guttmacher.org/gpr/2016/07/abortion-lives-women-struggling-financially-why-insurance-coverage-matters

#BreakThePatent Campaign. Accessed February 2020. https://breakthepatent.org

Brennan, Carol. "Cosmopolitan." Last updated January 24, 2020. Accessed February 2020. https://www.encyclopedia.com/literature-and-arts/literature-english/american-literature/cosmopolitan

Brought to Life. "Thalidomide." Accessed February 2020. http://broughttolife.sciencemuseum.org.uk/broughttolife/themes/controversies/thalidomide

Buncombe, Andrew. "AOC asks pharma CEO why $2,000 HIV drug costs just $8 in Australia: 'People are dying for no reason.'" *The Independent*. May 17, 2019. Accessed February 2020. https://www.independent.co.uk/news/world/americas/us-politics/aoc-hiv-drug-cost-us-australia-ceo-gilead-video-a8919316.html

Cairns, Gus. "VOICE trial: Microbicide gel may have stopped two out of three HIV infections—in the women who used it." *Aidsmap*. February 9, 2019. Accessed February 2020. http://www.aidsmap.com/VOICE-trial-Microbicide-gel-may-have-stopped-two-out-of-three-HIV-infections-in-the-women-who-used-it/page/2943410/

Center For Health and Gender Equity (CHANGE). "Global Gag Rule Fact Sheet." July 2018, 1-2. Accessed July 2019. http://www.genderhealth.org/files/uploads/change/publications/CHANGE_GGR_fact_sheet.pdf

CDC. "About DES." Accessed February 2020. https://www.cdc.gov/des/consumers/about/history.html

CDC Fact Sheet. "HIV Among African Americans." Undated. 1-2. Accessed February 2020. https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/cdc-hiv-aa-508.pdf

CDC Fact Sheet. "HIV in the United States: The Stages of Care." July 2012. 1-3. Accessed February 2020. https://www.cdc.gov/hiv/pdf/research_mmp_stagesofcare.pdf

CDC Fact Sheet. "Today's HIV/AIDS Epidemic." August 2016. 1-4. Accessed February 2020. https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/todaysepidemic-508.pdf

CDC. "HIV Risk Behaviors." Last updated November 13, 2019. Accessed February 2020. https://www.cdc.gov/hiv/pdf/risk/estimates/cdc-hiv-risk-behaviors.pdf

CDC. "HIV and STD Criminal Laws." Accessed February 2020. https://www.cdc.gov/hiv/policies/law/states/exposure.html

CDC. "HIV in the United States and Dependent Areas." December 2019. Accessed February 2020. https://www.cdc.gov/hiv/pdf/statistics/overview/cdc-hiv-us-ataglance.pdf

CDC. *Lets Stop HIV Together* Campaign Resources. Accessed February 2020. https://www.cdc.gov/stophivtogether/campaigns/index.html

CDC. "U.S. Statistics." Last updated January 16, 2020. Accessed February 2020. https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics

Chen, Michelle. "Trump's Global Gag Rule Is Making It Harder to Fight the AIDS Crisis." *The Nation*. March 25, 2019. Accessed February 2020. https://www.thenation.com/article/archive/global-gag-rule-trump-hiv-aids/

Children's Bureau. "The Abandoned Infants Assistance Initiative 1988-2017." August 2018. 1-18. Accessed February 2020. https://www.childwelfare.gov/pubPDFs/aia_summary.pdf

Cicatelli Associates Inc. (CAI). African American Women and PrEP. Accessed Feburary 2020. https://docs.wixstatic.com/ugd/68e4cb_8748d15a45cb453c91ff1d31ad368a65.pdf

De La Garza, Alejandro. "Number of U.S. Abortions Hits Lowest Rate Since Roe. Wade, CDC." *Time Magazine*. November 21, 2018. Accessed February 2020. https://time.com/5461616/abortions-lowest-rate-cdc/

Dias, Isabela. "When ICE Emptied Out an All-Women Detention Center in Texas, Chaos Ensued." *Texas Observer*. November 6, 2019. https://www.texasobserver.org/ice-karnes-all-women-detention/

