

Remaking a Life

HOW WOMEN LIVING WITH HIV/AIDS
CONFRONT INEQUALITY

Celeste Watkins-Hayes



UNIVERSITY OF CALIFORNIA PRESS

University of California Press, one of the most distinguished university presses in the United States, enriches lives around the world by advancing scholarship in the humanities, social sciences, and natural sciences. Its activities are supported by the UC Press Foundation and by philanthropic contributions from individuals and institutions. For more information, visit www.ucpress.edu.

University of California Press
Oakland, California

© 2019 by Celeste Watkins-Hayes

Library of Congress Cataloging-in-Publication Data

Names: Watkins-Hayes, Celeste, author.

Title: Remaking a life : how women living with HIV/AIDS confront inequality / Celeste Watkins-Hayes.

Description: Oakland, California : University of California Press, [2019] | Includes bibliographical references and index. |

Identifiers: LCCN 2018061419 (print) | LCCN 2019001371 (ebook) | ISBN 9780520968738 (Epub) | ISBN 9780520296022 (cloth : alk. paper) | ISBN 9780520296039 (pbk. : alk. paper)

Subjects: LCSH: HIV-positive women—United States. | AIDS (Disease) in women—United States. | Equality—Health aspects—United States. | HIV-positive women—Medical care—United States.

Classification: LCC RA643.83 (ebook) | LCC RA643.83 .w38 2019 (print) | DDC 362.19697/920082--dc23

LC record available at <https://lcn.loc.gov/2018061419>

28 27 26 25 24 23 22 21 20 19
10 9 8 7 6 5 4 3 2 1

I am so grateful to every single woman,
and everyone who loved her,
who we've had to say goodbye to.
Who we've had to bury.
Who we've had to hold,
whether physically or in our hearts,
for the rest of our lives.
And we continue to say their names
and hold them dear
and appreciate and love them
for being the ancestral guidance that we need.

—Dázon Dixon Diallo, Founder of SisterLove
Women Now! 2016 Summit
Durban, South Africa

Contents

	<i>List of Figures and Tables</i>	ix
	<i>List of Key Abbreviations</i>	xi
Introduction.	Injuries of Inequality and the Transformative Project	1
1.	Dying From: Sexual Violence, the Drug Economy, and the Persistence of HIV/AIDS	35
2.	The Safety Net that AIDS Activism Built	80
3.	Living With: The Emergence of Transformative Projects	135
4.	The HIV/AIDS Safety Net Meets the Test-and-Treat Revolution	178
5.	Thriving Despite: Social, Economic, and Political Restoration	204
Conclusion.	Inequality Flows through the Veins: Transformative Lessons from the HIV/AIDS Response	229

<i>Acknowledgments</i>	253
<i>Appendix A. Methods of Research</i>	259
<i>Appendix B. Health, Hardship, and Renewal Respondents</i>	273
<i>Notes</i>	281
<i>Index</i>	307

Figures and Tables

FIGURES

1. The Transformative Project	16
2. Estimated Number of Persons Living with HIV Infection and Estimated AIDS Deaths in the United States, 1981–2008	122
3. Transformation Indicators for Snapshot Study Respondents	206

TABLES

1. Women's Connectedness to the HIV Safety Net	151
2. The Health, Hardship, and Renewal Study	260
3. Our Storytellers	274
4. National HIV/AIDS Activists, Advocates, Policy Officials, and Service Providers	275
5. Sister to Sister Respondent Demographics	276
6. Snapshot Study Respondent Demographics	277

Key Abbreviations

ACT UP—AIDS Coalition to Unleash Power

ADAP—AIDS Drug Assistance Program

AIDS—acquired immunodeficiency syndrome

ART—antiretroviral therapy

AZT—azidothymidine

CDC—Centers for Disease Control and Prevention

GMHC—Gay Men's Health Crisis

HIV—human immunodeficiency virus

HSN—HIV/AIDS safety net

MMWR—Morbidity and Mortality Weekly Report (CDC)

