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Social Justice

Punishing Disease

HIV and the Criminalization of Sickness

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INTRODUCTION

Punishment

AIDS in the Shadow of an American Institution

The states should pass laws and/or step up enforcement of their laws against homosexual activity. As much of a moral issue as it is, homosexual activity is also now a health threat of epidemic proportions, and it simply cannot be allowed.

—Rev. Jimmy Swaggart, July 20, 1986¹

It is time for the homosexual community to publicly chastise itself for its promiscuous sexual practices that is causing the spread of AIDS more to its own people and now the heterosexual community.

—Louis Sheldon, October 5, 1985²

AIDS carriers are a threat to society, and the state has a compelling interest in protecting the uninfected. I am weary of politicians who pander to perverts with an eye to the next election.

—Former Indiana Representative Don Boys, June 24, 1988³

We sue for everything that our forefathers would never have done, and we blame everybody for everything. Now that we have done all of this, we have AIDS, child abuse, wife abuse, satanic cults, gang killings, rampant dope dealers and users, children killing children, people wanting everything free, having children to get more, AFDC, murder rising, rape more than ever in history, and the police cannot get the paper work done before some judge lets those arrested back out on the street.

—Joan Parrish, February 28, 1989⁴

From the very beginning of the epidemic, AIDS was linked to punishment. For evangelical Americans, AIDS represented divine punishment for the moral depravity sweeping America—namely, what conservatives derisively termed the “homosexual lifestyle.” According to a 1987 Gallup poll, 61 percent of American evangelicals and 50 percent of non-evangelicals agreed with the statement “I sometimes think AIDS is a punishment for the decline in moral standards.”⁵ Televangelists like Jimmy Swaggart and Pat Robertson took to the airways to publicly condemn homosexuality as the cause of AIDS. Their like-minded political counterparts, activists such as William F. Buckley and Lyndon LaRouche, spearheaded campaigns aimed at getting states to pass punitive laws: to criminalize homosexuality, to tattoo newly diagnosed patients, to raid gay establishments.⁶

AIDS activists fiercely resisted these policies as draconian efforts to trample on civil liberties—policies that they argued were stigmatizing and thus likely to be counterproductive in the fight against AIDS.⁷ Activists argued that freedom and privacy, not coercion and intrusive surveillance, were the keys to a successful disease control strategy. Despite their efforts, in the late 1980s state lawmakers around the country began to introduce criminal legislation targeting people living with HIV, whom they viewed as recklessly exposing their sexual partners to the disease. Echoing the sentiments of many Americans, a California newspaper editorial argued in 1987 that these laws were needed “to prevent unstable AIDS victims from passing on a death sentence to others.”⁸ Although they are sometimes mislabeled as “HIV transmission laws,” most criminal laws enacted in the United States governing HIV exposure and/or disclosure make no mention of transmission or even the risk of that outcome. Instead, these new offenses resemble what prosecutors call a “crime of omission”: by failing to reveal their HIV status to their partners, HIV-positive people in dozens of states can now face stiff prison penalties if charged under these felony statutes.

Although AIDS crystallized a specific set of social anxieties about sex, drugs, and death, the brand of punitive rhetoric and policies it spirited was not unique to AIDS in the 1980s. While President Reagan’s administration is notorious for its callous indifference to the epidemic, First Lady Nancy Reagan is equally notorious for her Just Say No campaign against drugs. President Nixon first announced a war on drugs in 1971, but it was ratcheted up to new heights in the 1980s as federal and state authorities instituted a swath of new policies aimed at keeping drug users behind bars for as long as possible.⁹ In the midst of these

epidemic, AIDS was linked to punishment. AIDS represented divine punishment on America—namely, what conservatives called “the gay lifestyle.” According to a 1987 *Gallop* survey, 50 percent of non-tele-evangelicals and 50 percent of non-tele-evangelicals “I sometimes think AIDS is a punishment for gay standards.”⁵ Televangelists like Jim Bakker looked to the airways to publicly condemn AIDS. Their like-minded political allies, such as F. Buckley and Lyndon LaRouche, urged states to pass punitive laws: to punish newly diagnosed patients, to raid

these policies as draconian efforts to punish what they argued were stigmatizing behaviors active in the fight against AIDS.⁷ Privacy, not coercion and intrusive surveillance, was the successful disease control strategy. As state lawmakers around the country passed legislation targeting people living with HIV by exposing their sexual partners to the virus, of many Americans, a California lawmaker argued that these laws were needed “to prevent passing on a death sentence to others mislabeled as ‘HIV transmission.’”⁸ In the United States governing HIV, there is no mention of transmission or even of these new offenses resemble what we call “on”: by failing to reveal their HIV status, people in dozens of states can now be punished under these felony statutes. A specific set of social anxieties about crime, punitive rhetoric and policies it inspired in the 1980s. While President Reagan’s callous indifference to the epidemic, his notorious for her Just Say No campaign first announced a war on drugs in the 1980s as federal and state levels in the 1980s as federal and state levels of new policies aimed at keeping crime as low as possible.⁹ In the midst of these

heated policy debates, some authorities even made extremely sensational calls for drug dealers to be put to death. In 1986, for example, Vice President George Bush told reporters that he would probably support the death penalty for large-scale drug dealers.¹⁰ Four years later, Los Angeles Police Chief Daryl Gates (founder of the D.A.R.E. school program) testified before Congress that he believed casual drug users were treasonous and “ought to be taken out and shot.”¹¹

There are striking similarities between the conservative backlash to AIDS and the crackdown on drugs. While conservatives promoted policies that targeted homosexuality in the face of AIDS, so too did they promote policies that targeted stigmatized minorities in their war on drugs. The racism underlying the Reagan-era drug war was belied by its special focus on a drug that was disproportionately used by poor Black Americans: crack cocaine.¹² Indeed, Congress enacted the Anti-Drug Abuse Act of 1986 that mandated extremely different sentences for crack cocaine (five years for five grams) and its powdered cousin more commonly used by Whites (five years for *five hundred* grams); while this one hundred-to-one disparity was on its face “color-blind,” critics nonetheless viewed it as racist because of its devastatingly disparate impact on Black men.¹³ By the end of the decade, America’s jail and prison population had doubled to over one million inmates; while African Americans constituted just 12.1 percent of the American population in 1990, they made up a lopsided 48.4 percent of its booming prison population.¹⁴ Like the homophobia that haunted the conservative backlash to AIDS in America, racism drove America’s obsession with punishing crack cocaine.

The war on drugs and the punitive response to HIV are but two examples of a more seismic shift in American corrections policy; lawmakers increasingly turned away from the rehabilitative spirit of the 1960s and 1970s in favor of far more punitive approaches that were rooted in retribution—or punishment for punishment’s sake. This trend away from rehabilitation was driven by three key social factors. First, crime rates had risen sharply from the 1960s, reaching historically high levels just as AIDS began to emerge in the early 1980s.¹⁵ Second, inconsistent social science findings had eroded the confidence of American criminal justice authorities in the effectiveness of such programs, although they had seen rehabilitation as a key part of their mission during the 1960s and 1970s.¹⁶ Third, conservatives organized a racist backlash to civil rights activism that linked criminality with race and frequently portrayed young Black men as lawless “superpredators” that needed to be controlled and punished.¹⁷ These three factors struck fear

into the hearts and minds of middle-class and White Americans, leading to escalating calls for “tough-on-crime” policies that disproportionately impacted the poor and racial minorities.¹⁸

This network of punitive policies led to dramatically higher rates of incarceration in the United States. Since 2002, America has had the highest incarceration rate in the world—surpassing even repressive regimes such as Russia.¹⁹ Although the total correctional population peaked in 2007, 716 of 100,000 Americans were behind bars in 2013 (the latest year this figure was available at the time of publication).²⁰ Far from being a reflection of increasing crime rates, incarceration rates have skyrocketed while crime rates have plummeted. This spike in incarceration cannot be entirely explained by increasing crime or even a rise in the number of arrests; sociologists instead explain that much of the increase in incarceration can be explained by determinations made after arrest: rather than issuing warnings or minor citations, criminal justice authorities are incarcerating a greater share of arrested defendants than ever before.²¹ This panoply of punishment has reinforced and deepened racial inequality in American society, leading to some to charge that it represents a new era of Jim Crow.²² For example, researchers estimate that in 2004, 33.4 percent of African American adult males had a felony conviction as compared to 7.5 percent of adults overall.²³ Higher rates of incarceration are associated with numerous negative outcomes, from unemployment to worsened health and family dissolution.²⁴ This “mass incarceration” has led sociologists to argue that punishment has become a new American institution that is fundamentally disrupting the way our society is organized.²⁵

The story of mass incarceration is now well known among social scientists and even among many Americans as popular books such as Michelle Alexander’s *The New Jim Crow* have helped to disseminate its central thesis: that a highly racialized war on drugs in the 1980s and 1990s helped to propel a massive spike in incarceration rates, with particularly devastating consequences for African Americans. However, scholars have recently pointed out that the war on drugs is but one of many theaters in the American war on crime. For example, experts argue that an undeclared war on sex simmered and eventually erupted just as Americans had begun to lose confidence in the war on drugs.²⁶ Even as the number of Americans under correctional supervision (including those in jail, in prison, on probation, and on parole) flattened and declined slightly between 2006 and 2013, the rolls of state sex offender registries ballooned 35 percent to include nearly 750,000 Americans.²⁷ A

class and White Americans, leading to "policies that disproportionately affect" them.¹⁸

led to dramatically higher rates of incarceration. Since 2002, America has had the highest incarceration rate in the world—surpassing even repressive regimes like China (the total correctional population in the United States was behind bars in 2013 at 2.3 million, compared to 1.5 million in China at the time of publication).²⁰ Far from declining crime rates, incarceration rates have plummeted. This spike in incarceration has not been explained by increasing crime or even a decline in crime. Sociologists instead explain that much of the increase in incarceration is explained by determinations made by judges, not juries, or minor citations, criminal records, and a greater share of arrested defendants being sentenced to prison. The system of punishment has reinforced and perpetuated the racial divide in American society, leading to some of the highest incarceration rates in the world since Jim Crow.²² For example, research shows that the incarceration rate for African American adult males has increased to 7.5 percent of adults overall.²³ This is associated with numerous negative consequences, including worsened health and family dissolution, as led sociologists to argue that punishment is an institution that is fundamentally organized.²⁵

is now well known among social scientists that the war on drugs in the 1980s and 1990s has helped to disseminate its policies as popular books such as *Jim Crow* have helped to disseminate its policies. The war on drugs in the 1980s and 1990s, with a spike in incarceration rates, with particular impact on African Americans. However, it is clear that the war on drugs is but one of many factors contributing to crime. For example, experts argue that the war on drugs has not deterred and eventually erupted just as it has in the war on drugs.²⁶ Even as the war on drugs has continued, the correctional supervision (including probation, parole, and on parole) flattened and the number of state sex offenders has increased. In 2013, the rolls of state sex offenders included nearly 750,000 Americans.²⁷ A

recent study found that Black Americans are registered at rates twice that of White Americans—reflecting the broader racialized dynamic of American criminal justice.²⁸

Because HIV is sexually transmitted and was immediately linked to homosexuality, it may be tempting to view efforts to criminalize HIV as merely another example of efforts to criminalize nonnormative sexuality. However, *Punishing Disease* reveals that punitive policies toward people living with HIV are not driven solely by an interest in policing sexual morality. The first three chapters of *Punishing Disease* reveal that, instead, the criminalization of HIV is but one of the more recent examples in public health history of an effort to control disease by coercion and punishment—what this book terms *punitive disease control*. Although calls for punitive HIV control measures quickly became intertwined with (and at times nearly indistinguishable from) calls to police sexual norms, these two social projects are not the same. As this book reveals, the impetus to control, segregate, and punish the sick has a long history that stretches back to plagues such as smallpox and the Spanish flu, epidemics whose spread had little to do with sex.

The popularity of punitive approaches to public health practice has waxed and waned over time in concert with a changing medical landscape. Public health began to make headway against infectious disease mortality in the early twentieth century through an emphasis on promoting nutrition and sanitation. There has been considerable debate over whether these improvements in quality of life were responsible for reducing mortality as compared to the advent of vaccines, antibiotics, and other new medical technologies in the mid-twentieth-century.²⁹ Whatever the true causes may have been, however, many medical authorities attributed much of the twentieth-century declines in mortality to medical technologies and, as such, came to view pills and needles as the public health tools of tomorrow. In light of this changing medical landscape, many medical authorities were hopeful that coercive measures would be unnecessary in a new era of low mortality associated with infectious disease. As *Punishing Disease* reveals, however, AIDS gravely undermined this new optimism as a chorus of critics trumpeted a return to the coercive strategies of the past.

Although the history of punitive disease control stretches back centuries, no disease in modern American history has been met with a similarly systematic campaign to criminalize people living with an infectious disease. The second half of this book examines a second story: how a social problem typically perceived as medical—in this case, infectious disease—

became a target for criminalization. This story flips on its head the classic approach in medical sociology to studying the process of “medicalization,” or how social problems previously understood as nonmedical come under the jurisdiction of medical authorities and institutions. Although this concept may seem foreign to readers new to medical sociology, many may recognize the sociological critique of its most famous example: attention deficit hyperactivity disorder (ADHD). Before that diagnosis was popularized in the 1960s, the same set of behaviors among children that would be diagnosed as disease today was historically viewed instead as kids behaving badly.³⁰ Crucially, pharmaceutical companies quickly began profiting off the sale of new stimulant therapies as doctors diagnosed ever-greater numbers of American children with the disorder.³¹ Medicalization is therefore often described as the transformation “from badness to sickness.”³²

The second half of *Punishing Disease* looks, instead, at how HIV was transformed from sickness to badness under the criminal law, or what this book terms the *criminalization of sickness*. Under what circumstances do police and prosecutors claim jurisdiction over social problems typically thought of as medical problems? How is HIV litigated in a criminal court? And what are the effects of criminalizing sickness? The final three chapters of this book grapple with these questions.

It is no mistake that authorities responded to the HIV epidemic with a new punitiveness. Three historical factors helped to shape the punitive response to AIDS. First, the coincidence of HIV’s emergence with the birth of mass incarceration as a social institution meant that lawmakers were already in the habit of proposing handcuffs and prisons as solutions to social problems. *Punishing Disease* reveals the consequences of the emergence of AIDS in the shadow of this American institution’s ascent.

Second, HIV was immediately linked to stigmatized social groups that were, at that historical moment, particularly hated and, in many cases, already viewed as suspected criminals. In 1981, when the first cases of AIDS were reported, consensual sex between same-sex partners was a criminal offense in twenty-two states and the District of Columbia. Initial news reports described the disease as a “gay cancer” that was linked to marginalized social groups collectively known as the 4-H club: homosexuals, Haitians, heroin users, and hemophiliacs.³³ That the epidemic was symbolically synonymous with so many highly stigmatized and potentially criminal classes of people—rather than housewives, babies, or some other sympathy-engendering group—made criminalization a more obvious response.

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Third, during the early 1980s, there was widespread uncertainty and fear over the cause and effects of AIDS. This uncertainty created an opportunity for alternative theories to emerge, particularly the theory that AIDS was caused not by a virus but by a deviant lifestyle (namely, drug use and promiscuous homosexual sex).³⁴ Early missteps by medical authorities allowed these alternative theories to thrive. For example, by originally naming the disease gay-related immune deficiency (G.R.I.D.), authorities communicated an implicitly causal relationship between homosexuality and infection to the general public.³⁵ Such lifestyle theories of AIDS were bolstered by the disease's bizarre and terrifying progression; instead of presenting with a unique set of symptoms, AIDS patients were instead disfigured and/or killed by a litany of normally rare and horrifying diseases described as "opportunistic infections." Sometimes analogized by conservatives to the Biblical plagues of Egypt, these diseases included Kaposi's sarcoma (a cancer that causes purplish splotches on the skin), cytomegalovirus (a virus that causes blindness), and toxoplasmosis (a fungal infection that can cause seizures and swelling of the brain).

Taken together, these three historical factors created a perfect storm for punitive rhetoric and criminalization on a level not seen before in the modern history of American disease control.

Although many readers are likely to associate punishment most readily with the criminal justice system, the analysis contained in these pages is not limited to that institution. The first section of the book examines how institutions of public health shaped punitive policies toward infectious disease historically and, more recently, toward AIDS. Although some readers may view public health as a comparatively benevolent institution, this book does not view either public health or criminal justice as inherently good or bad. Instead, this book adopts the classic sociological approach to examining how public health and the law label and control *deviance*—defined by sociologists as behavior perceived as violating social expectations.³⁶ *Punishing Disease* tracks the historical origins of these norms as well as the punitive responses to their violation. From this labeling perspective, understanding how punishment became a legitimate disease control strategy requires an examination of both institutions of criminalization and institutions of disease control. In this way, this book not only contributes to an understanding of how public health labels, surveils, controls, and *punishes* people living with infectious diseases ("punitive disease control"); it also illuminates how the criminal justice system has come to control a conventionally medical category and with what effects ("the criminalization of sickness").

Punitive disease control and the criminalization of sickness represent two sides of the same coin; they share an interest in enforcing social norms and sanctioning behavior labeled deviant but differ in their institutional contexts (for example, public health versus criminal justice). In some cases, the norms in question are literally spelled out, as is the case in the twenty-eight states with criminal statutes that require people living with HIV to disclose their HIV-status to sexual partners before having sex. In other cases, these norms may be less formalized and subject to greater degrees of interpretation, such as public health laws that grant health officials authority to sanction people living with infectious diseases whose behavior they determine constitutes a "health threat to others."

While criminal justice and public health policies may determine how authorities *ought* to respond to such norm violations, their enforcement is not automated; legal and health authorities (prosecutors, judges, health officials, nurses, and others) must investigate rule breakers and decide how to proceed in each case. Taken together, their actions bring the criminal, civil, and administrative law to life. In this way, *Punishing Disease* continues the long tradition in sociolegal studies of examining the gap between the law on the books and the law in action.³⁷

As this book shows, however, punishment is more than just the sum of state laws and policies and the actions of state authorities who enforce them. Stigma and ignorance often serve as invisible hands guiding the wheel as lawmakers draft statutes and authorities determine how they are applied.³⁸ Stigma—against HIV, against gay men, against prostitution—can lubricate the transition from "sickness to badness," while ignorance about how HIV is transmitted can facilitate punitive responses to scenarios that involve little or no risk of transmitting the disease.