Farrow, Kenyon. "New Campaign, Toolkit Gets Providers PrEP'd for Women." *TheBodyPro*. May 10, 2019. Accessed February 2020. https://www.thebodypro.com/article/new-campaign-toolkit-gets-providers-prep-for-women

Forbes, Anna. "HIV Affects Millions of Women. So Why Isn't a New PrEP Drug Approved for Their Use?" December 2, 2019. Accessed February 2020. https://rewire.news/article/2019/12/02/hiv-truvada-descovy-women/

Forbes, Anna. "Vital Microbicides May Soon Be Out of Reach." *Rewire.News*. November 9, 2017. Accessed February 2020. https://rewire.news/article/2017/11/09/vital-microbicides-may-soon-reach/

Forbes, Anna. "Women Deserve to Know About HIV Prevention Medication Too." *Rewire.News*. March 10, 2015. Accessed February 2020. https://rewire.news/article/2015/03/10/women-deserve-know-hiv-prevention-medication/

Forbes, Anna, and Samukeliso Dube, Megan Gottemoeller, Pauline Irungu, Bindiya Patel, Ananthy Thambinayagam. "In Our Own Hands: A case study on mobilizing demand for HIV prevention for women." 2013. 1-48. Accessed February 2020. https://path.azureedge.net/media/documents/APP_gcm_hiv_cs.pdf

Fowler, C. I., and J. Gable, J. Wang and B. Lasater. *Family Planning Annual Report: 2017 national summary*. August 2018. 1-B12. Accessed February 2020. https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2017-national-summary.pdf

Frost, Jennifer J., and Rachel Benson, and Amelia Bucek. "Specialized Family Planning Clinics in the United States: Why Women Choose Them and Their Role in Meeting Women's Health Care Needs." *Women's Health Issues* 22, no. 6. November 2012. 1-22. Accessed February 2020. https://www.guttmacher.org/sites/default/files/pdfs/pubs/journals/j.whi.2012.09.002.pdf

Gallucci, Maria. "Black women are dying of cervical cancer at twice the rate of white women, study shows." *Mashable UK*. January 23, 2017. Accessed February 2020. https://mashable.com/2017/01/23/cervical-cancer-study-racial-disparity/?europe=true

Gillette-Pierce, Kiersten, and Jamila Taylor. "The Threat to Title X Family Planning: Why It Matters and What's at Stake for Women." *Center for American Progress*. February 9, 2017. Accessed February 2020. https://www.americanprogress.org/issues/women/reports/2017/02/09/414773/the-threat-to-title-x-family-planning/

Glaze, Lauren E., and Laura M. Maruschak, "Parents in Prison and Their Minor Children." *Bureau of Justice Statistics*. August 2008. 1-25. Revised March 2010. Accessed February 2020. https://www.bjs.gov/content/pub/pdf/pptmc.pdf

Goodwin, Kristine. "Improving Women's Health: State Policy Options." National Conference on State Legislatures. December 2015. 1-11. Accessed February 2020. https://www.ncsl.org/Portals/1/Documents/Health/WHchecklist12-15.pdf

Governor Cuomo Announces Plan to End the AIDS Epidemic in New York State. June 29, 2014. *ny.gov*. Accessed February 2020. https://www.governor.ny.gov/news/governor-cuomo-announces-plan-end-aids-epidemic-new-york-state

Greenspan, Judy. "Voices from the Chowchilla Women's Prison." *Prison Legal News (Women Organized to Respond to Life Threatening Diseases, Oakland, CA)*. March 15, 1994. Accessed February 2020. https://www.prisonlegalnews.org/news/1994/mar/15/voices-from-the-chowchilla-womens-prison/

Guichard, Anne-Claire. "On International Women's Day, UNAIDS calls for greater action to protect young women and adolescent girls." UNAIDS Press Statement. March 8, 2019. Accessed February 2020, https://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2019/march/20190308_iwd

Guttmacher Institute. "State Funding of Abortion Under Medicaid." Last updated December 1, 2019. Accessed February 2020. https://www.guttmacher.org/state-policy/explore/state-funding-abortion-under-medicaid