MSM—men who have sex with men

NBLCA—National Black Leadership Commission on AIDS

PACHA—Presidential Advisory Council on HIV/AIDS

PEPFAR—President's Emergency Plan for AIDS Relief

PLWHA—people living with HIV/AIDS

PWID—people who inject drugs

PWN—Positive Women’s Network

SFAF—San Francisco AIDS Foundation

UNAIDS—Joint United Nations Programme on HIV/AIDS

WHO—World Health Organization

WLWHA—women living with HIV/AIDS

WORLD—Women Organized to Respond to Life-Threatening
Diseases

INTRODUCTION

Injuries of Inequality and the Transformative Project

“If it weren’t for HIV, I’d probably be dead.” The first time Dawn Stevens was diagnosed with HIV, it was 1985. Then only 24 years old, Dawn brought her six-month-old daughter Chyna to the emergency room with a high fever that would not break. The doctors were puzzled. After hours of tests, one physician thought to ask Dawn about her own health history. With little subterfuge, she disclosed her history of intravenous drug use. The doctor, convinced that he had solved the mystery, recommended that they test Dawn and her daughter for something called “H-I-V.” Chyna’s test came back negative, and doctors eventually diagnosed her with a treatable virus. Dawn, however, received the sobering news that she had in fact tested positive for HIV. The epidemic was still in its early stages, when information was limited and medical providers had few plans or protocols in place to guide the newly diagnosed. Dawn left the hospital with a life-threatening illness and little understanding of what it meant.

In many ways, the seeds of that fateful diagnosis had been planted years before. Dawn grew up in the 1970s and 1980s in a black working-class community on Chicago’s west side that was precariously situated near several high-poverty areas. She matured to adulthood at a time of

massive change in neighborhoods like hers. De facto racial and economic residential segregation and lack of investment by government and private businesses limited upward mobility for residents, including young adults.¹ Given the increasing availability of illegal drugs, the drug trade offered many in Dawn's cohort fast money and emotional escape from the blight that surrounded them. Rising intracommunity violence, declining funding for healthcare and other community services, and a precipitous rise in mass incarceration that warehoused many friends, family members, and neighbors made the barrier between life and death increasingly porous for young people like Dawn.²

When the sexual trauma of Dawn's childhood collided with the structural blows and deteriorating safety net afflicting her community, the effects were combustible. The first instances of molestation at the hands of two family members, including her stepfather, occurred when she was just five years old and would continue intermittently until she was 16. "My village wasn't safe," Dawn tearfully recalled as I interviewed her. She told no one about the sexual abuse, convinced that her mother wouldn't believe her and her biological father would retaliate violently against the perpetrators and she would lose him to prison. But she acted out in other ways. She snuck sips of her father's drinks at house parties and began smoking marijuana and cigarettes in the eighth grade. By sophomore year of high school, she was drinking regularly. By the time she was a 16-year-old junior, her rebellion intensified, tensions with both her parents escalated, and she ran away from home. "I had been sexually molested for years. So, when I left home, I was crazy," Dawn reflected.

Dawn moved in for a few weeks with the person she most idolized, her 19-year-old stepsister Jackie. Jackie had already graduated to the fast life, shooting drugs intravenously and dating the neighborhood dealers who maintained her supply. When those relationships dried up, Jackie began to "turn dates," selling sex for money or drugs. Dawn followed suit, learning how to inject by observing Jackie and trading sex for the next high. Her habits became a source of deep disappointment and sadness for her parents, who knew nothing about the molestation. Their lack of awareness fueled Dawn's sense of anger and betrayal, and she continued to distance herself.

DEATH AND LIFE IN THE EYE OF A SYNDEMIC

The environmental and personal turmoil in Dawn's life was occurring precisely when the AIDS epidemic was gaining an early and strong foothold in vulnerable communities, quietly taking up residence in neighborhoods and networks and weaving itself into the epidemiological fabric. Human immunodeficiency virus (HIV) attacks specific cells of the immune system, known as CD4 cells or T-cells, and reduces the body's ability to fight infections and diseases. It is communicable, transmitted through infected blood, semen, breast milk, or vaginal fluids.³ HIV progresses to acquired immunodeficiency syndrome (AIDS) when too many T-cells have been destroyed, and it can be fatal if left untreated.⁴ Worldwide, 36.7 million people live with HIV/AIDS; approximately 1.1 million live with it in the United States, with an estimated 40,000 new infections each year.⁵

From its early stages, HIV has had a disproportionate impact on black communities, and it would be years before the threat was fully understood and aggressively fought with prevention and treatment services.⁶ Despite making up only 12 percent of the US population, blacks comprised 45 percent of both new HIV infections and people living with HIV/AIDS (PLWHA) in 2015. Medical anthropologist Merrill Singer introduced the concept of syndemics to describe overlapping and mutually reinforcing epidemics of drug addiction, violence, and HIV that accompany severe health and social disparities.⁷ Although Dawn's associates in addiction were beginning to talk about AIDS with a note of concern in the 1980s, its early public association with a group that seemed far different from hers prevented Dawn from recognizing the growing syndemic in her midst. "I had no reason to get tested. HIV was a gay white man's disease," she stated. "I was in an all-black community. It didn't affect us. Now the majority of the people that I hung out with are dead."