This book also examines how individual events and actors can provoke the spread of criminalization under the right conditions. For example, sensationally reported crimes can quickly prompt a legislator to introduce a bill aiming to punish related future offenses. This is especially true when moral entrepreneurs (or individuals who champion a particular cause) lobby for lawmakers to draft legislation or for prosecutors to press charges.

Each chapter of *Punishing Disease* examines a different facet of a social problem that is collectively referred to as "the criminalization of HIV." While that moniker implies a unidirectional and monolithic social process, the reality is far less tidy; it involves a wide array of players operating in different institutional contexts and is dependent on numer-

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sease examines a different facet of a referred to as "the criminalization of a unidirectional and monolithic social ; it involves a wide array of players contexts and is dependent on numer-

ous cultural and political variables. Moreover, the pathways to crimi- nalization and end products vary tremendously by state and sometimes even by county. Laws might be passed but never enforced. Or lawmak- ers may have shunned HIV-specific criminal laws, but creative prosecu- tors nonetheless find ways to punish under general statutes (typically felony assault). Nor is criminalization a dichotomous state, with HIV being "criminalized" in some states and "not criminalized" in others; punitive approaches to HIV instead fall along a spectrum of possibilities. No single book could reasonably claim to have told all the stories about the relationship between punishment and HIV. Instead, each chapter of *Punishing Disease* tells a different slice of a complicated story.

As such, this book should not be read as an exhaustive review of every attempt by health and legal authorities to control infectious disease or even just HIV throughout recent history. For example, public health practitioners reading this book from progressive coastal cities such as San Francisco or New York City may find the punitive strain of public health practice described by some of their Midwestern counterparts in chapter 3 to be entirely foreign or even objectionable. In highlighting these punitive strategies, the goal is not to erase or negate less punitive approaches to controlling disease that certainly do exist. Instead, the goals of *Punishing Disease* are (1) to examine under what conditions an impulse to punish becomes fused to the social project of controlling dis- ease, and (2) to analyze the effects of this marriage.

OVERVIEW OF THE BOOK

The chapters in the first section, "Punitive Disease Control," collec- tively analyze policies and enforcement practices. This analysis focuses on a strain of public health and policy that promotes coercive and puni- tive strategies for controlling disease. This is sometimes evidenced through the direct action of health officials who surveil and coerce peo- ple living with diseases. Or punitive disease control may be achieved indirectly, by promoting the idea that people living with infectious dis- eases are (at least in part) individually responsible and thus culpable for their infection and the infection of others.

Chapter 1, "Controlling Typhoid Mary," mines the history of infec- tious disease control to analyze how AIDS prompted calls for a return to the coercive techniques of the past. For centuries, quarantine was a staple of public health efforts to combat such scourges as the plague and Spanish flu. However, that begin to change as improved nutrition and

sanitation and then the advent of vaccines, antibiotics, and new treatments effectively put an end to diseases that had once killed or maimed millions, such as polio and smallpox. In this optimistic context, public health practitioners in the mid-twentieth century began to view quarantine and coercive public health tactics as retrograde approaches of yesteryear. As chronic illness replaced infectious disease as the leading cause of death in the twentieth century, public health began to view individual health behaviors—such as smoking and diet—as the primary causes of disease. But the rise of an unknown and terrifying infectious disease eventually called AIDS threatened to turn back the clock on public health practice, as conservative advocates demanded that public health tattoo everyone diagnosed with HIV and quarantine or imprison those individuals deemed a threat to public health.

Chapter 2, “HIV Stops with Me,” examines how shifts in HIV prevention policy and practice have deepened the notion that HIV-positive people are individually responsible for the epidemic. While many Americans still imagine HIV prevention campaigns as billboards telling HIV-negative people to use a condom, that approach is increasingly a relic of the past. In practice, health authorities reorganized the entire prevention enterprise beginning in the 2000s: people already infected with HIV were urged not to infect their partners and, more recently, to take their medication. The most visible break in the nation’s prevention strategy came in 2003, when the Centers for Disease Control and Prevention (CDC) announced its new priorities for HIV prevention. Critics expressed alarm that condoms were virtually absent from the document. This announcement came on the heels of a growing sentiment among public health experts that declining rates of condom use required new strategies for keeping the epidemic in check. This chapter tells the story of how a series of CDC policy shifts over the next decade worked to “repolarize” the very notion of doing HIV prevention away from targeting HIV-negative people and toward targeting people living with HIV. As it turns out, there is a very fine line between assigning individual responsibility and assigning blame. By advocating for HIV-positive people to take individual responsibility for preventing new infections, public health has inadvertently contributed to the notion that people with communicable disease are responsible for their illness and, as such, blameworthy for its continued spread.

Chapter 3, “The Public Health Police,” examines how local health officials police the behavior of people living with HIV in their efforts to end new infections. As the HIV epidemic wore on in the 2000s, public

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health authorities became enamored with the idea of ending AIDS. Health
departments began to track HIV-positive clients more closely, aiming to
control their behavior and ensure their adherence to treatment regimens.
This chapter explores how local health authorities in Michigan ensure
that HIV-positive clients behave in a manner officials deem responsible—
and how they catch and punish those who do not. While the state main-
tains that the work of local health officials is done solely in the interest of
promoting public health, their efforts to control HIV-positive clients
reveal that they are also engaged in policing and law enforcement.

The second section of the book, “The Criminalization of Sickness,”
examines the history and application of HIV exposure and disclosure
laws in the United States. Taken together, these chapters reveal how
stigma, fear, and ignorance have driven efforts to criminalize people liv-
ing with HIV—sometimes with unexpected effects.

Chapter 4, “Making HIV a Crime,” analyzes the state legislative
debates that led lawmakers to pass new, HIV-specific criminal laws
across the United States. Initially, prosecutors pressed charges against
HIV-positive people under general assault and attempted murder stat-
utes. However, prosecutors repeatedly fumbled efforts to legally secure
defendants’ medical records or, in other cases, failed to prove that they
had acted with criminal intent—a key element in common law known
as *mens rea*. In the wake of a series of high-profile dismissals and acquit-
tals under general statutes, calls for HIV-specific criminal legislation
grew louder. Police organized early campaigns to criminalize HIV by
publicly shaming HIV-positive women arrested for prostitution. Misde-
meanor prostitution statutes, they argued, failed to protect society from
their recklessness; new felony laws were needed. In other cases, the
impulse to criminalize HIV grew out of simultaneous debates over the
decriminalization of sodomy. Lawmakers invoked the specter of legal
gay sex in their calls for new, HIV-specific criminal legislation. Finally,
one state lawmaker helped to institutionalize HIV criminalization when
a bill she introduced in Illinois formed the basis of a widely dissemi-
nated American Legislative Exchange Council (ALEC) model statute.
Together, these social anxieties and interest-group campaigns sparked
an epidemic of legislation that ultimately spread to forty-five states.

Chapter 5, “HIV on Trial,” goes inside American courtrooms to ana-
lyze how HIV exposure and disclosure laws were enforced between
1992 and 2010. After a widely reported and sensationalized conviction
in Michigan in 1992, the number of criminal cases against HIV-positive
people quickly grew throughout the 1990s. While medical advances

dramatically changed HIV outside the courtroom, those changes were scarcely evident in Michigan and Tennessee courtrooms over the next two decades: prosecutors and judges continually justified their harsh sentences by calling HIV-positive defendants murderers and by casting HIV as a deadly weapon—even in cases where HIV could not have plausibly been transmitted. By tracing the impact that stigmatizing language has on courtroom decisions, this chapter demonstrates that courtroom talk is more than “just words.”³⁹

Finally, Chapter 6, “Victim Impact,” analyzes which communities are most affected under HIV exposure and disclosure laws. In the wake of a sensational 2014 case involving a Black gay male defendant, some critics charged that HIV-specific criminal laws could be used to target Black gay men. This chapter draws on an original dataset of convictions under HIV-specific criminal laws in six states to evaluate whether the enforcement of HIV exposure and disclosure laws has discriminatory effects. Findings show that victim characteristics—rather than defendant demographics—shape uneven patterns in the application of the law. This “victim impact” flips expected patterns of discrimination, resulting in disproportionately high rates of convictions among heterosexual male defendants; yet, at sentencing, Black defendants are punished more severely, women are treated more leniently, and men accused of not disclosing to women are punished more harshly than those accused by men. This chapter digests these trends using the tools of sociology, epidemiology, and criminology to offer a specific diagnosis for reform.

The conclusion threads the needle of these six chapters, building a cohesive model of the engines driving the criminalization of sickness. In addition, the conclusion makes explicit the pitfalls of using the criminal justice system to tackle disease. Put simply, punishment is not the appropriate response to infectious disease; the criminal justice system is poorly suited for managing epidemics. The conclusion explains why this is so and what an alternative approach might look like.

At the heart of *Punishing Disease* is a central question: Why punish? Although public health and medical institutions are designed to manage epidemics and viruses, punishment as an institution is built to manage crime. The tools designed for one job—pills versus handcuffs, hospitals versus prisons—are not effective for the other. The tool for punishing deviance is a hammer ill-suited for managing disease. In criminalizing sickness, HIV exposure and disclosure laws threaten to erode the boundary between sickness and crime, paving the way for a new era of criminalization that targets disease.

the courtroom, those changes were Tennessee courtrooms over the next ages continually justified their harsh defendants murderers and by casting in cases where HIV could not have ing the impact that stigmatizing lan-ns, this chapter demonstrates that words."³⁹

impact," analyzes which communities sure and disclosure laws. In the wake ng a Black gay male defendant, some riminal laws could be used to target s on an original dataset of convictions in six states to evaluate whether the d disclosure laws has discriminatory i characteristics—rather than defend-patterns in the application of the law. d patterns of discrimination, resulting of convictions among heterosexual ing, Black defendants are punished d more leniently, and men accused of shed more harshly than those accused se trends using the tools of sociology, o offer a specific diagnosis for reform. edle of these six chapters, building a ving the criminalization of sickness. In xplicit the pitfalls of using the criminal . Put simply, punishment is not the s disease; the criminal justice system is demics. The conclusion explains why : approach might look like.

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Punishing Disease reveals that criminalization has predictable effects. It reproduces stigma. It does not prevent disease. And it codifies outdated and deeply flawed ideas about HIV into law. Now that the door to criminalizing sickness is open, what other ailments will follow? When our colleague shows up to work with the flu in the future, will we wonder whether we should call the police? While we cannot predict what will happen tomorrow, moves in several state legislatures to extend their HIV-specific criminal laws to include new diseases such as hepatitis and meningitis demonstrate that this possibility is more than academic.

Controlling Typhoid Mary

When reports began to emerge in October 2014 that a New York City doctor had fallen ill with Ebola, media outlets whipped themselves into a frenzy. Mayor Bill de Blasio attempted to reassure the public that there was no risk of an Ebola outbreak in the Big Apple at a press conference announcing that Dr. Craig Spencer had tested positive for Ebola. “We want to state at the outset—there is no reason for New Yorkers to be alarmed,” de Blasio said. The mayor’s efforts to assuage the public, however, did not dissuade a flurry of Twitter commenters, bloggers, and even mainstream media reporters from feeding public hysteria. Predictably, the New York City tabloids ran sensational front-page headlines that capitalized on New Yorkers’ fears: “EBOLA HERE!” (*New York Post*) and “NY DOC HAS EBOLA” (*New York Daily News*).

Over the next twenty-four hours, reporters began to piece together the timeline of Dr. Spencer’s movements through a combination of news releases from the governor, the New York City Health Department, and even the ride-sharing service Uber. New Yorkers were collectively outraged by the story that crystallized: not only did Spencer not remain in his apartment under self-quarantine, but he took an Uber to go bowling in Williamsburg! The *New York Times*—the city’s standard-bearer—ran a short, dry online piece headlined “Can You Get Ebola from a Bowling Ball?”¹ The *New York Daily News* ran a more sensational piece, “New Yorkers, Twitter Users Wonder Why Dr. Craig Spencer Went Bowling,”² that featured a collection of more than a dozen angry

posts from Twitter users condemning the doctor's actions.² That article cited a post from Twitter user ericbolling that encapsulated much of the public anger expressed towards Spencer online: "ABSOLUTELY NO SYMPATHY for a doctor who knows he's been in contact w/Ebola, goes bowling, takes 2 subways, has contact with girl, Uber. None."³ Online comment threads predictably devolved into angry disputes over issues as diverse as gentrification (keywords: uber, Williamsburg) and Ebola transmission pathways (keywords: saliva, bowling ball).

Dr. Spencer's infection came on the heels of the death of Thomas Eric Duncan, a Liberian man who became ill after traveling to the United States.⁴ Furious debate centered on Duncan's first visit to the hospital after he initially developed symptoms. Although he told a nurse he had traveled to Africa, that information was not communicated to other medical staff.⁵ When his providers asked him if he had been in contact with Ebola patients, he reportedly said no—a statement that was not true. Medical staff discharged him with a prescription for antibiotics, sending him back out into the world, where he might have inadvertently exposed others to the disease.⁶ Authorities in Liberia were outraged—not with medical providers or their failure to catch his infection earlier, but with Duncan himself. Liberian president Ellen Johnson Sirleaf characterized his failure to report contact with Ebola patients as "unpardonable."⁷ Airport officials went further, threatening to file criminal charges against Duncan should he ever return home.

Across the Hudson River, Nurse Kaci Hickox returned to New Jersey from Sierra Leone, where she had been treating Ebola patients. After being quarantined in New Jersey by health officials for two days, she was allowed to return home to Maine, where health officials pressured her to quarantine herself.⁸ She openly defied those calls and was photographed biking around her hometown (a fact jokingly cited in a *Saturday Night Live* skit about her case: "that's Kaci with an 'I'—as in I don't care if I got Ebola, I'm riding my damn bike!"⁹). Maine governor Paul LePage threatened to take action but hesitated to follow New Jersey's lead in instituting mandatory twenty-one-day quarantine policies for anyone who had been in contact with Ebola patients after Centers for Disease Control and Prevention (CDC) director Anthony Fauci called such policies "a little bit draconian."¹⁰ Backed by the American Civil Liberties Union, Hickox sued New Jersey for depriving her of her liberty in a case that remains pending.¹¹

The range of responses to these three cases—moral outrage, criminalization, and quarantine—illustrates the spectrum of coercive and punitive

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attitudes toward the sick, which have deep roots in public health history. The tension between individual liberty and public health stretches as far back as Typhoid Mary, an Irish immigrant and asymptomatic typhoid carrier who was quarantined in 1907 by New York authorities. For centuries, public health officials have waged a battle—sometimes against overwhelming odds—to promote and protect the health of populations and to prevent the spread of disease. Controlling the actions of individuals and communities believed to spread disease has been a core public health strategy, including persuading people to take up practices believed to be "healthy" while discouraging or regulating those actions believed to be "unhealthy."¹² In its battle to preserve population health, a key weapon of public health has been what sociologists refer to as social control.

This chapter traces the history of coercion, persuasion, and regulation in American disease control—first, by examining the rise of coercive practices such as quarantine in the face of deadly and rapidly spreading infectious diseases like the plague; second, by turning to the rise of persuasion and regulation in the twentieth century as improved sanitation, better nutrition, and the advent of antibiotics and vaccines erased the most horrific diseases from the American epidemiological landscape; and third, by revealing how the emergence of new infectious diseases in the late twentieth century such as AIDS and Ebola, as well as new antibiotic-resistant strains of old scourges like tuberculosis, sparked renewed demands for coercive and punitive approaches to disease control.

COERCION AND PUNISHMENT IN THEORY AND PRACTICE

Coercion and punishment are not necessarily the same.¹³ Health authorities have an interest in controlling disease and that has at times required restricting the freedom and movement of individuals and even entire communities. In the context of public health law, *coercion* is defined as restricting the liberty of a person or a group of people in the interest of protecting or promoting the public's health; it does not necessarily imply that the person or group of people has committed an offense.¹⁴ Punishment, on the other hand, is a social response to a person's wrongdoing; while it necessarily involves coercion (through fines, jail time, or other means), it is also specifically intended to punish.

Although on paper this distinction between coercion and punishment appears straightforward, in practice it can become muddled. For example, the Supreme Court has upheld "civil confinement" programs under

which convicted sex offenders are detained well beyond their court-ordered prison sentences, potentially indefinitely, as deemed necessary by corrections officials. The court has ruled that this continued detention does not violate constitutional guarantees against double jeopardy because the procedures are civil rather than criminal in nature; the prisoner's extended detention, the court further reasoned, is therefore not punishment at all because "the commitment determination is made based on a 'mental abnormality' or 'personality disorder' rather than on one's criminal intent."¹⁵ The fact that the conditions of civil commitment are virtually indistinguishable from prison is treated almost as a coincidence; the programs' intended function differentiates their constitutional standing. Public health experts have made similar observations of the state's power to quarantine: under certain conditions, the deprivation of liberty imposed through isolation exceeds what is constitutionally permitted under the criminal justice system.¹⁶

These legal and philosophical distinctions may prove cold comfort to the detained sex offender or the quarantined person; whatever the state's intent, the effect of detention may well be experienced as *punitive*. Although the coercive practices critically examined in this chapter may not constitute punishment in the strict, constitutional-law sense of the term, this chapter nonetheless considers historical cases in which public health practice has taken on characteristics of state-sanctioned punishment.¹⁷

When and how does coercion turn punitive in public health practice? The hallmark of a punitive campaign is the attribution of blame: punishment is meted out by the state against individuals who have been found culpable. Calls to blame someone for their actions are nearly invariably followed by calls for their punishment. This is most obvious in cases of criminalization in which individuals are tried before a court of law, found guilty, and punished accordingly. But criminal justice authorities do not have a monopoly on blame. Although medical problems are supposed to be handled neutrally, many people—including some doctors and public health officials—nonetheless ascribe blame to individuals who become sick.¹⁸ This chapter examines moments in public health history in which the line between coercion and punishment has been blurred.