Hamblin, James. "Stopping HIV Would Require an Entirely Different Trump." *The Atlantic*. February 6, 2019. Accessed February 2020. https://www.theatlantic.com/health/archive/2019/02/trump-state-of-the-union-hiv/582076/

Hamborsky, J., A. Kroger, and S. Wolfe. Epidemiology and Prevention of Vaccine Preventable Diseases. 13th edition. April 2015. 297-310. Accessed February 2020. https://www.cdc.gov/vaccines/pubs/pinkbook/downloads/polio.pdf

Heim, Joe. "National Archives exhibit blurs images critical of President Trump." *Washington Post*. January 17, 2020. Accessed February 2020. https://www.washingtonpost.com/local/national-archives-exhibit-blurs-images-critical-of-president-trump/2020/01/17/71d8e80c-37e3-11ea-9541-9107303481a4_story.html

Henry J. Kaiser Family Foundation. "Women and HIV/AIDS in the United States." March 6, 2014. Accessed February 2020. https://www.kff.org/hivaids/fact-sheet/women-and-hivaids-in-the-united-states/

Henry J Kaiser Family Foundation. AIDS 2010: Study Finds Microbicide Containing HIV Drug Lowers Infection Risk in Women by 39%. July 20, 2010. Accessed February 2020. https://www.kff.org/news-summary/aids-2010-study-finds-microbicide-containing-hiv-drug-lowers-infection-risk-in-women-by-39/

Henry J. Kaiser Family Foundation. "Women's Health Insurance Coverage." January 24, 2020. Accessed February 2020. https://www.kff.org/womens-health-policy/fact-sheet/womens-health-insurance-coverage-fact-sheet/

Highleyman, Liz. "Drug Company Antitrust Trial Gets 2022 Court Date." *Poz*. January 23, 2020. Accessed February 2020. https://www.poz.com/article/drug-company-antitrust-trial-gets-2022-court-date

Hiltzik, Michael. "Trump makes his most aggressive move yet to gut Medicaid." January 30, 2020. Accessed February 2020. https://www.latimes.com/business/story/2020-01-30/trump-moves-to-gut-medicaid

HIV Justice Network. "US: Florida Woman Guilty of Mother-To-Child HIV Transmission." October 28, 2008. Accessed February 2020. http://www.hivjustice.net/case/us-florida-woman-guilty-of-mother-to-child-hiv-transmission/

HIV Prevention Research & Development Investments, 2000-2015. Investment priorities to fund innovation in a challenging global health landscape. October 2016. 1-60. Accessed February 2020. http://www.hivresourcetracking.org/wp-content/uploads/2016/12/Resource_Tracking_Report_2015.pdf

International Committee of the Red Cross. Health in Prison: Looking after women in a man's world. February 27, 2009. Accessed February 2020. https://www.icrc.org/en/doc/resources/documents/interview/women-health-prison-interview-020309.htm

Institute of Medicine (US) Committee on the Ryan White CARE Act: Data for Resource Allocation, Planning, and Evaluation. "Measuring What Matters: Allocation, Planning, and Quality Assessment for the Ryan White CARE Act." Washington, D.C.: National Academies Press, 2004. Accessed February 2020. https://www.ncbi.nlm.nih.gov/books/NBK216136/

International Partnership for Microbicides. Our Donors. Accessed February 2020. https://www.ipmglobal.org/about-ipm/donors

International Partnership for Microbicides. Preparing for Access to Microbicides and the Dapivirine Ring for HIV Prevention. Current as of May 2011. 1-37. Accessed February 2020. https://assets.publishing.service.gov.uk/media/57a08af0ed915d3cfd000a20/IPMAccessStrategy.pdf

Jones, Kelly M. "Evaluating the Mexico City Policy: How US Foreign Policy Affects Fertility Outcomes and Child Health in Ghana." December 2011. v-26. Accessed January 2020. https://www.poppov.org/~/media/PopPov/Documents/events/6thAnnConf/jones-2011-mexico-city-fertility.pdf

Kahn, Samantha. "The End of Gender Rating: Women's Insurance Under the ACA." *Wharton Public Policy Initiative*. August 4, 2015. Accessed September 2019. https://publicpolicy.wharton.upenn.edu/live/news/819-the-end-of-gender-rating-womens-insurance-under