Ironically, the only HIV prevention message that Dawn recalled from those days was one delivered by a self-appointed public health advocate, an ex-pimp whom she knew who began distributing clean needles to his friends, restocking his supply during appointments at the free clinic. "I don't want y'all to get AIDS," he'd say. We really didn't know what he was saying; we just knew he didn't want us to have it. We didn't really know

what AIDS was. Again, it was a gay white man's disease. So we shared syringes on a regular basis."

Dawn's drug use continued and escalated after that 1985 visit to the hospital with Chyna, but it did not go unnoticed. Having recently come to terms with her sexuality, her first serious girlfriend asked Dawn to leave their shared apartment, insisting that Chyna remain in the girlfriend's care. Dawn agreed, knowing that she was in a deep downward spiral. This would be Dawn's third child to leave her custody. Several years prior, her grandmother, exasperated by Dawn's hard-partying ways, demanded that the son she bore at age 17 live with her. A second son was born three years later in 1981, and Dawn's first cousin offered to raise him. In 1991, yet another daughter would be born and immediately taken by the foster care system. Frustrated and fed up, her family stopped speaking to her, beginning a silence that would last for 16 years.

After exhausting all of her invitations to sleep on the couches of various family members and friends, Dawn ended up on the streets. She became an active trader in a drug and sex market patronized by individuals of every race and class, from the city to the suburbs, but located squarely in the poor black neighborhoods on the south and west sides of Chicago that Dawn called home. "There were a lot of white guys who came through," she recalled, "and a lot of them were looking for dates and to get high." Although Dawn's most meaningful intimate relationships were with women, sex with men proved to be an important economic survival strategy. Encounters with those who wanted to buy both sex and drugs from her were especially lucrative.

Abandoned buildings and hallways became Dawn's temporary homes, and jail served as her way station when she needed a break from the streets: "I could actually tell people when I was coming [to jail], and that was usually when I got tired of living somewhere else. So I'd do something to get arrested." This was a striking testament to how dire things had become: Dawn sometimes saw the brutality and vulnerability awaiting her in jail as a marginal improvement over the brutality and vulnerability that she both experienced and witnessed on the street:

I saw a woman get dragged by a car. I've seen women get beaten and raped. While I was out there, I refused to be one of those women. I fought. When I

was in a car with someone, and I saw him pulling up next to a wall of a building where I couldn't open my passenger door, trapping me inside the car, I'm like, "This is getting ready to get real interesting." And I would just look for any little break, any moment where I could pull out my knife and say, "Okay, now what're we gonna do? 'Cause I have my knife . . . and I'm going to cut it off. So you get one chance to open the door and step out."

Suffering through a life of mental, physical, economic, and social deterioration, Dawn estimates that she experienced more than 50 residential moves after turning 18 years old, driven by "addiction, bad relationships, in and out of jail, stuff like that." Confrontations with fellow members of the underground economy also shaped the patterns of her movements:

I'm originally from the west side, but in my addiction I changed sides of town and changed to the suburbs. [I lived] wherever it was conducive to my well-being at that time. In addiction you have many variables that would initiate you leaving a certain side of town. Running off with people's [drug] packages, owing people money, fighting. So sometimes I had to leave a side of town, and I'd stay gone basically until I figured those people were in jail, and then I'd go back. It was different . . . just everything that went with addiction.

For years, Dawn lived in this brutal cycle of drug addiction, survival sex, incarceration, and sometimes sincere, sometimes half-hearted, attempts at avoiding drugs. Shifting in and out of sobriety reflected a desire to stay clean, but the emotional scars of childhood sexual trauma and the toll of life on the streets could be papered over only so long before the pain required numbing.