QUARANTINE AND COERCION IN PUBLIC HEALTH HISTORY

On an otherwise ordinary winter afternoon in 1907, authorities arrived at a Park Avenue home in New York City to take the cook, Mary

re detained well beyond their courtially indefinitely, as deemed necessary. It has ruled that this continued detention guarantees against double jeopardy rather than criminal in nature; the prison further reasoned, is therefore not commitment determination is made or 'personality disorder' rather than on that the conditions of civil commitment from prison is treated almost as a dead function differentiates their constitutions. Experts have made similar observations: under certain conditions, the deprivation of isolation exceeds what is constitutional justice system.¹⁶

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ION IN PUBLIC

One afternoon in 1907, authorities arrived in New York City to take the cook, Mary

Mallon, into custody. Mallon was accused not of theft or murder but instead of unwittingly spreading typhoid to several members of the households in which she worked as a cook. Authorities had tracked Mallon down by following a trail of "breadcrumbs" left in her wake: a string of typhoid infections and deaths. Antibiotics did not yet exist, and nearly 10 percent of those infected with the disease died.¹⁹

Authorities told Mallon that she could have her freedom if she allowed them to remove her gallbladder (where the disease was believed to be festering) or agreed to change her profession. Mallon refused, in large part because she did not believe that she was a carrier of the disease, and, as such, she argued that her detention was unjust. In 1910, Mallon finally relented and agreed to stop cooking and work instead as a laundress. However, after her release, she became frustrated with the lower wages of laundry workers. Adopting an alias to conceal her widely reported identity, she returned to cooking. In 1915, authorities detained her again after food she had prepared was found to be the source of another outbreak. She spent the next twenty-three years in isolation on North Brother Island at Riverside Hospital, which was largely used to quarantine tuberculosis patients. The facility was notoriously isolating and poorly managed. One historian describes the site in this way:

Five miles up the East River, approximately 1,500 feet east of 140th Street in the South Bronx and, on a bad day, downwind from the city's garbage dump on Riker's Island, was the city lazaretto, Riverside Hospital on North Brother Island. Even a century later, when one stands on the rocky shoals of the island, peering into the distance, the city seems remote and inaccessible. The sense of loneliness on North Brother Island is almost palpable. The site had been used as a small hospital for the poor afflicted with contagious diseases since the 1850s. . . . The facilities lacked space, financial resources, adequate medical equipment, and nursing personnel.²⁰

Mallon spent the remainder of her life on North Brother Island's "rocky shoals," where she died in 1938. Soon after her first quarantine, a 1908 issue of the *Journal of the American Medical Association* labeled her "typhoid Mary"—a moniker that would live on in notoriety long after her death.²¹

Although Mallon's case is perhaps the most widely reported quarantine in public health history, she was hardly the first person in history to be quarantined. The fact that the hospital she called home was located on an island is the relic of a much longer history that begins in medieval Europe during the fourteenth century. The bubonic plague—colloquially known as the Black Death—claimed the lives of millions. (It has

been estimated that 75–200 million Europeans died of the plague between 1346 and 1353.) Scholars believe the epidemic began in central Asia and traveled along trading routes to Western Europe by way of Italian merchants. Sicily was wracked by one of the first known outbreaks in October 1347, followed quickly by Genoa and Venice in January 1348. Confronted with this rapidly spreading and poorly understood affliction, officials in the Italian city states forced ships from plague-infested countries to remain anchored for a period of time at island isolation stations known as *lazarettos*. Infected sailors were confined to hospitals on the island. Sailors and ships were originally confined for thirty days under a *trentino* policy; when it was extended to forty days, the policy became known as *quarantino*.²²

On land, infected people were isolated to their homes in cities across Europe. Authorities erected cordons sanitaires, blockades that sectioned off whole neighborhoods to prevent anyone from entering or leaving. Unfortunately, cordons sanitaires were rarely successful because the plague was not primarily spread by human-to-human contact. Instead, most scholars today agree that the disease was spread primarily through rodents infested with a species of flea that carried the bacteria *Yersinia pestis* in its gut; while blockades could restrict the movement of humans, they did little to prevent rodents from freely moving across cities.²³ But this fact was not yet known so authorities continued to cordon off homes and entire neighborhoods.

When colonists left Europe for the New World, they brought these practices with them. Quarantine and isolation were widely used from the seventeenth through the nineteenth century as America faced epidemics of smallpox, yellow fever, cholera and typhus.²⁴ Although the late-eighteenth-century sanitarian movement—which focused on providing clean water, sewage disposal, and hygienic housing—had a profound impact on infectious disease long before effective medical treatments or vaccines were developed, equally important were the more coercive practices of quarantine and isolation.

In the United States, two systems of quarantine gradually emerged. In ports, a system of maritime quarantine stations—eventually managed by the federal government—detained and inspected cargo, crew, and immigrants from countries with outbreaks of contagious diseases. In cities and towns, local outbreaks were managed by state and local health officials. In the wake of the Industrial Revolution, overcrowding, unsanitary living conditions, and urban poverty led to frequent outbreaks of infectious diseases. Local officials ordered the isolation and

million Europeans died of the plague. We believe the epidemic began in central routes to Western Europe by way of the Black Sea, and was quickly spread by Genoa and Venice in January 1347, rapidly spreading and poorly understood. Italian city states forced ships from the East to remain anchored for a period of time at the lazarettos. Infected sailors were confined. Sailors and ships were originally confined by the *quarantino* policy; when it was extended to land, it was known as *quarantino*.²² People were isolated to their homes in cities across Europe. Sanitaires, blockades that sectioned off the city to prevent anyone from entering or leaving, were rarely successful because the disease was spread primarily through human-to-human contact. Instead, the disease was spread primarily through the flea that carried the bacteria *Yersinia pestis*, which could restrict the movement of humans, but not from freely moving across cities.²³ But authorities continued to cordon off the city.

For the New World, they brought these methods of quarantine and isolation were widely used from the sixteenth century as America faced epidemics of cholera and typhus.²⁴ Although the focus was on movement—which focused on personal hygiene, and hygienic housing—had a process long before effective medical treatment, equally important were the methods of quarantine and isolation.

Systems of quarantine gradually emerged. Quarantine stations—eventually mandated—detained and inspected cargo, crew, and ships with outbreaks of contagious diseases. Outbreaks were managed by state and local health officials. In the late Industrial Revolution, overcrowding, and urban poverty led to frequent outbreaks. Local officials ordered the isolation and

confinement of infected individuals and suspected carriers to “pest-houses,” hospital wards, or their homes.²⁵ Nineteenth-century public health officials adopted other methods that were only slightly less coercive: compulsory vaccination, imposing fines or confinement of those who refused, mandatory reporting of infected patients by physicians to disease registries, contact tracing, and other surveillance techniques.

Better nutrition, improved sanitation, and the advent of vaccines and modern medicine began to turn the tide against many widespread infectious diseases in the twentieth century. In the wake of these shifts in mortality and morbidity, many public health experts came to view coercive strategies for containing epidemics as old-fashioned or even regressive. Medical historian Eugenia Tognotti describes the perspective at the turn of the century:

In 1911, the eleventh edition of *Encyclopedia Britannica* emphasized that “the old sanitary preventive system of detention of ships and men” was “a thing of the past.” At the time, the battle against infectious diseases seemed about to be won, and the old health practices would only be remembered as an archaic scientific fallacy. No one expected that within a few years, nations would again be forced to implement emergency measures in response to a tremendous health challenge.²⁶

That challenge came in the form of the devastating influenza epidemics that traveled around the world in 1918, claiming the lives of between 20 and 40 million people. In the face of such a rapidly spreading and deadly disease, local municipalities closed churches, schools, and movie theaters and prohibited attendance at funerals and other public gatherings.²⁷

New York City health authorities tried to control the rapidly spreading influenza outbreak while allowing for a certain amount of freedom of movement.²⁸ Instead of shutting down businesses altogether, the city’s health commissioner, Dr. Royal S. Copeland, implemented staggered business hours in an attempt to limit congestion in public places. “Offices opened at 8:40 A.M. and closed at 4:30 P.M., while wholesalers started their days earlier, and nontextile manufacturers moved their start time to 9:30.”²⁹ The effectiveness of these policies is not known, but historical analyses suggest the death rate may have been slightly mitigated in the Big Apple as compared to its neighbors, Boston and Philadelphia, which did not implement similar policies.³⁰

Confinement and isolation continued through the first half of the twentieth century, used occasionally during outbreaks of scarlet fever and polio and more frequently for tuberculosis. Until antibiotic treatments for tuberculosis were developed in the 1940s, confinement in a

sanatorium for three to six months was the standard treatment for tuberculosis.³¹ Even with the development of antibiotics, however, coercive practices for containing tuberculosis did not end. Tuberculosis patients who refused treatment were handled especially aggressively. In 1949, for example, Seattle's Firland Sanatorium established a locked ward intended for the treatment of only the most noncompliant and "recalcitrant" of tuberculosis patients, who were deemed a threat to public health. In practice, however, the facility was used much more widely and ultimately housed over a thousand patients. The vast majority of patients quarantined at Firland were poor alcoholics living in one destitute neighborhood, Seattle's Skid Road, who were detained even if they were noncontagious or adhering to treatment protocols. Medical historian Barron Lerner describes the facility in stark terms:

Known as Ward 6 and located in the old naval brig, the unit was equipped with both locked doors and heavily screened windows. All patients admitted to Ward 6 (most of whom were intoxicated) spent the first 24 hours in one of seven locked cells, which contained only concrete slabs covered by thin mattresses.³²

Historical examples like Firland reveal how well-intentioned disease control strategies can turn punitive when disproportionately applied to specific marginalized groups. The facility—described as a "model" for others around the country—persisted and even expanded for over a decade despite accusations that the facility had effectively institutionalized quarantine as a form of punishment without due process for poor alcoholics.³³

Sexually transmitted infections (STIs) were also the target for a wide array of coercive policies aimed at controlling infectious diseases in United States history. During World War I, states implemented policies in response to public anxiety over "venereal diseases," such as mandatory screening to obtain a marriage license and screening of newborns. However, just as Seattle's tuberculosis program targeted poor alcoholics, America's venereal disease response during World War I reserved the most invasive and punitive policies for commercial sex workers. Authorities believed prostitutes were carriers and repositories for STIs. By March 1918, over thirty-two states had passed laws requiring that individuals arrested for prostitution be screened for STIs.³⁴ Just as in Seattle, this frequently involved medical detention that was not subject to the normal legal safeguards of the criminal justice system. Medical historian Allan Brandt offers a telling example:

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In San Francisco, the Department of Health provided arrested women with circulars explaining, “You are in quarantine and cannot be released on bail. . . . If you are found ill with venereal disease you will go to the hospital and stay there until found negative. . . . No lawyer or other person can obtain your release.”³⁵

That their detention was done in the name of public health rather than in the name of punishment perversely allowed the state to more severely restrict the liberty of commercial sex workers. Despite the public health label attached to their detention, however, the fact that women engaged in a criminal offense, prostitution, were singled out for detention by the state suggests a punitive motive.

On the other side of the country, the Virginia State Board of Health provided its officers with the authority to detain anyone “reasonably suspected” of carrying an STI, which included “vagrants, prostitutes, keepers, inmates, and frequenters of houses of ill fame, prostitution and assignation, persons not of good fame, persons guilty of fornication, adultery, and lewd and lascivious conduct.”³⁶ Despite such broadly construed categories, however, no efforts were made during the time to quarantine men for STIs; these policies were systematically enforced against women.

STIs again became the subject of coercive and punitive policies during World War II. For example, a 1945 Baltimore ordinance gave public health officials the power to isolate patients with syphilis or gonorrhea who refused penicillin treatment.³⁷ But just as before, the most aggressive tactics were reserved for female sex workers. The Army appointed former Prohibition champion Eliot Ness (whose efforts to take down Al Capone were fictionalized most recently in the HBO series *Boardwalk Empire*) to lead a campaign against prostitution. Sex workers were once again detained in large numbers, subjected to mandatory STI screening, and placed under quarantine until treated. During this time, estimates suggest that over seven hundred cities and towns closed down their red-light districts. With so many women arrested for sex work, many jails became overcrowded. Ness attempted to ease the strain on local corrections facilities by setting up nearly thirty “civilian conservation camps” to house detained prostitutes. These facilities offered more than just medical testing and treatment. Public health scholar Troy Thompson describes one Florida woman who ended up in such a camp in 1944:

In light of the 1943 Florida laws on prostitution, the police apprehended Jean and gave her an invasive vaginal examination. The court then convicted

her and sent her to one of Florida's newly converted civilian conservation camps. Jean spent the next five weeks there receiving treatment, job training, and lessons in socially sanctioned morality.³⁸

Despite detaining thousands of prostitutes, the Army's efforts failed to eliminate new STI infections among troops. Officials lamentingly changed their tune, blaming not prostitutes but "amateur girls—teenagers and older women—popularly known as 'khaki-wackies,' 'victory girls,' and 'good-time Charlottes.'"³⁹

Estimates suggest that more than thirty thousand prostitutes were detained between World War I and World War II. These strident efforts reflect a pattern noted by historians: from their inception in the Middle Ages, campaigns to control the spread of infectious disease through coercion have frequently targeted particular groups: disfavored immigrant groups, the poor, the "deviant," and the "disenfranchised." Typhoid Mary is a telling example not just for her brazen resistance to public health quarantine but also because she was a poor immigrant woman working in service for wealthier families—a woman in a precarious social position, a woman without the resources to contest her detention. Mary Mallon became historical legend not just for her actions, but also because of her denigrated social standing. Other typhoid carriers living at the same time are all but forgotten—carriers such as Frederick Moersch, a German-born immigrant working as a confectioner, who infected more people with typhoid fever than Mallon. Moersch, like Mallon, was confined on North Brother Island in 1915 but, as a father and "skilled workman," was viewed far more favorably by the staff; after a brief detention, he was allowed to live at home, where the state even arranged for his rent to be paid.⁴⁰ Despite the similarities in their cases, Moersch was treated far more leniently, and his case is all but unknown to history.

This disparity is not unique to American public health history: public health measures have been enforced in deeply discriminatory ways for centuries, with the harshest, most coercive measures reserved for the most marginalized communities and people. It is in these historical moments that coercion becomes punitive. It would be impossible to review every example of this trend. Instead, figure 1 illustrates key examples of coercion and discrimination in public health history. In each case listed in figure 1, coercive measures intended to combat disease were aimed at marginalized groups. In fact, labeling a person or a community a threat to public health casts the sick as hostile aggressors rather than sympathetic victims. During epidemics, fear and stigma of contagion have

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heightened the social exclusion of already-stigmatized groups. Viewed in
this light, quarantine comes dangerously close to being a metaphor for
the need of elites to protect themselves from the "dangerous" classes.

The policies that this chapter describes did not go uncontested. Coer-
cive measures, such as compulsory vaccination programs, mandatory
treatment, quarantine, and isolation, often provoked popular resistance
and were the subject of many legal challenges. However, these challenges
rarely proved successful. Presented with a choice between promoting the
freedom of the sick and protecting the health of the masses, U.S. courts
have typically deferred to public health authorities and affirmed their
prerogative to use coercive measures to control epidemics.

Perhaps the most important such decision came over a century ago
with the Supreme Court's ruling in *Jacobson v. Massachusetts*. The case
was brought by a Swedish immigrant to the United States, Henning
Jacobson, who objected to an order from the Cambridge, Massachu-
setts, city council requiring that all adults be vaccinated for smallpox.
The penalty for not complying was set by the state at \$5 (about \$100
today), and there was no set procedure for actually forcing anyone to be
vaccinated. Jacobson was already familiar with state vaccination pro-
grams, which were in place in his home country of Sweden, but he
objected to Cambridge's program on the grounds that he and his son
had experienced adverse reactions to previous inoculations. The court
ruled 7–2 against Jacobson, ruling that the state had the power to
impose punishment (either a fine or imprisonment) for failing to com-
ply, but that it could not force anyone to be vaccinated.⁴¹

The sweeping power of public health authorities to quarantine and
isolate sick people against their will falls within the civil law, but it
rivals the power of the criminal justice system to infringe on individual
liberties. Moreover, "until relatively recently," notes medical ethics
expert Ronald Bayer, "the protections accorded to defendants in crimi-
nal prosecutions have not been extended to those viewed as a threat to
the public health."⁴² This changed during the 1970s when courts began
to reconsider due process claims from mental patients who were facing
civil commitment against their wishes. After a federal district court
struck down Wisconsin's commitment law in *Lessard v. Smith* (1972),
other courts began to rule that patients were entitled to the due process
protections of the Fourteenth Amendment: the rights to notice, to a fair
hearing, to be represented by counsel, to cross-examine witnesses, and
to hold the state to a clear and convincing standard of proof. One of the
most important doctrines to come out of these decisions was the least

Coercion and Punishment in Modern Public Health History

1892

Following outbreaks of typhus and cholera, nativist sentiments led to quarantines of Jewish immigrants who arrived in New York City, while Italians arriving on the same boat were detained only briefly; that same year, first-class passengers were confined to hotels, while those in steerage consigned to an overcrowded quarantine facility with squalid conditions.¹

1894

Milwaukee officials forced immigrants and poor residents into a quarantine hospital for smallpox.

1900

A San Francisco ordinance required that all Chinese residents of the city receive a dangerous experimental vaccine for plague. Following reports of nine deaths from plague, city officials roped off the Chinese quarter, quarantining 25,000 residents and closing Chinese businesses, while explicitly exempting non-Asians. The court overturned both ordinances, ruling that officials had acted with "an evil eye and an uneven hand."²

1902

After smallpox cases were identified in Boston, public health officials, with police in tow, forcibly inoculated African Americans and immigrants.³

1907

New York health authorities quarantined Mary Mallon, a poor immigrant woman working as a cook in a private home and carrier of Typhoid. Nicknamed "Typhoid Mary," Mallon would become synonymous with the spread of infectious disease.

1. Markel, *Quarantine!*

2. Parmet, "Legal Power and Legal Rights"; Tyson, "Short History of Quarantine."

3. George J. Annas, Wendy K. Mariner, and Wendy E. Parmet, *Pandemic Preparedness: The Need for a Public Health—Not a Law Enforcement/National Security—Approach* (New York: American Civil Liberties Union, 2008).

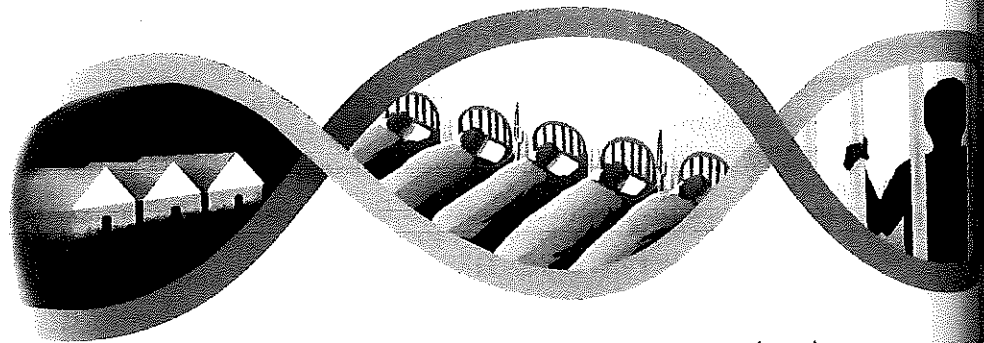


FIGURE 1. Coercion and punishment timeline. Design: Jonathan Lefrançois. Illustration: Justin Karas for Pulp & Pixel.