Kajstura, Aleks. "Women's Mass Incarceration: The Whole Pie 2018." October 29, 2019. Accessed February 2020. https://www.prisonpolicy.org/reports/pie2019women.html

Kelly, Caroline. "Freshman Democrat presses JPMorgan CEO Jamie Dimon over pay disparity." *CNN*. April 11, 2019. Accessed February 2020. https://edition.cnn.com/2019/04/10/politics/katie-porter-jamie-dimon-bank-employees/index.html

Kerr, Theodore. "How to Have an AIDS Memorial in an Epidemic." *C Magazine*. No. 142. Summer 2019. Accessed February 2020. https://cmagazine.com/issues/142/how-to-have-an-aids-memorial-in-an-epidemic

Khazan, Olga. "The Biggest Consequences of Trump's New Abortion Rule Won't Be for Abortion." *The Atlantic*. March 5, 2019. Accessed February 2020, https://www.theatlantic.com/health/archive/2019/03/trumps-title-x-rule-change-planned-parenthood/584005/

Kinsella, Chad. "Corrections Health Care Costs," Lexington: Kentucky. January 2004. 1-29. Accessed February 2020. https://www.prisonpolicy.org/scans/csg/Corrections+Health+Care+Costs+1-21-04.pdf

Kremer, William. "The return of the female condom?" *BBC World Service*. December 15, 2013. Accessed February 2020. https://www.bbc.co.uk/news/magazine-25348410

Levintova, Hannah. "Iowa Just Gutted Planned Parenthood and the Results for Women Are Brutal." *Mother Jones*. September/October 2017. Accessed February 2020. https://www.motherjones.com/politics/2017/07/iowa-just-gutted-planned-parenthood-and-the-results-for-women-are-brutal/

Lim, Charleston. "Lawsuit Accuses Gilead Sciences of propping up cost of lifesaving HIV treatments by blocking generic competition." *CNBC*. May 14, 2019. https://www.cnbc.com/2019/05/14/lawsuit-alleges-gilead-propped-up-cost-of-hiv-drug.html

Lite, Jordan. "New Push for Woman-Controlled AIDS Prevention." *Women's Enews*, May 19, 2002. Accessed February 2020. https://womensenews.org/2002/05/new-push-woman-controlled-aids-prevention/

Mahdavi, Elle. "Patents and the Pharmaceutical Industry." *BerkeleyHaas*. May 26, 2017. Accessed February 2020. https://cmr.berkeley.edu/blog/2017/5/patents-and-pharmaceuticals/

Maruschak, Laura M., and Marcus Berzofsky, and Jennifer Unangst. "Medical Problems of State and Federal Prisoners and Jail Inmates, 2011-12," Washington: Bureau of Statistics. 2015. 1-22. Revised October 4, 2016. Accessed February 2020. https://bjs.gov/content/pub/pdf/mpsfpji1112.pdf

Matson, Erin. "Dear CVS: A Real 'Health-Care Company' Guarantees In-Store Access to Birth Control." *Re.Wire News*, February 27, 2014. Accessed February 2020. https://rewire.news/article/2014/02/27/dear-cvs-real-health-care-company-guarantees-store-access-birth-control/

McCammon, Sarah. "Planned Parenthood Withdraws From Title X Program Over Trump Abortion Rule." *npr*. August 19, 2019. Accessed February 2020. https://www.npr.org/2019/08/19/752438119/planned-parenthood-out-of-title-x-over-trump-rule

McTighe, Laura. "Refusing to Vanish: Muslim Women's AIDS Activism." *the revealer*. December 1, 2017. Accessed January 2020. https://therevealer.org/refusing-to-vanish-muslim-womens-aids-activism/

Meyer, Ilan H., and Andrew R. Flores, Lara Stemple, Adam P. Romero, Bianca D. M. Wilson, and Jody L. Herman. "Incarceration Rates and Traits of Sexual Minorities in the United States: National Inmate Survey, 2011-2012." *American Journal of Public Health*.