Old News Becomes New Again

In 1992, seven years after her initial diagnosis, Dawn was arrested for knifing a customer who attempted to sexually assault her. It was a sad irony that the incident that finally led this survivor of childhood sexual abuse into extended incarceration had to do with her forceful resolve to fight back against a subsequent violation—her girlhood experience setting the stage for how she interpreted, experienced, and attempted to resist sexual violence later in life.⁸ Instead of one of her relatively short stints in

the Cook County Jail, she was sent to prison, where she experienced her second HIV diagnosis:

In the penitentiary, when I went in they asked me, “Have you ever had tuberculosis?” . . . I’ve had TB. And the nurse goes, “Well, we’ve got to test you for HIV.” I’m like, “Okay.” And it didn’t register that I’d already had this test. I didn’t know what HIV was, what it meant to be HIV positive. So when they called me back to the clinic, she goes, “Ms. Stevens, you have HIV.” I’m like, “Okay.” And she goes, “Is there anything you need?” “No.” And, again, that was the end of it. There was no explanation. I still didn’t know any more than I did the first time I got tested. So . . . now two tests with no information.

Dawn served her time, aware of her status but unaware of its seriousness. She told no one. “I didn’t know *what* to tell anybody,” she shrugged. Upon her release three years later, Dawn completed a county-sponsored HIV education program, a requirement for being granted visitation rights with Chyna, who had been living in foster care since Dawn’s ex-girlfriend died. A whopping ten years after her first HIV diagnosis, the county program served as Dawn’s first substantive orientation to her condition. By this time, AIDS was the leading cause of death for all Americans aged 25 to 44.⁹ The program initiated Dawn’s efforts to grapple with the meaning and significance of her diagnosis. As she explained in her characteristically frank style, Dawn felt a sense of resignation, even acceptance: “When I finally began learning about HIV, I was surprised, but not really, because I did everything you could do to get it. I had unprotected sex. I was an intravenous drug user. I did everything possible to get it. . . . I don’t question where it came from. I mean, there were so many people that I got high with, it’s hard to say.”

The program facilitators informed Dawn about the practical implications of living with HIV. “[They told me] that I was going to have it for the rest of my life, and that there were things that I had to do, such as start sleeping again. I needed to take better care of myself.” Dawn knew this would be easier said than done. Homeless, estranged from family, struggling with drug addiction, and embedded in a world of criminal activity with few opportunities for second chances—just living, let alone living with HIV, would be a feat. “They’re not supposed to release you to the streets, but they do,” she commented about her post-incarceration experience. “I ended up at a shelter, and they had no idea what HIV was. They

had no idea what to do with an HIV-positive person, especially someone who was out about their status.”

Dawn stayed clean for stretches, securing a spot in a transitional housing facility run by Catholic nuns, regaining custody of Chyna, and celebrating almost two years of sobriety by the late 1990s. But she struggled to fully escape the uncompromising grip of the drugs. She started using again, pawning everything she owned to support her habit. She lost her job at a small nonprofit, her apartment, and custody of her daughter within a span of six months. Chyna, Dawn explained, “was smart enough at 12 to tell a teacher that I was using, so [Child Protective Services] came and got her.”

This time when Dawn returned to life on the streets, she understood that she was also living with HIV. Negotiating that status as a sex worker in the drug economy would prove to be difficult:

In that life, the men have the power. Because the men have the money, very few women who are out there are going to say no when the guy doesn't want to use a condom. You know the risk to yourself, “But right now, I need that money.” So, okay, [he doesn't] want to use a condom, that's on him. It's easier to let him do what he's going to do without the condom and be gone. And you get high and don't even think about it anymore, 'cause you gave him an opportunity to protect himself and he chose not to. . . . And you don't want to argue about condom use. [If you do], first thing they go, “Why? You got something?” That's the last thing you need, a rumor in the neighborhood that you got something. So you go along with it. And knowing that I have HIV, and you're not ready to use a condom may in some way also give me some satisfaction for you berating me, “Yep come on, let's do this, I got ya,” you know. Sometimes that in itself is a high for the woman. It's about who holds the power.

Dawn's health suffered grievously over this period as she was entangled in what I term the sexualized drug economy. She ignored the advice she had received in the county program. She barely slept. “In addiction, nobody thinks about health. When you don't feel good, you get high and you feel better. The depression comes when you're coming off the drugs. So you take another hit and you feel better. I was smoking crack all day, every day.” She became a frequent patient in emergency rooms with fevers and opportunistic infections. During a particularly low moment, Dawn attempted suicide by washing down an overdose of antidepressants with tequila, feeling hopeless

about the tailspin that she was in and physically worn down. At this point in time, Dawn had so few T-cells that she was diagnosed with AIDS.