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1916

During the 1916 polio epidemic in New York City, health
workers conducted door-to-door searches, forcibly removing
sick children from their homes, but allowing the children of
wealthy families to remain in a separate room in their homes.⁴

1944

Military officials set up civilian conservation camps in the
United States to house imprisoned prostitutes, who were
rounded up in raids in an unsuccessful effort to squash
sexually transmitted infections among American servicemen.

1949

Seattle's Firland Sanatorium opened its tuberculosis ward,
which was used to quarantine over 1,000 mostly alcoholic
tuberculosis patients—whether or not they were contagious
or compliant with their treatment regimen.

1987

Author Randy Shilts published *And the Band Played On*,
which blamed the spread of HIV in the United States on
a promiscuous gay male flight attendant referred to
as "Patient Zero."

1993

New York City began a program of directly observed
treatment and quarantine in response to an outbreak
of tuberculosis, disproportionately detaining poor
and homeless patients who were deemed likely to be
noncompliant.⁵

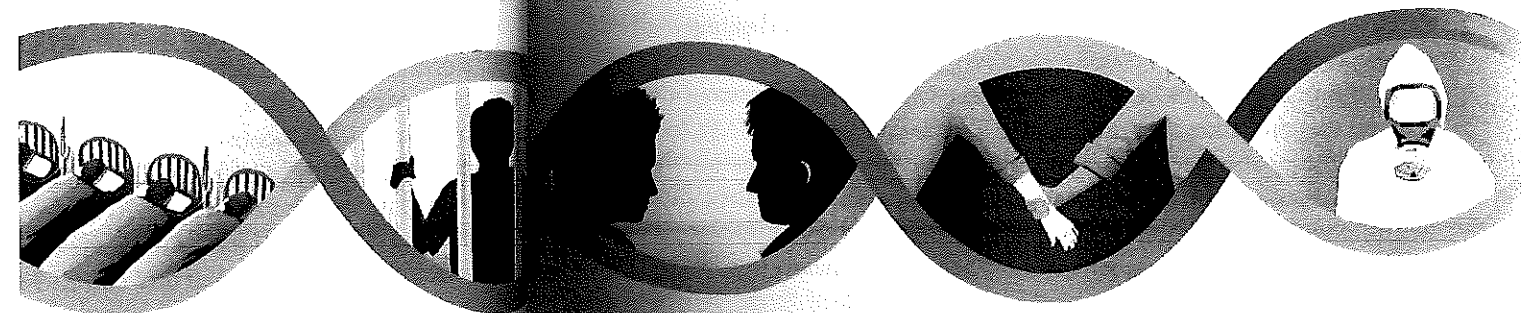
2014

Liberian president Ellen Johnson Sirleaf characterized
Thomas Eric Duncan's failure to report contact with
Ebola patients to Texas health care providers as "frankly,
unpardonable." Airport officials threatened to file criminal
charges against Duncan should he ever return home.

4. Guenter B. Risse, "Epidemics and History: Ecological Perspectives and Social Responses," in *AIDS: The*

Burdens of History, ed. Elizabeth Fee and Daniel M. Fox (Berkeley: University of California Press, 1988), 33–66.

5. Gostin, Burris, and Lazzarini, "Law and the Public's Health"; and M. Rose Gasner, Khin Lay Maw, Gabriel
E. Feldman, Paula I. Fujiwara, and Thomas R. Frieden, "The Use of Legal Action in New York City to
Ensure Treatment of Tuberculosis," *New England Journal of Medicine* 340, no. 5 (1999): 359–66.



timeline. Design: Jonathan Lefrançois.
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restrictive alternative doctrine, which holds that patients have the right to be treated in the least restrictive setting that meets their needs.⁴³

CONTROLLING CHRONIC DISEASE THROUGH EDUCATION, PERSUASION, AND REGULATION

At the dawn of the twentieth century, infectious disease claimed more lives than any other cause of death. According to the CDC, the five leading causes of death in the United States in 1900 were⁴⁴

- influenza and pneumonia (202.2 deaths per 100,000 people);
- tuberculosis (194.4 deaths per 100,000 people);
- gastrointestinal infections (142.7 deaths per 100,000 people);
- heart disease (137.4 deaths per 100,000 people);
- stroke and other cerebrovascular diseases (106.9 deaths per 100,000 people).

By 1950, however, dying in America had changed drastically. With dramatic improvements in nutrition, sanitation, and, finally, the advent of antibiotics and vaccines, infectious disease was dethroned as the leading cause of death in America and was replaced by heart disease (355.5 deaths per 100,000 people) and cancer (139.8 deaths per 100,000 people).⁴⁵

This radical shift in mortality in the United States had a profound impact on public health practice. Better nutrition, improved sanitation, vaccines, and antibiotics had effectively stomped out diseases like smallpox, polio, and the measles—diseases that once maimed or killed millions. In their place were more complex diseases, such as heart disease and cancer, that were not communicable and that could not be traced to a single bacterial or viral agent. Instead, public health argued that these diseases were linked to specific “lifestyle” behaviors such as smoking, drinking alcohol, not getting enough physical exercise, and eating high-calorie foods.

Communicating this new model of disease to the public proved challenging for public health practitioners. For the past century, Americans had gradually come to understand the germ theory of disease, which linked disease and infection to the spread of bacteria and viruses. Public health now had to explain that behaviors, too, could cause disease—but the scientific link between them was harder to demonstrate. Exactly how many hamburgers does one need to eat to get fat? To get diabetes?

which holds that patients have the right to a private setting that meets their needs.⁴³

DISEASE THROUGH AND REGULATION

In the early twentieth century, infectious disease claimed more deaths than any other. According to the CDC, the five leading causes of death in the United States in 1900 were⁴⁴

- 1. Pneumonia (202.2 deaths per 100,000 people);
- 2. Tuberculosis (142.7 deaths per 100,000 people);
- 3. Heart disease (139.8 deaths per 100,000 people);
- 4. Cancer (106.9 deaths per 100,000 people);
- 5. Influenza (106.9 deaths per 100,000 people).

America had changed drastically. With dramatic improvements in sanitation, and, finally, the advent of antibiotics, infectious disease was dethroned as the leading cause of death. It was replaced by heart disease (355.5 deaths per 100,000 people).⁴⁵ The shift in the United States had a profound effect. Better nutrition, improved sanitation, and antibiotics effectively stomped out diseases like smallpox, diphtheria, and tetanus—diseases that once maimed or killed millions. Instead, public health argued that these new “lifestyle” behaviors such as smoking, lack of physical exercise, and eating high-fat diets were the new threats.

The model of disease to the public proved challenging. For the past century, Americans had stood by the germ theory of disease, which held that the spread of bacteria and viruses caused disease. Public health behaviors, too, could cause disease—but it was harder to demonstrate. Exactly how much fat did one need to eat to get fat? To get diabetes?

How many cigarettes does one need to smoke to get lung cancer? The answers were not black and white.

Smoking proved to be the low-hanging fruit. Although scientists are still debating whether x amount of salt or y amount of saturated fat causes heart disease, there has long been consensus that smoking tobacco causes lung cancer. Beginning in the 1950s, epidemiological studies came out in rapid succession demonstrating a causal relationship between smoking and lung cancer. Based on this research, the Surgeon General's Advisory Committee on Smoking and Health released its first report on smoking in 1964; the report analyzed over seven thousand studies to conclude that smoking directly causes lung cancer, emphysema, and other diseases.⁴⁶

Once the public health establishment agreed that smoking caused cancer, they needed to find ways to convince the sizable proportion of the American public to give up the habit. That proportion was, indeed, sizable: the CDC estimates that in 1965 42.4 percent of adults in the United States smoked tobacco.⁴⁷ The mandatory vaccination, quarantine, and coercive strategies of yesteryear were obviously not the right tools for the job.

In their place, public health experts developed new strategies for disease control aimed at getting individuals to take care of their own well-being by avoiding “risky” behaviors—in this case, smoking. Authorities turned to two primary strategies to get Americans to stop smoking: regulation and persuasion. First, they regulated tobacco companies' business practices, the sale of tobacco products, and the locations in which people were allowed to smoke. In 1965, Congress passed the Cigarette Labeling and Advertising Act requiring that all cigarettes sold in the United States carry a warning label advising consumers that “Caution: Cigarette Smoking May Be Hazardous to Your Health.”⁴⁸ Authorities followed quickly to ban cigarette advertisements on television and radio in 1969; to limit the ability of smokers to use tobacco in public places beginning in the 1970s; and to increase federal excise taxes on cigarettes beginning in the 1980s.⁴⁹ Over the next fifty years, local, state, and federal lawmakers would continue to ratchet up regulations on advertising and smoking in public while continuing to increase the cost to consumers through taxation.

Alongside these regulations, public health authorities at all levels began designing education programs and mass media campaigns to persuade the public to stop smoking. Young people, whose habits were perceived to be still malleable, were typically the target of media campaigns

that cast smoking as unhealthy, unsexy, and uncool. Health departments were aided by Federal Communications Commission (FCC) regulations implemented in 1967 that required broadcasters to air one antismoking message for every three cigarette commercials.⁵⁰ In 1988, California voters approved Proposition 99, which raised taxes on cigarettes by twenty-five cents and required that 20 percent of the tax revenue collected be used to establish a statewide antitobacco education program featuring a mass media campaign.⁵¹ Other states followed suit, implementing similar programs that significantly increased the scope and production quality of antitobacco messaging.

The implicit goal of these efforts was to erode the number of tobacco users in the United States while appearing to support freedom of individual choice. No one was coerced to stop smoking or quarantined for doing so. Instead, authorities regulated smoking to make it more costly and more difficult to do in public places while also persuading Americans that smoking was dangerous and uncool. This combination of strategies at local, state, and national levels had a sizable impact: between 1965 and 2014, the proportion of American adults who smoked tobacco fell from 42.4 percent to 16.8 percent.⁵²

The model of regulation and persuasion proved to be a useful framework for public health efforts in many areas. Health educators persuaded through advertising campaigns and other interventions designed to change health behaviors by promoting driving with seat belts and helmets, making healthy choices based on the food pyramid, and, more generally, prodding Americans to determine their risk profile.⁵³ Occasionally, public health turned to regulation, enacting policies requiring that people wear seat belts and helmets and that restaurants post the caloric content of their food, and in New York, lobbying for legislation that would prohibit the sale of large sugary drinks.⁵⁴

Despite success in domains like smoking, public health's focus on individual health behaviors has troubled some. Opponents criticized these regulations as paternalistic products of a "nanny state," while proponents pointed to the harmful effects of careless, risky health behavior on both the risk-taker's body and society at large. Instead of debating their legitimacy, social theorists have drawn attention to the ways in which focusing on health behaviors have both echoed and reinforced a general trend in American society toward emphasizing individual responsibility.⁵⁵ By promoting the notion that individuals need to take responsibility for their own health as well as the health of the collectivity, public health has ushered in an era in which the smoker, the drinker, the

isexy, and uncool. Health departments' Communications Commission (FCC) regulations told broadcasters to air one antismoking commercial.⁵⁰ In 1988, California voters raised taxes on cigarettes by twenty-percent of the tax revenue collected by the tobacco education program featuring a contest. States followed suit, implementing similar measures and increased the scope and production qual-

ity. One strategy was to erode the number of tobacco stores appearing to support freedom of individual choice by forcing smokers to stop smoking or quarantined for illegal smoking to make it more costly. Other strategies included places while also persuading Americans to quit. This combination of strategies had a sizable impact: between 1965 and 1995, the number of adults who smoked tobacco fell from

100 million to 50 million. Persuasion proved to be a useful framework in many areas. Health educators persuaded drivers to wear seat belts and promoted driving with seat belts based on the food pyramid, and, more recently, to determine their risk profile.⁵³ Occasional regulation, enacting policies requiring restaurants to post the number of calories in New York, lobbying for legislation to ban sugary drinks.⁵⁴

Like smoking, public health's focus on individual responsibility troubled some. Opponents criticized the products of a "nanny state," while proponents argued the effects of careless, risky health behavior on society at large. Instead of debating the merits of individual actions, they have drawn attention to the ways in which individual actions have both echoed and reinforced a trend toward emphasizing individual responsibility toward emphasizing individual responsibility that individuals need to take responsibility for the health of the collectivity, public health, and the ways in which the smoker, the drinker, the

obese person, and the careless driver have become the new "health threat." Their behavior is not just viewed as unhealthy but is blamed for a wide array of negative consequences, from soaring health care costs to moral decay.

This shifting approach to social control—from coercion to regulation and persuasion—was not unique to public health. French social theorist Michel Foucault has shown how approaches to punishment followed a similar path; he tracks the rise of Western penal systems from the eighteenth to the twentieth century to show how governments phased out the public torture and executions of medieval times in favor of building prisons to discipline prisoners.⁵⁶ The idealized form of this new penal system was the Panopticon, a circular prison in which inmates are always visible to a single guard; under such surveillance, prisoners are trained to believe that they are always being watched and, thus, ought to police their own behavior. In many ways, the Panopticon and the food pyramid, emblematic of this "new public health," have similar aims: to prod individuals to police their own behavior rather than coercing them to change their ways.⁵⁷

Experts have noted that morality messages are deeply embedded in modern public health campaigns that blame individuals for engaging in "risky" behaviors, blurring the line between risk and sin.⁵⁸ While ostensibly a neutral term, the way in which health authorities attach risk to some practices but not others reveals its moral underpinnings. Many people die in car accidents every year, yet we do not label driving as a risky behavior. Gay men having sex without condoms is described by public health practitioners as risky and labeled as "bareback"; sex between heterosexuals is almost never similarly described by health authorities—except, perhaps, when it is done by the poor (especially African Americans, women, and people receiving public benefits). Every step we take in life carries some form of risk, but only certain steps taken by certain people in certain contexts are labeled and controlled as risk.

CONTAGION REDUX: THE PUNITIVE TURN IN MODERN AMERICAN DISEASE CONTROL

In the early 1970s, scientists reported a cluster of unusual rheumatoid arthritis cases affecting children in Lyme, Connecticut. After exploring a number of possible causes, researchers noted that all of the children who were ill lived near wooded areas and that their symptoms typically began during the summer. Although researchers began referring to the

set of symptoms as "Lyme disease," it would take nearly a decade to conclusively identify the cause: a bacteria, *Borrelia burgdorferi*, spread by deer-tick bites.⁵⁹

Not far from Lyme, 221 attendees of a July 1976 American Legion convention in Philadelphia fell ill with strange symptoms: pneumonia and fevers reaching over 107 degrees. Within a month, news outlets were reporting that between six and fourteen men had died of what was colloquially known as Legionnaires' disease. The cause was a mystery. Fearing a major outbreak, the Pennsylvania health secretary reportedly "contemplated seizing control of all hospitals in the state and imposing quarantines."⁶⁰ Apart from the Legionnaires, however, no new cases emerged; in total, 221 cases were documented, including thirty-four deaths. After a six-month investigation, medical authorities determined the cause: a bacteria spread through the conference hotel's air conditioning system.

As the twentieth century wore on, outbreaks of new diseases like Lyme and Legionnaires' cast doubt on the optimistic claims of the 1950s that modern medicine would forever vanquish infectious disease. Alongside these new, unknown diseases came outbreaks of old scourges such as tuberculosis and the mutation of old microbes into antibiotic-resistant strains such as MRSA (methicillin-resistant *Staphylococcus aureus*). Across the globe, even more deadly epidemics of diseases such as Ebola, SARS, and avian flu shook the public confidence in medicine. Both at home and abroad, inequality appeared to be driving many of these new outbreaks; experts cite local factors such as overcrowding in prisons and homeless shelters and broader patterns such as poverty, malnutrition, and HIV infection, which increase susceptibility to disease.⁶¹ With global travel and migration reaching historic levels, experts feared that the epidemics of the future would quickly become global.

In the United States, this resurgence in infectious disease coincided with the rise of neoliberalism (commonly defined as the twentieth-century emphasis on laissez-faire economic policies, namely through deregulation, free trade, and privatization) in the Reagan-Thatcher years and the growing influence of religious conservatism, or the New Right.⁶² Evangelical conservatives played to Americans' fear and ignorance of diseases like HIV, blaming those they deemed responsible for the spread of disease. Public health was not immune to these politics, especially as it had spent the last several decades promoting the idea that individuals and their risky health behaviors were to blame for modern epidemics. Given this context, public health officials not only returned to the restrictive measures that had been used to control the spread of infec-

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indeed of a July 1976 American Legion with strange symptoms: pneumonia and es. Within a month, news outlets were fourteen men had died of what was colloquial disease. The cause was a mystery. Fearing pneumonia health secretary reportedly "contaminated" hospitals in the state and imposing quarantines, however, no new cases emerged; instead, including thirty-four deaths. After a while authorities determined the cause: a bacteria hotel's air conditioning system. Moreover, outbreaks of new diseases like doubt on the optimistic claims of the 1950s never vanquish infectious disease. Along with new outbreaks of old scourges such as a host of old microbes into antibiotic-resistant penicillin-resistant *Staphylococcus aureus*. Badly epidemics of diseases such as Ebola, eroded public confidence in medicine. Both appeared to be driving many of these new threats such as overcrowding in prisons and patterns such as poverty, malnutrition, and migration, which increase susceptibility to disease, reaching historic levels, experts predicted future would quickly become global. The resurgence in infectious disease coincided (commonly defined as the twentieth-century economic policies, namely through deregulation) in the Reagan-Thatcher years and religious conservatism, or the New Right.⁶² Fed to Americans' fear and ignorance of disease they deemed responsible for the spread was not immune to these politics, especially as decades promoting the idea that individuals were to blame for modern epidemics. Public health officials not only returned to the old been used to control the spread of infec-

tious disease historically, but they also developed new, sometimes more coercive laws and practices. This was most apparent in the response to two of the most common diseases of the late twentieth century: tuberculosis and HIV.

Tuberculosis (TB) is a disease primarily affecting the lungs and is caused by a range of bacteria, most commonly *Mycobacterium tuberculosis*. Humans have suffered from the disease throughout much of documented history, with evidence of the disease stretching back to the spines of Egyptian mummies.⁶³ Most people who are infected with TB are asymptomatic—so-called latent carriers—and cannot transmit the disease. However, about 10 percent of infections progress to what is known as active TB, which is extremely contagious via coughing or sneezing; characteristic symptoms of active TB include blood-tinged sputum, fever, night sweats, and weight loss (giving the disease its historic nickname, consumption). Left untreated, more than half of people with active TB die.