February 2017. 234-240. Accessed February 2020. https://williamsinstitute.law.ucla.edu/wp-content/uploads/Meyer_Final_Proofs.LGB_.In_.pdf

Miller, Anna Medaris. "What It's Like to Be a Woman With HIV." *U.S. News*. March 10, 2015. Accessed February 2020. https://health.usnews.com/health-news/patient-advice/articles/2015/03/10/what-its-like-to-be-a-woman-with-hiv

Millhiser, Ian. "The Biggest lie in Trump's State of the Union Speech." February 4, 2020. Accessed February 2020. https://www.vox.com/2020/2/4/21123495/biggest-lie-trump-state-of-the-union-2020-preexisting-conditions

My PrEP Story: Yasmin (part 1). August 8, 2018. Accessed February 2020. https://prepster.info/2018/08/prep-story-yasmin-part-1/

National AIDS Trust (NAT). "PrEP Drug Patent Overturned in UK—NAT Respond." Tuesday 18, 2018. Accessed February 2020. https://www.nat.org.uk/press-release/prep-drug-patent-overturned-uk-nat-respond

Nocera, Joe. "Why Big Pharma Is Winning the Drug Price Wars." *Bloomberg*. April 8, 2019. Accessed February 2020. https://www.bloomberg.com/opinion/articles/2019-04-08/why-drug-prices-keep-rising-despite-congress-s-efforts

Ollstein, Alice Miranda, and Rachel Roubein. "Trump administration begins enforcing abortion 'gag rule.'" *Politico*. July 16, 2019. Accessed February 2020. https://www.politico.com/story/2019/07/16/trump-administration-abortion-gag-rule-1593665

Our Bodies, Ourselves: The Nine U.S. Editions. Accessed February 2020. https://www.ourbodiesourselves.org/publications/the-nine-u-s-editions/

Pagilarulo, Ned. "Gilead CEO pressured on PrEP pricing at House hearing." *Biopharmadive*. May 17, 2019. Accessed February 2020. https://www.biopharmadive.com/news/gilead-ceo-house-hearing-prep-hiv-drug-pricing/555028/

Park, Alice. "6 Resigned from Trump's HIV/AIDS Advisory Board. Here's Why One Doctor Stayed." *Time Magazine*. June 20, 2017. Accessed February 2020. https://time.com/4824456/trump-hiv-aids-council-resign/

Pattillo, Ali. "Sexist Science Makes Women's Reproductive Health a Guessing Game." *Inverse*. November 16, 2019. Accessed February 2020. https://www.inverse.com/article/60989-gender-gap-research-and-womens-health

Planned Parenthood. "Courting Disaster: Trump's Judicial Nominees." Accessed February 2020. https://www.plannedparenthoodaction.org/issues/trump-judicial-nominations

Planned Parenthood. "The Effects of Defunding: Texas and Indiana." Accessed February 2020. https://www.plannedparenthood.org/uploads/filer_public/9e/71/9e713a00-4844-43aa-adf6-3cc9e6cf30e0/the_effects_of_defunding_texas_and_indiana.pdf

Planned Parenthood. "The Impact of Defunding Planned Parenthood." Accessed February 2020. https://www.istandwithpp.org/defund-defined/impact-defunding-planned-parenthood

Planned Parenthood. "Medicaid and Reproductive Health." Accessed February 2020. https://www.plannedparenthoodaction.org/issues/health-care-equity/medicaid-and-reproductive-health

Positive Justice Project. *Ending and Defending Against HIV Criminalization: A Manual for Advocates* 1. First Edition. Fall 2010. 1-214. Accessed February 2020. https://hivlawcommission.org/wp-content/uploads/2017/06/Ending-and-Defending-Against-HIV-Criminalization-A-Manual-for-Advocates.pdf

PrEP in Europe. "Intermittent PrEP: Do you have to take it every day?" Accessed February 2020. http://www.prepineurope.org/en/faqs/does-prep-work/intermittent-prep/

Rapaport, Lisa. "Women are missing from HIV drug trials." *Reuters*. October 2, 2015. Accessed February 2020. https://in.reuters.com/article/us-health-hiv-women-idINKCN0RW2E520151002