As noted earlier in the chapter, TB was once a leading cause of death in the United States, second only to influenza and pneumonia. The prognosis for infected patients remained poor until streptomycin was discovered in 1946. This new treatment, along with other public health efforts to control the disease, helped to dramatically reduce the number of new TB cases by the 1950s. However, driven in part by rising rates of drug use, poverty, and homelessness, several U.S. cities saw new TB outbreaks in 1985 that disproportionately impacted racial minorities, including Latinos, African Americans, and Asians.⁶⁴ Public health authorities were especially troubled because many new TB cases were resistant to standard antibiotic treatments and thus harder to treat and more deadly.

Rather than citing a lack of access to affordable housing or poverty as the forces behind these new outbreaks, some in public health blamed these new resistant cases instead on *patients* who failed to complete the six- to eight-month treatment protocol required for curing TB. Most patients who are otherwise healthy can be successfully treated and cured of the disease.⁶⁵ Most patients do take their medication during the acute phase of their illness when they feel sick, but many drop out during the post-acute phase when they feel relatively healthy. In New York City, for example, only 53 percent of all patients completed treatment during these outbreaks (although completion rates have risen to over 90 percent more recently).⁶⁶ While these patients may feel healthy and are no longer contagious, their TB infection could come back. Worse yet, it could return as a newly mutated strain resistant to antibiotic treatments.⁶⁷

To ensure that patients followed through with a lengthy treatment protocol, scientists pioneered direct observed therapy (commonly known as DOT) in Madras, India, and Hong Kong in the 1960s.⁶⁸ These programs typically require a patient to routinely visit a health care provider who can directly observe the patient swallowing the antibiotic treatment. Initially, DOT was mandated only for patients deemed likely to be noncompliant. But in practice, this often meant that doctors disproportionately targeted the poor and homeless as they were most likely to be viewed as potential health threats. For these reasons, some experts suggested that all patients treated for tuberculosis should be required to undergo mandatory DOT. However, this proposal was ultimately rejected as too broad and too intrusive on patients' civil liberties. Moreover, blanket DOT programs turned out to be unnecessary; most patients accept DOT and complete treatment, especially when their alternative is quarantine.⁶⁹

Faced with the new outbreaks of TB, the New York City Public Health Department revised its health code to allow coercive actions to protect against these threats to public health. Under the new regulations, the health commissioner could order compulsory examinations for patients suspected of having tuberculosis, require that patients continue treatment until cured, order mandatory treatment under direct observation, and issue orders for involuntary detention of those deemed unwilling or unable to comply with treatment.⁷⁰ The city's new regulations proved controversial. Critics charged that the requirement that patients undergo treatment until cured expanded the notion of a health threat beyond just those individuals with active TB who were contagious. Under the new rules, individuals with latent infections who were not presently contagious but might at some point become contagious could be labeled a health threat and detained accordingly. Such a broad policy could set the stage for a repeat of Seattle's previously discussed approach to tuberculosis in 1949 that ended up systematically quarantining poor alcoholics. Further, the city was not required to provide social supports, such as transportation and housing for homeless patients, that would enable them to complete treatment. Finally, the ordinance violated the least-restrictive doctrine by not requiring the city to explore less restrictive measures before issuing confinement orders.

In actual practice, the city did attempt to remove barriers to nonadherence by providing housing, bus tokens, and incentive payments for patients undergoing DOT. Moreover, department policy was to use less restrictive measures before restrictions were imposed—for example, to offer voluntary DOT before imposing mandatory treatment, and DOT

ed through with a lengthy treatment program: observed therapy (commonly known as "Kong" in the 1960s).⁶⁸ These programs routinely visit a health care provider who swallow the antibiotic treatment. Initially for patients deemed likely to be noncompliant meant that doctors disproportionately as they were most likely to be viewed as these reasons, some experts suggested that all should be required to undergo mandatory treatment was ultimately rejected as too broad a violation of liberties. Moreover, blanket DOT program; most patients accept DOT and compare their alternative is quarantine.⁶⁹ Outbreaks of TB, the New York City Public Health Code to allow coercive actions to protect public health. Under the new regulations could order compulsory examinations regarding tuberculosis, require that patients consider mandatory treatment under direct supervision or involuntary detention of those deemed not to comply with treatment.⁷⁰ The city's new regulations charged that the requirement that patients be cured expanded the notion of a health threat: individuals with active TB who were contagious, individuals with latent infections who were not, might at some point become contagious again, and detained accordingly. Such a broad definition was a repeat of Seattle's previously discussed 1949 that ended up systematically quarantining, the city was not required to provide transportation and housing for homeless patients to complete treatment. Finally, the restrictive doctrine by not requiring the city to ensure compliance before issuing confinement orders. The city did attempt to remove barriers to nonadherence, bus tokens, and incentive payments for compliance. Moreover, department policy was to use less restrictive measures were imposed—for example, to impose mandatory treatment, and DOT

before confinement.⁷¹ This led the authors of a study of the program in its first two years to conclude, "For most patients with tuberculosis, even those with severe social problems, completion of treatment can usually be achieved without regulatory intervention."⁷² Although involuntary confinement was imposed on only 2 percent of the eight thousand tuberculosis patients, the actual number of patients subjected to involuntary confinement was notable: between 1993 and 1995, New York City confined more than one hundred patients who refused voluntary treatment, most of them confined to the secure ward of a hospital for six months.⁷³

At nearly the same time that tuberculosis outbreaks were being reported, health authorities also began to report cases of a new deadly disease that seemed to be primarily affecting homosexuals. In June 1981, the CDC first reported a cluster of unusual cases of *Pneumocystis pneumonia* that appeared to be killing otherwise healthy young gay men.⁷⁴ The outbreak coincided with the election of Ronald Reagan and the ascendancy of the New Right, a coalition of conservative politicians and the Christian conservatives who would become a formidable force in American politics. Health authorities were flummoxed by the new disease, and Americans were increasingly terrified. Conservatives capitalized on Americans' fear and ignorance of the disease, which they heralded as a symbol of America's moral decline. Medical authorities originally called the disease G.R.I.D. (gay-related immunodeficiency), a grave misstep that facilitated the New Right's characterization of the disease as a gay plague—divine retribution for sexual sin, or in the words of Jerry Falwell, "the wrath of a just God against homosexuals."⁷⁵

Combining racism, homophobia, and xenophobia, commentators began to speak of the 4-H risk groups: homosexuals, heroin addicts, hemophiliacs, and Haitians. However, the New Right focused most of its ire on the perceived transgressions of gay men. Political pundits fed the homophobia of a terrified public with doomsday proclamations about the plague imposed on general public by the hedonistic lifestyles of drug addicts and homosexuals. A 1987 Gallup Poll showed that, like conservative religious leaders, 43 percent of Americans said that AIDS was a punishment for moral decline.⁷⁶ In communities across the country, tensions were high. When a Florida couple successfully sued the DeSoto County School District to allow their three hemophiliac, HIV-positive sons to attend school, they found their house had burned down, forcing them to leave town.⁷⁷

By the mid-1980s conservative politicians and religious leaders, such as Jesse Helms and Pat Robertson, argued for draconian and excessively

esting of all those “at risk” of spreading the AIDS with a visible tattoo, and quarantining of “recalcitrant” AIDS carriers.⁷⁸ In times were joined by members of a public spread of an incurable disease. Public in 1986 showed that between 28 and 30 that “people with AIDS should be put away from the general public.”⁷⁹

The debates was a murky figure blamed for gay communities. “Patient Zero,” as he was called, a Canadian, gay male air steward who reported his partners in his travels. Although the media strongly urged him to stop having sex, he did not, in fact, suspect him of being the cause. But he made for a great story for San Francisco, who was putting the finishing touches on the government’s lackluster response to the epidemic. His publisher worried that the book might fail to find a way to make it more sensa-

the initial dismal prospects for *And the Band Played On* to find a more creative way to promote the book. Patient Zero and present him as the hand-drawn Canadian airline steward who may have brought the virus to the bestseller list, and it worked.

But Mary Mallon had been blamed for the disease too. She was Canadian air steward Gaëtan Dugas, a man of HIV. While Shilts had hoped his book would give activists in calling out the federal government’s “Patient Zero” and his culpability overshadowed, playing right into the hands of religious

“Patient Zero” was ideal propaganda for conservatives of their latest campaign to isolate [people]. As an immigrant with AIDS, Gaëtan stood in the way of being kept out of the country. Meanwhile, as he reckoned libido and an AIDS carrier who reckoned those who deserved to be locked up for

In the minds of many Americans, the AIDS epidemic was a dangerous and deadly disease fueled by the reckless sexual behaviors of unrepentant gay men. The Patient Zero mythology represented that recklessness, providing the perfect villain for angry and fearful Americans.

Despite the fiery rhetoric on the Right, however, AIDS activists resisted these calls for invasive and coercive measures against people living with HIV—but only in part. Conservatives such as Jerry Falwell and Pat Buchanan demanded that lawmakers institute blanket quarantine measures such as Cuba’s policy of indefinitely confining all HIV-positive people to a sanatorium upon diagnosis.⁸¹ Legislators rejected such blanket measures, but in several states they did debate and ultimately enact quarantine and isolation procedures for HIV-positive individuals classified as a “health threat to others.” Discussed in greater detail in chapter 3, these policies target people living with HIV who have been warned by health authorities to change their behavior but continue to engage in conduct expressly prohibited by public health authorities—typically sexual intercourse without first disclosing one’s HIV-positive status.

In many states, however, legislators went a step further and enacted even more coercive measures aimed squarely at punishing HIV-positive people labeled a health threat. Between 1986 and 2011, thirty-three states enacted HIV-specific criminal statutes that made it a crime (usually a felony) for people who know that they are HIV-positive to engage in a wide range of behaviors without first disclosing their HIV-status.⁸² According to a recent report coauthored by CDC and Department of Justice staff, twenty-five states criminalize one or more behaviors that pose a low or negligible risk for HIV transmission, such as oral sex, biting, spitting, or throwing blood.⁸³ Several statutes do not specify which behaviors are criminalized; it is a crime simply to expose another person to HIV—wording that one observer calls “unconstitutionally vague.”⁸⁴ Even HIV-positive people living in a state without an HIV-specific law have been incarcerated under similar circumstances. In states like Texas and New York without such a recalcitrant criminal law, prosecutors charge HIV-positive defendants under general criminal laws against assault and battery, reckless endangerment, or attempted murder.

Many of these statutes reflect the climate of the period in which they were enacted: a time when there was an exaggerated perception of the risk of transmission of HIV and punitive attitudes toward persons living with HIV. In 2010, however, the Obama White House released its

coercive measures: mandatory testing of all those "at risk" of spreading the disease, branding people with AIDS with a visible tattoo, and quarantine and criminal incarceration of "recalcitrant" AIDS carriers.⁷⁸ In their call for coercion, conservatives were joined by members of a public increasingly frightened by the spread of an incurable disease. Public opinion polls conducted in 1985 and 1986 showed that between 28 and 51 percent of respondents agreed that "people with AIDS should be put into quarantine to keep them away from the general public."⁷⁹

At the center of many public debates was a murky figure blamed for the disease's rapid spread in gay communities. "Patient Zero," as he was called, was a French-Canadian, gay male air steward who reportedly had infected numerous of his partners in his travels. Although the CDC did interview the man and strongly urged him to stop having sex, scientists and health authorities did not, in fact, suspect him of being the source of HIV in the United States. But he made for a great story for San Francisco journalist Randy Shilts, who was putting the finishing touches on his 1987 book chronicling the government's lackluster response to AIDS, *And the Band Played On*. His publisher worried that the book would fall flat and pressured Shilts to find a way to make it more sensational:

[Shilts's publisher] described the initial dismal prospects for *And the Band Played On* that motivated them to find a more creative way to promote the book. The solution was to use Patient Zero and present him as the handsome, promiscuous French-Canadian airline steward who may have brought AIDS to America. This was the pathway to the bestseller list, and it worked.

Just as nearly a century before Mary Mallon had been blamed for the spread of typhoid fever, so too was Canadian air steward Gaëtan Dugas blamed for the spread of HIV. While Shilts had hoped his book would be a boon to AIDS activists in calling out the federal government's inaction, debates over Patient Zero and his culpability overshadowed the rest of the book—playing right into the hands of religious conservatives:

Shilts's salacious story of Patient Zero was ideal propaganda for conservatives because it played into the tenets of their latest campaign to isolate [people living with HIV] and gays. As an immigrant with AIDS, Gaëtan stood in for others like him who should be kept out of the country. Meanwhile, as both a gay man with an unchecked libido and an AIDS carrier who recklessly infected others, he embodied those who deserved to be locked up for their sociopathic behavior.⁸⁰

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national HIV/AIDS strategy, stating that "in some cases, it may be appropriate for legislators to reconsider whether existing laws continue to further the public interest and public health."⁸⁵ For the many critics of these laws, these recommendations may come as welcome news. However, given that many of these points had been made as early as the late 1980s and that antiretroviral drugs have been in use since 1996, some may also wonder why these recommendations came so late.⁸⁶

PUNISHING PATIENT ZERO

The impulse to punish the sick has a long history in public health—a history shot through with calls to coerce and quarantine the sick. Those efforts have repeatedly disproportionately impacted the poor, racial minorities, sex workers, and other stigmatized communities—sometimes by design, but more often as a matter of practice. Yet, despite the long, sordid affair between sickness and stigma, disease control remained a matter of civil law for most of American public health history. What begat this punitive turn?

As the HIV epidemic crystallized, it did so alongside the New Right's calls for Americans to take personal responsibility for their lives by putting an end to New Deal welfare programs. Conservatives in federal and state legislatures worked in concert to gut welfare programs while declaring a war on crime that prompted a rise in incarceration rates unprecedented in human history.⁸⁷ Funding to higher education was drastically cut while the number of prisons exploded, leading modern activists to demand "schools, not prisons."⁸⁸ For Black men especially, sociologists have demonstrated that incarceration has become a normal and even *probable* life event.⁸⁹

It is in this context that the first cases of HIV began to be reported in major urban areas in the United States—cities such as San Francisco and New York City, which conservatives already associated with hedonism and immorality. Perhaps if the disease had struck middle-class heterosexuals in the suburbs, the New Right's reaction to HIV might have been different. Instead, the disease was immediately associated with gay men, sex workers, Haitians, and injection drug users—some of the most stigmatized communities in the United States at the time. As many of these groups were already suspected criminals, criminalization was already top of mind for authorities tasked with managing these populations.

Evangelical conservatives capitalized on this association, issuing damning proclamations that the "gay plague" would cross over and

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infect middle-class American families. The cover of the July 1983 issue of Jerry Falwell's *Moral Majority Report* perfectly encapsulates the stig- matizing narrative invented by conservatives. Featuring a photo of a White, middle-class family with two children whose faces are covered with medical surgical masks, the headline read: "Homosexual Diseases Threaten American Families."

Although far more extreme, this punitive view of the epidemic reso- nates with public health's message that risky individual health behaviors cause disease and need to be prevented. The logical leap from arguing that we need to prevent individual health behaviors that cause disease to blaming individuals for engaging health behaviors labeled "risky" was not so great. Medical historian Allan Brandt observed in 1997 that

AIDS has been placed strongly within the paradigm of responsibility. If one "merely" avoids the risk behaviors associated with transmission of the virus—unprotected sexual intercourse and sharing needles for intravenous drug use—one can avoid AIDS. Therefore, infection is a clear—and usually terminal—marker of individual risk taking, of engaging in behaviors typi- cally held to be deviant or criminal. According to this view, those who are infected are *responsible* for their plight. AIDS is *caused* by a moral failure of the individual.⁹⁰

In ushering in a new era of risk avoidance in which the responsibility for one's health was placed on each individual's shoulders, public health inadvertently contributed to a context in which blame and punishment seem apt disease control strategies.

Patient Zero proved a compelling narrative not simply as an exercise in tracing the epidemiological origins of the epidemic; rather, his story helped *And the Band Played On* become a best seller because many Americans desperately wanted someone to blame. A gay male flight attendant made the perfect scapegoat for a terrified public. The con- servative magazine *The National Review* branded Dugas the "Colum- bus of AIDS" and blamed him for bringing the disease to America. In such a context, criminalizing HIV was a logical response in this march of shame and blame.

Although Patient Zero was a fictional character invented by a jour- nalist, his story fueled calls for public health to institute coercive and punitive measures in response to AIDS. These demands for control resembled many of the historical cases reviewed in this chapter in that they typically singled out especially marginalized people for control: in the case of Patient Zero, an immigrant gay man; in other cases reviewed in this chapter, the poor, racial minorities, sex workers, and even

alcoholics. When public health institutions discriminatorily targets specific groups of people for coercive measures that are not applied to other groups, their efforts reinforce the view that certain social groups are to blame for the spread of disease. Their implicit offense is not their risky behaviors but their social difference. In this way, the history of punitive disease control is at times indistinguishable from America's troubled history of social marginalization.

We cannot know what would have happened if more cases of Ebola had been brought to American shores, or what will happen when the next infectious disease becomes epidemic in the United States. As this book reveals, however, disease and punishment are more closely linked than even before in modern history.

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CHAPTER 2

"HIV Stops with Me"

The Repolarization of Post-AIDS HIV Prevention

Last year the Centers for Disease Control and Prevention (CDC) announced an initiative that would essentially eliminate the culturally and psychologically sensitive HIV prevention gay men have achieved over these past two decades. Little in the CDC's [initiative] is actually new. Rather, it invokes the "enforcement" model that spawned the discipline of public health in the TB epidemic of early twentieth-century America. . . . Perhaps most disturbingly, the initiative imposes, in the guise of "prevention," the humanly repressive values of the political right that now controls CDC funding.

—Walt Odets, *POZ Magazine*¹

When the CDC announced its new priorities for HIV prevention in 2003, many public health advocates were alarmed: *where were the condoms?* Although there was a growing sense in the field that condoms were failing as an HIV prevention strategy, no one was prepared to admit defeat publicly. The announcement came in the pages of the CDC's *Morbidity and Mortality Weekly Report*. The report outlined "four key strategies" that would guide the organization's future HIV prevention efforts:

1. increase the number of people tested for HIV;
2. increase access to twenty-minute rapid HIV tests;
3. focus prevention efforts on individuals already diagnosed as HIV positive;
4. decrease mother-to-child transmission of HIV.²

For decades, the very *notion* of doing HIV prevention had become practically synonymous with promoting “safer sex” to the masses. When it came to HIV, condoms were public health’s bread and butter. The CDC’s announcement seemed to be signaling the end of an era. As it would turn out, that’s exactly what it would be.

For most Americans, the term *HIV prevention* conjures images of unsexy posters asking HIV-negative people to “wrap it up” or “use protection.” But that approach has largely been abandoned in public health practice. In the decade that followed its 2003 announcement, the CDC moved further away from promoting safer sex to HIV-negative people and toward developing new strategies specifically targeting HIV-positive people. How and why did this happen?

This chapter explores that “repolarization”—from negative to positive—in HIV prevention. The chapter explains how the notion of targeting people living with HIV for HIV prevention—or what became known as “positive prevention”—came about. While positive prevention has long roots, it began to gain traction in the late 1990s as new treatments transformed HIV from a terminal illness into a chronic, manageable disease—simultaneously transforming HIV-positive people from passive victims into active managers of their disease. However, even as public health practitioners came to agree that targeting HIV-positive people was important and necessary in this new context, there remained considerable debate over the content and character of the interventions. Social scientists cautioned against framing people living with HIV as individually responsible for HIV prevention, arguing instead for situating their lives and challenges within a broader social context. Failure to do so, they warned, could facilitate shaming and blaming individuals viewed as acting irresponsibly. As this chapter shows, their warnings were not always heeded in practice. The repolarization of HIV prevention analyzed in this chapter ushered in a new era in public health practice in which the HIV-positive person is portrayed as being individually responsible for ending the epidemic—and, implicitly, the one to blame when things go wrong.³

It is important to note that these efforts to endow people living with HIV with a sense of personal, individual responsibility for ending HIV were not punitive in intent or in their most immediate effects. Indeed, many of the campaigns analyzed in this chapter were explicitly and directly informed by people living with HIV who genuinely want to do their part to end HIV and contribute to fighting the epidemic. This chapter should not be read as an attack on that altruistic spirit. Instead, this

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"repolarization"—from negative to positive. Chapter explains how the notion of targeted HIV prevention—or what became known as "safer sex"—while positive prevention has been in the late 1990s as new treatments turned HIV illness into a chronic, manageable disease, distancing HIV-positive people from passive victims of their disease. However, even as public health agreed that targeting HIV-positive people in this new context, there remained considerable character of the interventions. Socializing people living with HIV as individualism, arguing instead for situating their behavior in broader social context. Failure to do so, blaming and blaming individuals viewed as responsible. Chapter shows, their warnings were not the repolarization of HIV prevention analysis in a new era in public health practice in which is portrayed as being individually responsible—and, implicitly, the one to blame when

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chapter argues that the execution of these campaigns has at times characterized the responsibility in individualistic terms—an approach that can resonate with efforts to assign blame, punish, and, ultimately, criminalize individuals viewed as failing to live up to those individual responsibilities. In this way, this chapter reveals how even well-intentioned disease control strategies that portray people living with infectious disease as individually responsible can have punitive ripple effects.

AIDS VICTIMS NO MORE

The notion that public health campaigns should target individuals already infected with HIV seems almost obvious today. We live in a world where public health campaigns routinely promote individual responsibility for people who are suffering from all kinds of ailments, from obesity to heart disease: Make better choices. Take care of your own health. Eat your vegetables. However, in 1985, any notion that people living with HIV might be considered responsible for managing their disease stood in conflict with harrowing images of helpless AIDS patients suffering a horrible, untimely death: how could we possibly describe these poor souls as "responsible" for anything?

When nighttime news programs first began reporting a new, strange disease affecting homosexuals, people suffering from AIDS were depicted in bleak terms. Newsreels cut to heart-wrenching images of shrunken figures dying in hospital beds. There was no treatment for the disease itself or for the many bizarre and extremely rare opportunistic infections that colonized defenseless HIV-positive immune systems. With gay men dying left and right, AIDS activists likened the havoc wreaked on communities and on HIV-positive bodies to the Holocaust.⁴ The images of AIDS victims broadcast into American homes were hardly that of people ready to take responsibility for their own health; instead, they were *victims* of a tragic, mysterious illness that left doctors scratching their heads (or worse yet, running in the opposite direction).

This powerful AIDS-victim narrative controlled media representations of HIV for many years, ultimately crafting a public understanding of people living with HIV as isolated, disfigured, and dying. But two important factors helped shift public perception. First, AIDS activist organizations like the AIDS Coalition to Unleash Power (ACT UP) explicitly advocated against the label "AIDS victim." Even before ACT UP began organizing in the late 1980s, people living with HIV rejected the "victim" label." In a 1983 manifesto colloquially known as the

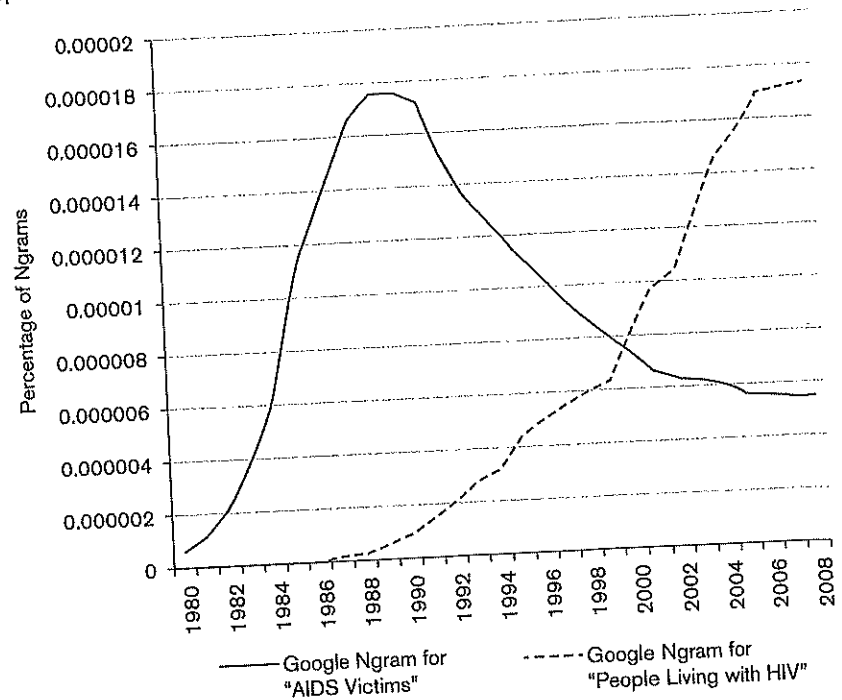
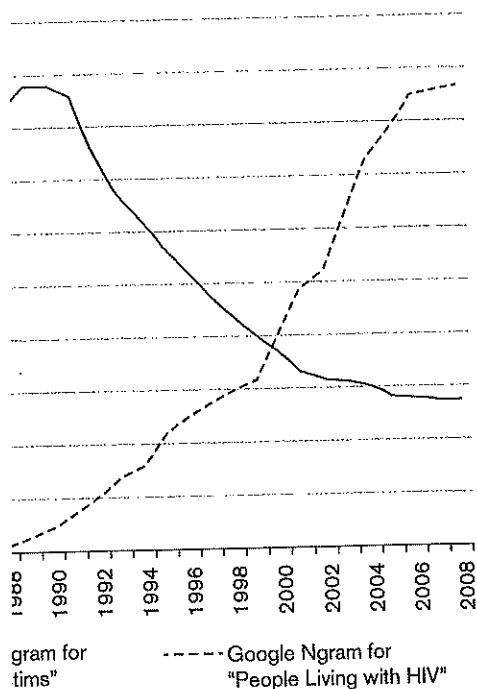


FIGURE 2. Google Ngrams for "AIDS victims" and "people living with HIV," 1980–2008. Source: Trevor Hoppe.

Denver Principles, a small group of people living with HIV condemned "attempts to label us as 'victims,' a term which implies defeat."⁵ Activists promoted language that focused on *living with* the illness rather than *dying from* it.⁶ Instead of focusing endlessly on people dying, ACT UP demanded coverage examining the institutions that were failing communities affected by AIDS. ACT UP pointed the finger at government agencies' callous indifference and at pharmaceutical companies' greed. Their chants—"ACT UP, fight back, fight AIDS!"—came to the doorsteps of powerful organizations across the country.

Their organizing had profound effects, changing government policies and, ultimately, the way medical research was done.⁷ It also reshaped how we talked about AIDS. Data analyzing how often particular words and phrases are used in Google's massive collection of digitized books and other publications help demonstrate these effects. According to these data (see figure 2), the term *AIDS victims* begins to fall out of favor in the early 1990s. After 1992, the term loses traction year over



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year as *people living with HIV* gains in popularity—until *people living with HIV* outpaces *AIDS victims* in 2000.

But even though ACT UP's activism was important in driving this shift in language, it was not the only variable at work. Science played an equally important part in reshaping how we understood people living with HIV. While an HIV-positive test result was a largely terminal diagnosis in the 1980s, the introduction of effective treatment in 1996 dramatically changed the outlook for people living with the disease. These drugs—called antiretrovirals, or ARVs for short—removed the threat of impending doom that prevented many people from seeing HIV-positive people as anything other than victims. Immediately after ARVs' introduction, mortality rates plummeted. CDC surveillance data indicate that AIDS-related deaths declined, from a peak of 50,489 in 1995, by over 25 percent in 1996, over 50 percent by 1997, and by nearly 65 percent by 1998.⁸ Once expected to die a quick and untimely death, those diagnosed as HIV positive were suddenly expected to live for decades. Seemingly overnight, HIV-positive individuals were transformed from victims of a terminal illness to active managers of a chronic disease.

And with management comes responsibility.

POSITIVE PREVENTION AND SHIFTING RESPONSIBILITY IN HIV PREVENTION

In 2000, one of the nation's leading HIV research centers, the Centers for AIDS Prevention Studies (CAPS) at University of California at San Francisco, issued an early report outlining the need for prevention targeting HIV-positive people. The report, *Designing Primary Prevention for People Living with HIV*, cites the changing landscape for HIV-positive people as a primary rationale: "The success of new treatments for HIV infection means that there are now more people living with HIV disease than ever before, and many of these individuals are feeling healthier and are better able to participate in the normal activities of life, including sex."⁹ The implication was that if HIV-positive people are going to live long lives with the virus, public health agencies needed to devise strategies to make sure they keep the virus to themselves.

In order to justify the need for positive prevention, the report points to one HIV-positive man's story in particular. In the late 1990s, American media outlets exploded with the news that an African American man in New York had been arrested after allegedly infecting nearly a dozen White women. Some of the girls were underage, making the case

ripe for a sensational news cycle. The report's authors point to this "chilling" case as evidence for the need to target HIV-positive people for prevention:

In October 1997, a chilling story out of Chautauqua County, New York, manifested the fears of AIDS advocates and the general public alike. A man named Nushawn Williams, in jail for the sale of crack, admitted to public health authorities that he had had unprotected sex with 50 to 75 young women, most of them teenagers. The story was exceptional, since only isolated incidents of willful exposure to HIV had ever been reported in the press. But the political reaction was swift, with a state assemblywoman calling for mandatory names reporting of HIV infection and proposing a new category of crime from knowingly exposing someone to HIV.¹⁰

Sensational media reports depicted Williams as an "HIV monster."¹¹ Because New York did not have an HIV-specific criminal law at the time, Williams was ultimately convicted for sexual assault and, at the time of publication, remains incarcerated despite the completion of his court-ordered prison sentence in 2010.¹²

That scholars chose William's controversial case to evidence the need for positive prevention highlights the delicate politics of responsibility involved. In early scientific papers on positive prevention, public health experts urged caution when framing responsibility for HIV-positive people. In one of the earliest academic publications on the subject, the authors urged public health practitioners to take care in framing the responsibility for preventing HIV in "collective" terms:

The concept of collective responsibility emphasizes that all of us, infected or not, low risk or high, bear a responsibility to change our attitudes and behaviors that may promote HIV infection. Without this balance, calls for personal responsibility become almost indistinguishable from that of blaming the victim and are likely to be counterproductive to prevention efforts.¹³

A commitment to promoting collective responsibility for preventing HIV would require depicting it as something shared by everyone in a community, by both HIV-positive people and their HIV-negative counterparts, not just certain individuals.

Other scholars echoed these concerns. In a set of principles designed to guide public health practitioners developing positive prevention campaigns, sociologist and HIV policy expert Judith Auerbach goes even further by suggesting that efforts to promote individual or collective responsibility must be "embedded in larger and more comprehensive efforts to promote positive physical and emotional development, life

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skills and chances, poverty alleviation, and gender equity."¹⁴ In short, it takes a village; individual responsibility can reasonably go only so far. Without also highlighting the broad range of needs facing both HIV-negative and HIV-positive people and communities, Auerbach argues that calls for HIV-positive people to take responsibility for ending the epidemic will likely be unproductive.

The CDC first signaled its interest in positive prevention in 2001 when it announced the Serostatus Approach to Fighting the Epidemic (SAFE) in the pages of the prestigious *American Journal of Public Health*.¹⁵ The SAFE model included five strategies:

1. increase the number of HIV-infected persons who know their serostatus;
2. increase the use of health care and preventive services;
3. increase high-quality care and treatment;
4. increase adherence to therapy by individuals with HIV;
5. increase the number of individuals with HIV who adopt and sustain HIV-STI risk reduction behavior.¹⁶

In developing SAFE, the CDC had largely reoriented prevention around the surveillance and medical treatment of HIV-positive people. The responsibilities assigned to HIV-positive people were far more numerous than those assigned to HIV-negative individuals.

Two years later, the CDC gave SAFE teeth by announcing new funding priorities built largely around this approach, which sparked an explosion in research on positive prevention. Between 1992 and 2002, the phrase *positive prevention* appears no more than a handful of times in academic publications indexed by Google Scholar. However, beginning in 2003, the number of citations of this phrase increases rapidly, to nearly three hundred citations per year by 2013.¹⁷ Further, while roughly one-third of the CDC's HIV prevention grant applications in 1999 listed people living with HIV as a key population, that figure increased to 58 percent by 2001.¹⁸ Thus, the CDC announcement clearly was not just lip service; it had the effect of prompting new research and new interventions targeting people living with HIV.

CDC funding streams did more than just generate new lines of academic research on positive prevention; that money directly supported the development of new HIV prevention interventions targeting HIV-positive people. While it is not possible to analyze the broad array of HIV

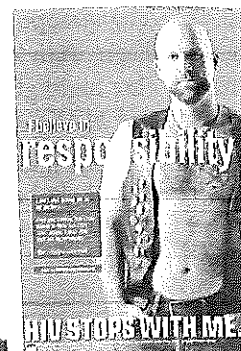
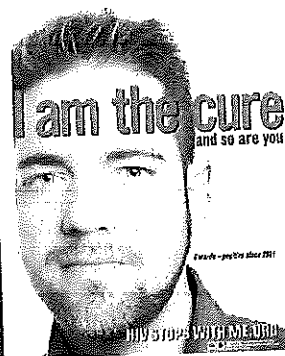
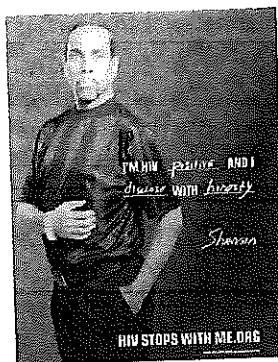


FIGURE 3 (Left). HIV Stops with Me ad: "I disclose with honesty." Source: Better World Advertising.

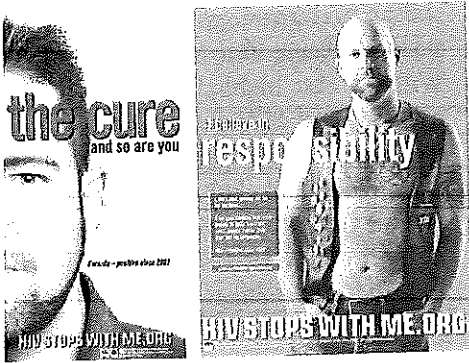
FIGURE 4 (Middle). HIV Stops with Me ad: "I am the cure." Source: Better World Advertising.

FIGURE 5 (Right). HIV Stops with Me ad: "I believe in responsibility." Source: Better World Advertising.

prevention campaigns across the country enacted under these policies, social marketing campaign has achieved dominance. Initially launched in San Francisco in 1999, HIV Stops with Me has since been adopted in various forms by over a dozen state and local health departments across the country, from Los Angeles to New York City to Alaska.¹⁹ Each iteration is typically funded by city or state health departments. It uses posters, billboards, and other media featuring "real HIV-positive people" speaking openly about the realities they face in managing HIV and its transmission. As perhaps the most widely disseminated and longest-running prevention campaign targeting HIV-positive people, it provides a useful case study for examining how positive prevention has been applied in the field.²⁰

Figures 3, 4, and 5 feature three emblematic examples of the HIV Stops with Me campaign. Each takes a slightly different tack in representing how its HIV-positive subject takes responsibility for his disclosure. In the image depicted in figure 3 from a 2012 campaign targeting New York, Boston, Virginia, and Alaska, the message from "Shannon" is "I'm HIV positive and I disclose with honesty." By tying disclosure to a personal value—honesty—the 2012 campaign is intended to provide a moral context for the practice of disclosing one's HIV-positive status: disclosure is not just a strategy for managing HIV risk; it is the right thing to do.

The poster depicted in figure 5 takes a similar approach. Using eleven metropolitan areas in 2003, the spokesperson declares: "I be-



"I disclose with honesty." Source: Better World

ad: "I am the cure." Source: Better World

d: "I believe in responsibility." Source: Better

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in responsibility" and "I feel good knowing that I care enough to make sure I don't infect anyone. I value other guys and my community." The ad thus suggests that taking measures to prevent transmission means one is a responsible community member who cares for others and one's community.

Finally, in the image depicted in figure 4, which was used in 2006 in Boston, Los Angeles, Long Beach, San Francisco, and Oregon, "Gerardo" declares himself to be "the cure"—suggesting that, while they cannot cure themselves, HIV-positive people can provide a "cure" by taking care not to infect others. The president of the advertising firm that designs and manages the HIV Stops With Me brand proclaimed in a press release announcing the I Am the Cure campaign that "HIV positive individuals have the power to prevent new infections and they can be the cure."²¹

Each of these ads promotes responsibility in different ways. Figure 3 depicts taking responsibility as a *behavior*, the act of disclosing one's HIV-positive status to one's partner. Figure 4 does not promote a specific behavior; rather, it promotes responsibility by suggesting that HIV-positive people can "be the cure" for HIV by playing their part in ending HIV. Figure 5 picks up a similar thread, promoting the idea that HIV-positive people should not infect anyone else. In this ad, taking responsibility for HIV is an expression of caring for one's partner and community.