Resource Tracking for HIV Prevention Research & Development. *HIV Prevention Research & Development Investments, 2000-2015: Investment priorities to fund innovation in a challenging global health landscape*. October 2016. 1-60. Accessed February 2020. http://www.hivresourcetracking.org/wp-content/uploads/2016/12/Resource_Tracking_Report_2015.pdf

Rowland, Christopher. "An HIV treatment cost taxpayers millions. The government patented it. But a pharma giant is making billions." *Washington Post*. March 26, 2019. https://www.washingtonpost.com/business/economy/pharma-giant-profits-from-hiv-treatment-funded-by-taxpayers-and-patented-by-the-government/2019/03/26/cee5afb4-40fc-11e9-9361-301ffb5bd5e6_story.html

Russell, Asia. "AIDS Activists Disrupt Gilead Shareholder Meeting Over Access." *Health Gap Global Access Project*. May 8, 2019. Accessed February 2020. https://healthgap.org/press/aids-activists-disrupt-gilead-shareholder-meeting-over-access-to-hiv-prevention-medicine/

Ryan, Benjamin. "An Estimated 136,000 People are on PrEP in the U.S." *POZ*. August 18, 2017. Accessed January 2020. https://www.poz.com/article/estimated-136000-people-prep-us

Samant, Anjana. "The First Step Act is a Small Step for Incarcerated Women." *ACLU Blog*. December 27, 2018. Accessed February 2020. https://www.aclu.org/blog/prisoners-rights/women-prison/first-step-act-small-step-incarcerated-women

Sagonowsky, Eric. "Gilead tries—and fails—to dodge lawsuit claiming it delayed safer HIV meds." *FiercePharma*. May 14, 2019. Accessed February 2020. https://www.fiercepharma.com/pharma/gilead-fails-to-convince-judge-to-toss-hiv-drug-case

Salzman, Sony. "Trump Touted Gilead's Donation of HIV-Prevention Medication, But Doctors Want Generics—Not Charity." *Rewire.News*. May 23, 2019. Accessed February 2020. https://rewire.news/article/2019/05/23/trump-touted-gileads-donation-of-hiv-prevention-medication-but-doctors-want-generics-not-charity/

Sawyer, Wendy. "The steep cost of medical co-pays in prison puts health at risk." *Prison Policy Initiative*. April 19, 2017. Accessed February 2020. https://www.prisonpolicy.org/blog/2017/04/19/copays/

Schlack, Julie Wittes. "The Title X 'Gag Rule' Plays Politics by Attacking Women's Health." *wbur news*. March 1, 2019. Accessed February 2020. https://www.wbur.org/cognoscenti/2019/03/01/title-x-gag-rule-julie-wittes-schlack

Stallings, Erika. "This is How the American Healthcare System Is Failing Black Women." *The Oprah Magazine*. August 1, 2018. Accessed February 2020. https://www.oprahmag.com/life/health/a23100351/racial-bias-in-healthcare-black-women/

Stewart, Heather, and Charlotte Denny, and Andrew Clark. "Bayer bows to pressure on anthrax antidote." *The Guardian*. October 23, 2001. Accessed February 2020. https://www.theguardian.com/business/2001/oct/23/anthrax.businessofresearch

Straube, Trenton. "Here's How We Can Get Universal Access to PrEP." *Poz*. July 25, 2018. Accessed February 2020. https://www.poz.com/article/universal-access-prep-hiv-prevention

Talvi, Silja J. A. "Eight Prisoner Deaths in California Women's Prison." *Prison Legal News*. May 15, 2001. Accessed February 2020. https://www.prisonlegalnews.org/news/2001/may/15/eight-prisoner-deaths-in-california-womens-prison/

Trenton Straube. "Generic PrEP to Arrive in September 2020, but Will Big Savings Follow?" *POZ*. May 9, 2019. Accessed February 2020. https://www.poz.com/article/generic-prep-arrive-september-2020-will-big-savings-follow

Talbot, Margaret. "How the Trump Administration is Stigmatizing Abortion." *New Yorker*. August 24, 2019. Accessed https://www.newyorker.com/news/daily-comment/how-the-trump-administration-is-stigmatizing-abortion