Yet, while each ad takes a slightly different approach to promoting responsibility, each construes the responsible party as "me"—an individual who should take action to prevent HIV transmission. The campaign's slogan is, after all, HIV Stops with Me, *not* HIV Stops with We. HIV-negative partners and their role in preventing HIV are not represented. While the third ad does make reference to a need to value "other guys and my community," the job of protecting that community from HIV is depicted as solely that of the HIV-positive spokesperson.

In short, HIV Stops with Me promotes a notion of individualized responsibility that resembles an approach cautioned against by many public health scholars.

TREATMENT AS PREVENTION: HIV-POSITIVE BODIES AS THE NEW FRONTIER

As the decade wore on, more and more HIV prevention advocates became exasperated with what seemed like signs of failure. In the first half of the 2000s, researchers designed dozens (if not hundreds) of studies to measure how many people were not using condoms. They repeat-

edly published the same finding: across the country, many men who have sex with men (MSM) reported having sex without condoms.²² While gay men had always been having sex without condoms, these studies seemed to suggest that rates of condomless sex were on the rise.

As *barebacking* (intentionally engaging in condomless sex) became a common term in HIV prevention circles, public health advocates expressed frustration that—thirty years into the epidemic—condoms remained the only tool in their toolbox.²³ In the pages of the *American Journal of Public Health*, one public health scholar ominously wrote:

Behavioral interventions to promote condom use—the only strategy currently available to stem the MSM epidemic—are failing. Under the best of circumstances, when proven effective, they are not promptly and easily disseminated, and certainly not straightforwardly translatable across the age spectrum, ethnic groups, and subcultures. Without sustained but costly quality assurance procedures, they drift.²⁴

Among the potential alternatives to condom promotion, authors typically cited vaginal and rectal microbicides or gels that would be applied to the genitals to reduce the risk of infection. In putting all their eggs in the condom basket, had public health missed opportunities to develop other options?

In trying to decide what public health should do next, advocates and scholars often drew a line in the sand between behavioral interventions (condoms) and biomedical interventions (such as microbicides). Although studies demonstrated that a handful of interventions could get people to use condoms for a few months, none was highly effective in the long run. Faith that public health could do much to change behavior was eroding. But what if we could develop a medical technology—a “silver bullet”—that could stop HIV in its tracks? Biomedicine became HIV prevention’s great hope.

Unfortunately, findings from the first published studies testing biomedical interventions were sometimes underwhelming. Data from the most promising vaccine trial in years suggested that the vaccine was, at best, only partially effective.²⁵ While clinical trials evaluating the efficacy of male circumcision demonstrated up to a 60 percent reduction in the risk of contracting HIV among African men,²⁶ results from microbicide trials have yielded more mixed results. An initial trial failed to show that the gel had any effect,²⁷ and a later trial with a different gel demonstrated only a 30 percent efficacy among women.²⁸ A third candidate was thought promising after initial results suggested it could

g; across the country, many men who reported having sex without condoms.²² In having sex without condoms, these rates of condomless sex were on the rise. (engaging in condomless sex) became a nation circles, public health advocates thirty years into the epidemic—condoms toolbox.²³ In the pages of the *American* public health scholar ominously wrote:

promote condom use—the only strategy curbing the M epidemic—are failing. Under the best of circumstances, they are not promptly and easily disseminated straightforwardly translatable across the age and cultures. Without sustained but costly qualitative effort.²⁴

As to condom promotion, authors typically microbicides or gels that would be applied to prevent infection. In putting all their eggs in one basket, health missed opportunities to develop

what health should do next, advocates and a gap between behavioral interventions and medical interventions (such as microbicides). But that a handful of interventions could be effective in a few months, none was highly effective. What health could do much to change behavior? Could we develop a medical technology—a vaccine? HIV in its tracks? Biomedicine became

But the first published studies testing microbicides were underwhelming. Data from the early years suggested that the vaccine was, at best, ineffective. While clinical trials evaluating the efficacy of microbicides up to a 60 percent reduction in HIV among African men,²⁶ results from microbicide trials were mixed. An initial trial failed to show efficacy,²⁷ and a later trial with a different gel showed efficacy among women.²⁸ A third candidate, after initial results suggested it could

reduce risk up to 54 percent among "high adherence" patients.²⁹ However, the National Institutes of Health prematurely halted a follow-up study that was unable to replicate these findings.³⁰

In the eyes of many public health authorities, none of these interventions were blockbusters. Many suffered from conflicting scientific data. Others seemed too costly with too little return. While male circumcision was cheap and highly effective at preventing heterosexual HIV transmission, many in the West viewed promoting circumcision to African men as unethical—especially as circumcision directly protected only men from infection, not women (who are disproportionately impacted by HIV in many African countries).³¹

Scientists instead placed their bets on the growing body of science that suggested treating HIV could also help to prevent it—an idea called "treatment as prevention." Anti-HIV medications lower the amount of virus present in the bodily fluids of HIV-positive individuals. At such low levels, HIV becomes scientifically undetectable, making it difficult or even impossible to transmit. Many HIV advocates and researchers had suspected this was true since the first treatments had been rolled out in the mid-1990s. Indeed, a 1998 Australian AIDS campaign targeting gay men featured the message "While we are still in the dark about viral load, use a condom."³² Despite these suspicions, however, science had yet to weigh in on the matter.

The Australian viral load campaign reveals that some communities had long believed that treatment could be a form of prevention. Yet it took at least a decade for any established HIV scientist to publicly give credence to this idea. That moment came in 2008 when a group of Swiss scientists issued a report that became known as the Swiss Statement. Their report shocked many because it argued that there was *zero risk* of sexual transmission for HIV-positive individuals under three conditions:

1. if they were on treatment;
2. if their viral load was undetectable; and
3. if they did not have another sexually transmitted co-infection.³³

American HIV prevention experts did not warmly embrace the Swiss Statement. The director of the CDC's Division on HIV/AIDS Prevention, Robert Janssen, argued that the Swiss scientists' conclusion was "premature."³⁴ Epidemiologist Myron Cohen (ironically, the very scientist whose findings would later validate the Swiss claims)

argued similarly that there was not yet sufficient evidence to support the Swiss claims:

We have every reason to pause and reflect. The protection provided from [antiretroviral therapy] is not absolute and is not absolutely predictable. In a study involving discordant couples in Africa, Sullivan et al. reported that 4 (2.3 percent) of 175 transmission events among a group of 2,993 discordant couples occurred when the index patient was receiving therapy. In a very recent evaluation of discordant couples in Henan, China, 84 HIV transmission events were noted among a group of 1,927 couples who were followed up from 2006 through 2008, and these transmission events were equally distributed among patients who were receiving and those who were not receiving ART.³⁵

If these debates sound familiar to readers, it may be because they closely parallel debates over the initial promotion of *condoms* by gay health advocates in the United States in the early 1980s. When New Yorkers Richard Berkowitz and Michael Callen famously distributed their pamphlet promoting condom use, "How to Have Sex in an Epidemic: One Approach," in May 1983 on the heels of HIV's discovery, they did so without a scientific consensus on condom efficacy to back up their recommendations.³⁶ At the time, many scientists wrung their hands over whether it was appropriate to promote condom use without conclusive evidence. To this day, condoms are not yet FDA-approved for anal sex.³⁷

In a scientific analysis of condom studies published *ten years* after Berkowitz and Callen's pamphlet, epidemiologist Susan Weller argued in 1993:

Until more is known about condom effectiveness, condom use promotion may have both positive and negative effects. . . . Condoms will not eliminate risk of sexual transmission and, in fact, may only lower risk somewhat. . . . Empirical data (reviewed in this report) indicate that a 90 percent reduction in risk due to condom use may be overly optimistic. The protective effect as estimated from human studies, regardless of use definitions, indicates a possible 69 percent reduction in risk.³⁸

Well over one hundred thousand Americans died of AIDS in the ten years between Berkowitz and Callen's pamphlet and Weller's waffling statement on condoms. Communities could not (and did not) wait for scientific consensus. While less urgent, the need to promote *anything* to help prevent HIV in 1983 was not entirely dissimilar from the need twenty-five years later to find alternatives to condoms.

Public health's collective anxiety about the Swiss Statement reveals the gap—or rather, the *chasm*—separating community-based and scien-

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and reflect. The protection provided from absolute and is not absolutely predictable. In a study in Africa, Sullivan et al. reported that 4 transmission events among a group of 2,993 discordant couples in Henan, China, 84 HIV transmission events among a group of 1,927 couples who were followed and these transmission events were equally likely in those who were receiving and those who were not.

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Condom effectiveness, condom use promotion and negative effects. . . . Condoms will not eliminate risk, in fact, may only lower risk somewhat. . . . (his report) indicate that a 90 percent reduction in risk may be overly optimistic. The protective effect as measured, regardless of use definitions, indicates a possible risk.³⁸

Thousands of Americans died of AIDS in the ten years since Callen's pamphlet and Weller's waffling communities could not (and did not) wait for more urgent, the need to promote *anything* to reduce risk was not entirely dissimilar from the need for alternatives to condoms.

The anxiety about the Swiss Statement reveals the tension between separating community-based and scientific

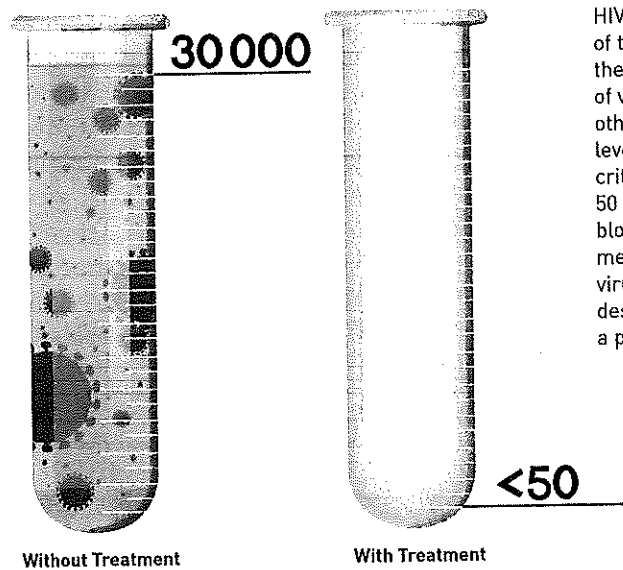
expertise. While many gay men were well aware as early as the late 1990s that treating HIV had a preventive effect, public health policy required cold, hard evidence. Despite their initially frigid response to the Swiss Statement, public health scholars and practitioners quickly warmed up to the concept as study after study validated its arguments in the 2010s. While studies of couples in which one person is HIV positive and the other is HIV negative had already shown that providing HIV-positive people with access to treatment reduced the risk of infection to their HIV-negative partners,³⁹ the results published in 2011 from a randomized control trial (HPTN 052) of early treatment sent tidal waves through the world of prevention science and public health practice.⁴⁰ In a cover story, the prestigious journal *Science* declared "Treatment as Prevention" was 2011's "Breakthrough of the Year." The author describes how the trial's results "stunned" the lead researchers behind it:

The researchers planned to compare the groups until 2015. But on 28 April, an independent monitoring board that periodically reviewed the data stunned Cohen and his collaborators when it recommended that the results of the trial be made public as soon as possible. Of the 28 people who became infected with HIV that genetically matched the viruses in their long-term partners, only one was in the early treatment group—which also experienced 41 percent fewer serious health problems associated with HIV. Infected people in the delayed arm of the study were offered ARVs immediately.⁴¹

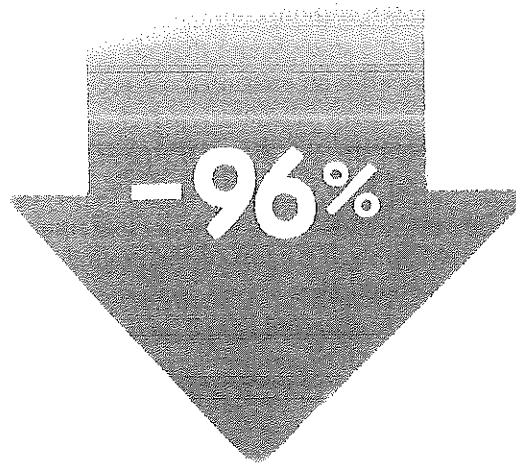
At a conference in early 2014, preliminary results were announced from a study monitoring 767 heterosexual and same-sex serodiscordant couples in which one partner was HIV positive, on treatment, and had a suppressed viral load, and the other was HIV negative. In order to participate, couples had to report having sex without condoms at least some of the time. After a two-year period, the study found that no transmissions had occurred between partners after an estimated 44,400 sexual encounters.⁴² When a conference participant asked the researchers in the Q&A what the findings revealed about the risk of an HIV-positive person with a treatment-suppressed viral load transmitting the virus, the lead researcher responded: "Our best estimate is it's zero."⁴³ Final results from the PARTNER study released in 2016 confirmed the preliminary results: After over 58,000 reported condomless sexual encounters (representing 1,238 couple-years), the study observed *zero* linked transmissions.⁴⁴ In light of these stark findings, AIDS activists have now begun trumpeting a new message: "Undetectable = Untransmittable."⁴⁵

In the scientific equivalent of a blink of an eye, treatment as prevention (TasP) went from being a dubious European theory to one of the

Un/Detectability



HIV treatment blocks the ability of the virus to reproduce in the body, reducing the amount of virus in blood, semen, and other bodily fluids. When the level of virus drops below a critical threshold (typically 50 copies per milliliter of blood), medical tests cannot measure the presence of the virus; at this point, the virus is described as "undetectable" in a person's body.



It is much harder to transmit HIV sexually when a person's bodily fluids contain very few copies of the virus. In 2011, scientists published the results of a study evaluating whether initiating early treatment reduced the risk of transmission in couples in which one partner is HIV positive and the other is HIV negative. The study found that starting treatment reduced the risk of transmission by 96 percent.

FIGURE 6. Undetectable = Uninfectious. Design: Jonathan Lefrançois. Illustration: Justin Karp for Pulp & Pixel.

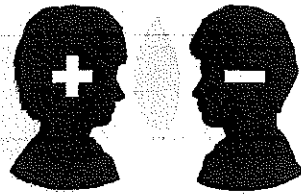
PARTNER Study

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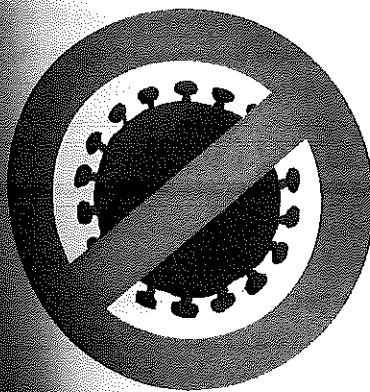
With Treatment

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58 000



In 2016, scientists published the results of a trial evaluating whether having an undetectable viral load (rather than starting treatment at all, as in the aforementioned 2011 study) reduced the risk of transmission in couples in which one partner is HIV positive and the other is HIV negative. The study—known as the PARTNER study—enrolled 1,166 such couples; 38 percent were gay male couples, and the remaining couples were heterosexual.

One important condition of enrollment in the PARTNER study was that partners had to be having sex without condoms at least some of the time. This condition allowed scientists to isolate the effects of having an undetectable viral load from the protective effect of condoms. In total, scientists estimate that the couples enrolled engaged in 58,000 condomless sexual encounters during the study.

After nearly four years of following enrolled couples, scientists reported zero linked transmissions between HIV-positive and HIV-negative partners. While eleven HIV-negative partners did contract HIV during the study period, genetic testing revealed that they were not infected by their primary partner. This finding has led advocates to declare that "undetectable = untransmittable."

most prestigious science journals' breakthrough of the year. Scientists suddenly agreed that treatment was, indeed, prevention. The number of scientific papers referencing TasP followed in kind, from virtually no references to the subject in academic papers catalogued by Google Scholar published in 2008 to nearly one thousand published in 2014.⁴⁶

The CDC responded to these ongoing advances by announcing its latest plan for controlling the epidemic, high-impact prevention (HIP), in 2011.⁴⁷ HIP aimed to combine "scientifically proven, cost-effective, and scalable interventions targeted to the right populations in the right geographic areas."⁴⁸ Although HIP includes interventions targeting HIV-negative individuals at least on paper, the emphasis is on identifying and treating HIV-positive people. Indeed, the first two prevention strategies in the announcement were "testing and linkage to care" and "antiretroviral therapy." In a 2012 presentation from a public health consulting firm advising agencies adapting to HIP guidelines, the authors note that the "standard proposal . . . probably won't be fundable next CDC round" and that interventions "must primarily target PwP [prevention with positives]."⁴⁹

The implications of this new framework for HIV prevention were important. Because HIV medications were reframed as a tool for prevention, treatment was no longer just an intervention done solely for the benefit of the HIV-positive patient. Under TasP, HIV therapy also became an intervention for the sake of future (or current) HIV-negative partners. It was perhaps no coincidence that this new justification for HIV treatment emerged at precisely the same time that a global recession had hampered massive, multibillion dollar campaigns to treat every person infected with HIV globally. The largest of these efforts, the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), allocated over three-quarters of its budget to the treatment and care of HIV-positive individuals.⁵⁰ Reframing their work as both treatment and prevention provided a new rationale for funders looking to get more done with fewer dollars.

On the ground, public health agencies had taken their marching orders and reorganized their work. "Use a condom" was no longer their mantra; under TasP, "test and treat" became the rallying cry of agencies across the world. Unlike previous HIV prevention strategies that emphasized behavior change and condom use, test-and-treat emphasized biomedical technologies such as rapid HIV-antibody tests and antiretrovirals. This message carried significant political appeal: HIV tests and pills were far less politically contentious than the tools of the behavioral HIV prevention programs of yore: namely, condoms and clean needles.⁵¹ In foregrounding concerns over access to health care and compliance

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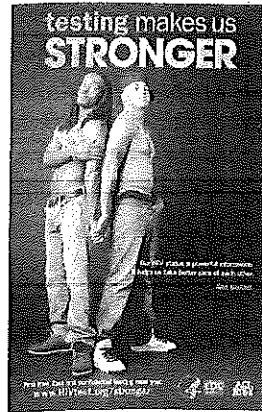


FIGURE 7 (Left). HIV testing campaign: "Testing makes us stronger." Source: Centers for Disease Control and Prevention.

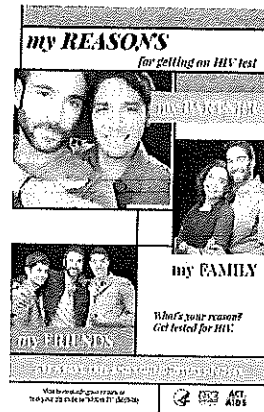


FIGURE 8 (Middle). HIV testing campaign: "My reasons for getting an HIV test." Source: Centers for Disease Control and Prevention.

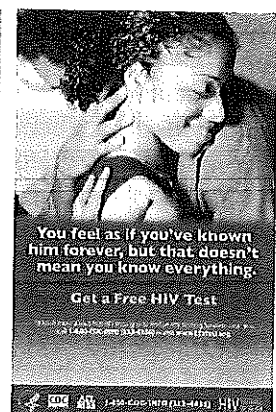


FIGURE 9 (Right). HIV testing campaign: "Get a free HIV test." Source: Centers for Disease Control and Prevention.

with treatment regimens, test-and-treat effectively relocated challenging conversations about sex and drugs to the back burner. Given the cycle of moral outrage from elected officials that frequently threatened public health budgets, health authorities may have viewed the shift to test-and-treat as particularly welcome.

The approach quickly caught on. At time of writing, of the five CDC-developed HIV prevention campaigns aimed at at-risk populations, four encourage people at risk to get tested and one raises general awareness about HIV. None focus primarily on encouraging safer sex practices for HIV-negative people, nor do any promote treatment for HIV-positive people.⁵² Figures 7, 8 and 9 illustrate three of the campaigns encouraging people at risk to get tested. The first, "Testing makes us stronger," targets African American MSM. The second ad, "My reasons," is similar, except that it targets Latino MSM. The third ad targets African American women.

Most of these ads promote a collective version of responsibility that resembles the public health recommendations examined earlier in this chapter. The third ad could be interpreted as promoting an individualistic form of responsibility similar to that depicted in the HIV Stops with Me campaign, in that the woman is depicted as making a decision on her own to get tested. It is not immediately obvious whether she is motivated to get tested for her sake or her partner's—or for both. The

ad implies that she may have been unknowingly exposed to HIV by her male partner. Although it does not plainly state that he knew he was infected and did not tell her, it does not foreclose suspicion of that possibility. In fact, it seems to be *promoting* suspicion as a primary motivating factor for getting HIV tested.

It is notable that the "Take Charge. Take the Test" campaign depicts an African American woman's decision to get tested in different terms from those depicted in the campaigns targeting Latino and Black MSM. The campaign necessarily walks a tightrope of political sensibilities between race, gender, and sexuality. On the one hand, while the ad is opaque about what knowing "everything" might entail, popular discourse on African American men is rife with racist narratives about their "down-low" sexual practices and untrustworthiness that facilitate readers coming to their own conclusion: get tested because you cannot know what your man does in his free time.⁵³ On the other hand, in a condom-focused HIV prevention context, women do report frustration with having to rely on men to truthfully report whether or not they have been faithful or recently tested.⁵⁴ In such a context, promoting suspicion may be a useful strategy for navigating this gendered uncertainty.⁵⁵

Taken together, these HIV testing campaigns would seem to be placing responsibility on HIV-negative individuals. But what does that responsibility entail? Under test-and-treat, the only explicit obligation assigned to HIV-negative people is to get tested; protective behaviors that would explicitly implicate their responsibility for preventing their own infection are no longer emphasized. Indeed, the only HIV-negative individuals of interest under the test-and-treat model are those who are *not*, in fact, HIV negative, but undiagnosed *HIV positive*. On the other hand, the potential infectiousness of HIV-positive bodies comes into focus, implicating their responsibility for preventing infecting others. Thus, the notion of responsibility that comes out of the test-and-treat model seems to relieve HIV-negative individuals of much of their responsibility for protecting themselves.

Notably, CDC did not develop a treatment-focused social marketing campaign targeting HIV-positive people until 2016, when it introduced the HIV Treatment Works campaign.⁵⁶ The campaign presents HIV-positive people living happy, productive lives, unencumbered by their diagnosis. However, in the dozens of posters and materials produced for the campaign, the preventive benefits of treatment are barely mentioned, suggesting the CDC remains uncertain over how to best promote treatment as prevention. This uncertainty was further evidenced when the CDC announced new recommendations the following year for HIV

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negative women wishing to become pregnant with a male partner who
is HIV-positive; many AIDS activists and experts promptly criticized
those guidelines for continuing to support expensive techniques like
"sperm-washing" instead of recommending that couples combine the
preventative benefits of treatment (for the HIV-positive man) and pre-
exposure prophylaxis (for the HIV-negative woman).⁵⁷

The CDC's tepid embrace of treatment's prevention-oriented benefits
may be in part due to the private nature of the doctor-patient relation-
ship in which treatment decisions are made. Rather than investing in
billboards or radio ads, some recent CDC-developed HIV prevention
campaigns aimed at HIV-positive people target them indirectly through
their health care providers. Included in the materials of one such inter-
vention—Prevention Is Care—is a patient brochure targeting HIV-posi-
tive patients in serodiscordant relationships (or relationships in which
one partner is living with HIV and one is HIV-negative). The brochure's
tips for how you can stop the spread of HIV are broken into two parts.
The first, "Do tell," encourages patients to disclose their HIV-positive
status to their partners so "he or she will know it's important to be safe
during all sexual activity and to be tested often for HIV."⁵⁸ The second
part, "Don't take risks," which is on preventing transmission, states
that "abstinence (not having sex) is the best way to prevent the spread
of HIV. But if abstinence is not possible, use condoms."⁵⁹ In regard to
whether lower viral loads might reduce or eliminate the risk of trans-
mission, the brochure states definitively:

Don't think you have "safe" times. Even when tests show that your viral
load (the amount of HIV in your blood) is very low or undetectable, you can
give HIV to your partner because the virus is still in your body. HIV can be
high enough in other body fluids to be spread to your partner.⁶⁰

Forgetting, for a moment, that the CDC brochure promotes abstinence
as the "best way" to prevent HIV (despite its high failure rates observed
throughout human history), recent studies show that having an unde-
tectable viral load reduces the risk of HIV transmission by somewhere
between 99.9 and 100 percent. Of course, when this brochure was pub-
lished in 2011, these figures were not yet available to the CDC. None-
theless, the brochure's claim that an HIV-positive person with an unde-
tectable viral load "can give your partner HIV" appears to have become
quickly outdated.

More broadly, the brochure again implies a host of individual
responsibilities for HIV-positive people for managing HIV. Despite

targeting HIV-serodiscordant relationships, the brochure does very little to acknowledge what the HIV-negative person might do to share the responsibility of managing that risk. HIV-positive partners are instructed to disclose their status so that their partners “will know it’s important to be safe,” which presumes that the HIV-negative partners would not otherwise know that they should protect themselves against infection. Despite studies showing that partners can play an important role in helping HIV-positive people adhere to their medication regimen, the brochure does not advise HIV-positive people how or why they might discuss their treatment with their partners.⁶¹ Although the brochure does note that anal sex is much riskier than oral sex, studies have long demonstrated that there is a wide range of harm-reduction strategies beyond using a condom that both HIV-negative and HIV-positive people can employ to reduce the risk of transmitting HIV.⁶² These practices—sometimes referred to as *seroadaptation*—are not discussed. In short, the brochure provides a wide array of responsibilities for HIV-positive people, while mostly ignoring their partners.

Yet, while CDC-developed prevention materials indirectly targeted HIV-positive people to encourage them to go on treatment, outside agencies funded with CDC dollars had already begun developing more explicit social marketing campaigns. A new iteration of the HIV Stops with Me campaign was announced in 2014 that depicted its spokesmodels before and after suppressing their viral load (see figure 10). The campaign’s tagline plainly stated its intended effect: “Find doctor / Keep appointments / Take meds / Check lab results.” In this series, the spokesmodel’s portrait was divided. On the left side, having a “detectable” viral load was described in negative, shameful terms. On the right side, having an “undetectable” viral load was depicted in positive terms. The ad’s central message was reinforced by visual cues: having a detectable viral load was depicted in black and white, suggesting an old-fashioned or antiquated way of being. Having an undetectable viral load was depicted in full color, suggesting progress and a happier, modern way of living.

According to the campaign, suppressing one’s viral load was only a matter of accepting one’s HIV-positive status and feeling in control of one’s life. But surely there are many reasons why HIV-positive people are not linked to care, many of which are not merely psychological and that are outside an individual’s control. These could include housing instability, an inability or fear of navigating a complex health care bureaucracy, negative experiences with stigmatizing health care providers, or a fear that showing up at the local health clinic for HIV treat-

relationships, the brochure does very little. HIV-negative person might do to share the risk. HIV-positive partners are instructed that their partners "will know it's important that the HIV-negative partners would should protect themselves against infection that partners can play an important role: adhere to their medication regimen, the HIV-positive people how or why they might infect their partners."⁶¹ Although the brochure is riskier than oral sex, studies have long shown a wide range of harm-reduction strategies for both HIV-negative and HIV-positive people. The risk of transmitting HIV.⁶² These practices—*seroadaptation*—are not discussed. In a wide array of responsibilities for HIV-positive people, ignoring their partners.

Prevention materials indirectly targeted HIV-positive people to go on treatment, outside agencies had already begun developing more explicit materials. A new iteration of the HIV Stops with Me campaign, released in 2014 that depicted its spokesmodels before and after treatment (see figure 10). The campaign's intended effect: "Find doctor / Keep appointments / Get results." In this series, the spokesmodels are shown on the left side, having a "detectable" viral load in negative terms. On the right side, having an undetectable viral load depicted in positive terms. The ad's central message: having a detectable viral load was suggesting an old-fashioned or antiquated way of living, while having an undetectable viral load was depicted in full as a happier, modern way of living.

But, suppressing one's viral load was only a part of the solution. HIV-positive status and feeling in control of one's life are many reasons why HIV-positive people seek treatment, of which are not merely psychological and medical but also social. These could include housing instability, fear of navigating a complex health care system, and experiences with stigmatizing health care providers. The campaign encouraged HIV-positive people to go to the local health clinic for HIV treat-

ment might spark hurtful gossip. These obstacles are not reducible to "wishing away" one's HIV-status: they are social problems, not personal issues.

More than a decade has passed since public health experts warned against individualistic positive prevention campaigns. At time of publication, no widely distributed campaign targeting HIV-positive people has done much to connect that personal responsibility to wider institutions and social problems. This problem is not limited to HIV prevention, of course. Critics of modern public health campaigns have long argued that health marketing tends to focus solely on the individual and do little to consider the broader social context in which those individuals live.⁶³ Consider, for a moment, the most recent public health campaign you can remember—whether anti obesity, anti teen pregnancy, or some other health issue. The tagline most likely had something to do with encouraging you (the individual) to make a "smarter" or "healthier" (personal) choice. The problem is more systemic and has to do with the way we conceive of "health" as the cumulative result of a series of individual choices. But while the promotion of individual responsibility is common in public health campaigns, in later chapters we will see that the stakes are considerably higher when it comes to HIV: if you are HIV positive, being labeled irresponsible can land you in prison.

THE PROMISE OF PREP?

Although the condom is not yet extinct, HIV prevention campaigns targeting HIV-positive people have reshaped notions of responsibility in public health practice. Prevention with positives repolarized the field, switching its focus from HIV-negative people to people living with HIV. In doing so, it turned our assumptions about who should be responsible for preventing future HIV infections on their head.

But the field is never static. A new technology appears poised to push back against this trend. In July 2012, the Food and Drug Administration (FDA) approved an antiretroviral already used for treating HIV for use by HIV-negative individuals in order to protect against infection. Pre-exposure prophylaxis—PrEP, for short—is a prevention strategy that involves taking a pill daily to protect against infection. Some gay activists have likened the approach to a kind of gay "birth control."⁶⁴ PrEP was approved on the heels of remarkable clinical trial data that showed it could reduce an HIV-negative person's risk of contracting the virus by 96 percent when taken daily.⁶⁵ Although critics were initially

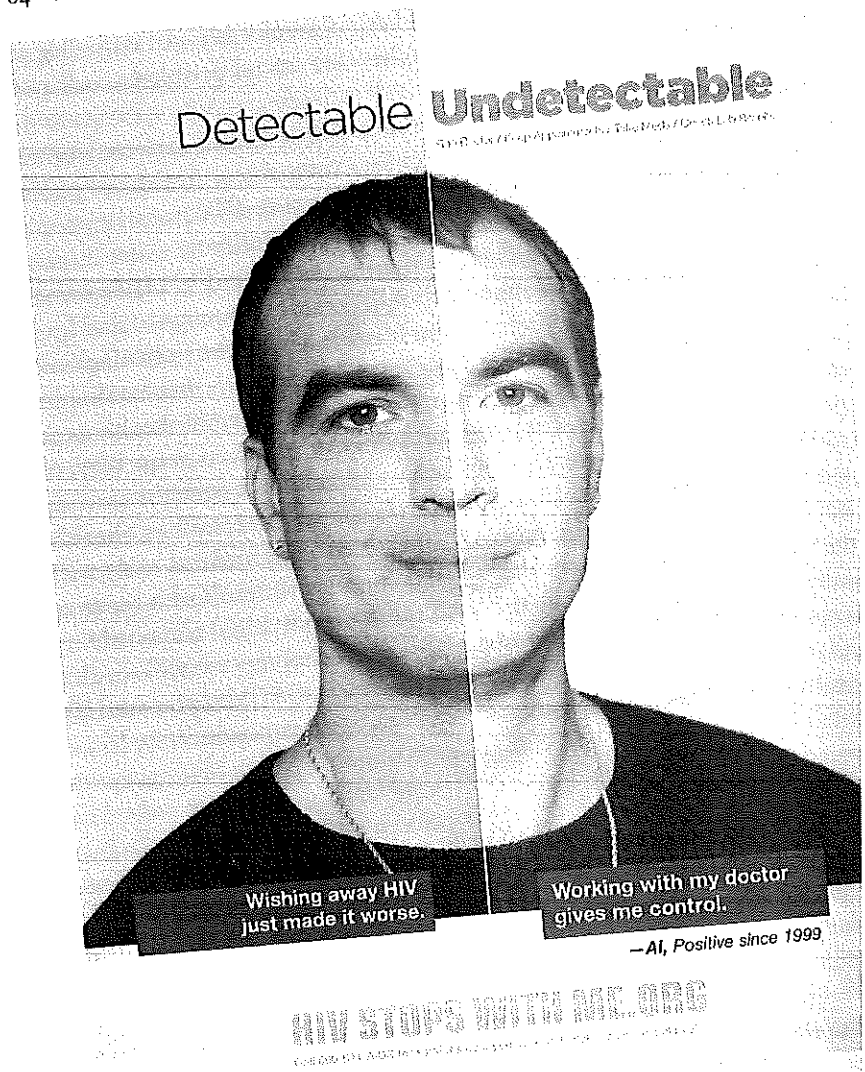


FIGURE 10. HIV Stays with Me ad: "Detectable/Undetectable." Source: Better World Advertising.

concerned that PrEP's remarkable success might be limited to the clinical trial environment where patients are monitored closely, data from Britain's PrEP demonstration project measuring the pill's effectiveness in the real world, announced in 2015, show it to be just as effective in practice.⁶⁶ In short, taking a pill a day can protect against HIV infection.

not speculate as to what might be driving this surprising finding, it may be related to the average man's habitual avoidance of doctors; in this study, HIV-positive men were presumed to regularly see a physician).⁷³ The remarkably healthy prognosis for HIV-positive people today will almost certainly make promoting HIV prevention more challenging.

But if HIV-negative people *are* called to take responsibility for protecting themselves against HIV infection, how will that responsibility be represented? Will it be presented as an individual choice made for one's own personal health? For the love of a partner? Or will it be sold as a way to come together as a community to fight the epidemic? Only time will tell. At the time of writing, PrEP's lackluster adoption in nonwhite communities means that identifying HIV-positive people and getting them linked consistently to care remains a key strategy of twenty-first-century HIV prevention.

THE POLITICS OF RESPONSIBILITY

Individualistic positive prevention campaigns like HIV Stops with Me fall into many of the traps experts caution against. Their HIV-positive spokespeople proudly proclaim disclosing and caring for their communities. However, the social context for these efforts to prevent HIV is largely absent. For example, HIV Stops with Me does not connect disclosure to emotional well-being or structural problems that many HIV-positive people face, such as housing insecurity, financial instability, and domestic violence. Yet we know that the decision to disclose one's HIV-positive status can be influenced by many such factors. Not accounting for these broader issues facing HIV-positive people leaves the viewer with the impression that HIV-positive people could stop HIV if they would only choose to do so: the perfect recipe for blame and shame.

On the other hand, the HIV testing campaigns targeting HIV-negative individuals promote a different, more collective kind of responsibility. In the ads in figures 7 and 8, the decision to get tested is situated within a particular social context: a relationship, a family, a group of friends. Whereas the responsibilities promoted for HIV-positive people by the HIV Stops with Me campaign were largely individualistic ("I disclose with honesty"; "I am the cure"; "I believe in responsibility"), HIV-negative MSM are depicted as taking on a socially embedded responsibility alongside family, friends, and romantic partners. If they fail to get tested, presumably the blame extends beyond the individual.

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Why was their community not more supportive? Was their partner judgmental about HIV testing? These are the kind of questions asked when a collective responsibility is not met.

When individual responsibility is not met, however, the questions are markedly different. As described earlier in the chapter, researchers justified the need for developing prevention strategies targeting HIV-positive people by citing a criminal case against a New York man, Nushawn Williams, accused of infecting nearly a dozen women. As the second half of this book will reveal in greater detail, criminal laws punishing HIV-positive people have spread during the very same time as the repolarization of HIV prevention analyzed in this chapter. To date, more than thirty U.S. states have enacted HIV-specific criminal statutes that generally make it a crime for HIV-positive people to have sex without first disclosing their HIV-positive status.⁷⁴

It is no coincidence that public health scholars directly invoked Williams's criminal case as a justification for targeting HIV-positive people for prevention. HIV-specific criminal laws depend on the same notion of individual responsibility for people living with HIV promoted in the HIV Stops with Me campaign. Although unintentional, the repolarization of HIV prevention may have inadvertently contributed to the criminalization of HIV.

The next chapter examines this relationship more closely. How do the big-picture policies and rhetoric explored in this chapter play out on the ground? In the age of test-and-treat, local health departments are ramping up their surveillance programs targeting HIV-positive people. These programs are not only useful for public health purposes; they also happen to be useful for enforcing the law.