The African American Policy Forum. "SayHerName: Resisting Brutality Against Black Women." Accessed February 2020. https://aapf.org/sayhernamereport

"The gender gap in employment: What's holding women back?" *International Labour Organization*. Published December 2017. Updated March 2018. Accessed May 2020. https://www.ilo.org/infostories/en-GB/Stories/Employment/barriers-women

The Pew Charitable Trust. "Prison Health Care: Costs and Quality: How and why states strive for high-performing systems." October 2017. 1-135. Accessed November 2019. http://www.pewtrusts.org/~/media/assets/2017/10/sfh_prison_health_care_costs_and_quality_final.pdf

The PREP4ALL Collaboration. "A National Action Plan for Universal Access to HIV Pre-Exposure Prophylaxis (PrEP) in the United States." July 2018. 1-40. Accessed February 2020. https://www.poz.com/pdfs/national-action-plan-prep-2018.pdf

The Sentencing Project. Fact Sheet: Incarcerated Women and Girls. Updated June 2019. 1-5. Accessed February 2020. https://www.sentencingproject.org/wp-content/uploads/2016/02/Incarcerated-Women-and-Girls.pdf

Tolbert, Jennifer, Robert Rudowitz, and MaryBeth Musumeci. "How Will Medicare-for-all Proposals Affect Medicaid?" *Kaiser Family Foundation*. September 12, 2019. Accessed February 2020. https://www.kff.org/medicaid/issue-brief/how-will-medicare-for-all-proposals-affect-medicaid/

Quinn, Mattie. "Why Texas Is the Most Dangerous U.S. State to Have a Baby." *Governing*, May 2017. Accessed February 2020. https://www.governing.com/topics/health-human-services/gov-maternal-infant-mortality-pregnant-women-texas.html

UNAIDS. "Women and HIV: A Spotlight on Adolescent Girls and Young Women." 2019. Accessed February 2020. 1-19. https://www.unaids.org/sites/default/files/media_asset/2019_women-and-hiv_en.pdf

Washington, D.C., PrEP Awareness Campaign for all Women. Accessed February 2020. https://sexualbeing.org/get-involved/prep-for-her/

Welch, Jon. "Opinion: Trump's Reinstated 'Global Gag Rule' On Abortion is Cruellest to the Poorest." *wbur news*. January 26, 2017. Accessed February 2020. https://www.wbur.org/commonhealth/2017/01/26/new-mother-die-gag-rule

The Well Project. "Lessons from GRACE: A US Study Focused on Women Living with HIV." March 20, 2019. Accessed February 2020. https://www.thewellproject.org/hiv-information/lessons-grace-us-study-focused-women-living-hiv

White House. "Support for Trump Administration's Proposed Title Rule." Issued on May 22, 2018. Accessed February 2020. https://www.whitehouse.gov/briefings-statements/support-trump-administrations-proposed-title-x-rule/

White, Vanessa A., and Christine Brazell. "Family Planning Provides Key in Fight Against HIV." *HIV.gov*. Undated. Accessed February 2020. https://www.hiv.gov/blog/family-planning-providers-key-in-fight-against-hiv

Wise, Akilah. "In Prison, Women are 9 Times More Likely to be HIV-Positive." *The Nation*. November 24, 2017. Accessed February 2020. https://www.thenation.com/article/in-prison-women-are-9-times-more-likely-to-be-hiv-positive/

"Women's Health Insurance Coverage." *Kaiser Family Foundation*. January 24, 2020. Accessed May 2020. https://www.kff.org/womens-health-policy/fact-sheet/womens-health-insurance-coverage-fact-sheet/

World Health Organization (WHO). Violence Against Women and HIV/AIDS: Critical Intersections. Intimate Partner Violence and HIV/AIDS. No. 1. 2004. 1-9. Accessed February 2020. https://www.who.int/hac/techguidance/pht/InfoBulletinIntimatePartnerViolenceFinal.pdf

Young, Donna. "Gilead CEO defends HIV drug Truvada's price, insists CDC patents invalid." *S&P Global*. May 16, 2019. Accessed February 2020. https://www.spglobal.com/marketintelligence/en/news-insights/latest-news-headlines/51879834