As the Bottom Drops Away, Caught by a Safety Net

Dawn's 1999 stint in St. Mary's, a housing facility for women struggling with both HIV/AIDS and drug and alcohol addiction, helped her turn things around. At 38 years old, and 14 years after her initial HIV diagnosis, Dawn knew that she desperately needed another chance to change course. It was perhaps nothing short of a miracle that she had made it this far, her body bruised, somehow managing to survive on a steady diet of illegal drugs and no consistent HIV medication regimen. When she was released from the hospital after overdosing, she begged St. Mary's to take her, having previously used it as one of her temporary way stations when she was deep in her addiction.

This time, Dawn actually took her time, staying at St. Mary's for two full years to get strong enough to make it in the world without numbing herself with drugs. She began systematically gathering the tools she would need to change her life's course. She finally absorbed and accepted the incompatibility between abusing drugs and alcohol and managing HIV and got clean: "I realized that doing drugs was killing my body more [than HIV]. I decided that I wasn't ready to die. I didn't want HIV to take me out. So I had to stop getting high."

Further radical changes would be necessary. Dawn became a proactive advocate for her health, approaching the healthcare system with a new mindset: "I paid my physician a visit. I did my research and had this list of unacceptable HIV medications [those that people were saying were the most toxic]. It just so happened that my doctor and I were on the same page. She recommended the same medications that I was thinking about trying out. So that was a good beginning for us because she had just become my doctor."

Her stay at St. Mary's also enabled Dawn to meet a fellow resident named Raquel. "[I had a lot of] jailhouse relationships, a lot of relationships in my addiction. I guess my best relationship was with cocaine. So nobody else had a chance with that," Dawn reflected. Raquel represented something different and soon became Dawn's romantic partner: "She was in recovery, I was in recovery. The relationship didn't initiate in jail, it didn't initiate in my addic-

tion.” Meeting at a transitional facility for women living with HIV/AIDS also eliminated the challenging work of HIV status disclosure. “I guess my mind told me that it was time to actually look for a long-term relationship,” Dawn explained. “I wanted to stop doing things the way I used to do them.”

Putting the Pieces Together

Dawn’s decision to “stop doing things the way she used to do them” applies to many aspects of her life, not just her romantic partnerships. When in 2005 Dawn enrolled in the research study for this book, just six years from living on the streets, the distance between her former and new life was vast. Up most days at 6:30 a.m., Dawn now concentrated on family and her extensive work in the HIV advocacy community. Dawn and Raquel had moved out of the St. Mary’s facility in 2001 and remained in a deep and loving partnership, two souls who counted on each other as they created new ways of existing in the world. Like any couple, they had their pet peeves. Raquel found it endlessly frustrating that Dawn so often turned off her cell phone or refused to answer it. “But then Raquel will answer my phone for me and go, ‘Here, it’s for you.’ Well, no shit, it’s *my* cell phone!” Dawn laughed. But Dawn saw this period, with Raquel by her side, as one of the best of her life. There was someone in her life who cared about her, who “kept her in line,” and who wouldn’t allow her to withdraw into herself. Perhaps that was at the root of their tiffs over the phone. Part of their new life was reminding each other that they had obligations that mattered and loved ones to whom they were accountable.

While in the throes of addiction, Dawn’s four children were taken away one by one. When our research team met her, she and Raquel were the trusted caretakers of a four-year-old girl named Daisy, whose teenage mother had asked Dawn and Raquel to care for her when Daisy was just six months old—the same age Chyna had been when Dawn was first diagnosed. This time things would be different. “I did the potty training, I got her out of diapers, all the shots, the doctor visits. We read together. Raquel likes to let Daisy help her cook. When we got her, she was rocking and pulling her hair out. She’s stable now, mentally, physically, and emotionally.”

Dawn’s personal story also led her into political work. After leaving St. Mary’s and throughout the decade during which my research team

followed her, Dawn has been a prominent voice in the HIV community, a trusted leader. She has traveled the country speaking about HIV prevention, met with politicians to advocate for increased funding for AIDS programs and services, and served on the boards of some of the most prominent national and local HIV organizations. “I think my real work comes from being an activist and an advocate,” she commented. “The only risky behavior that I do now is telling a politician what I really think of him.”

As her political engagement built up both her confidence and her network, Dawn parlayed her volunteer work into paid employment in several human service organizations, addressing issues ranging from domestic violence to homelessness to HIV. She has worked as the assistant director of a small housing program, a case manager, and a personal assistant for other PLWHA.

Over the course of ten years, my research assistants and I would interview Dawn more than half a dozen times, tracing her health, social, economic, and political transformation.¹⁰ When we met, her graying hair reflected a 20-year journey with HIV, which evolved into a 30-year journey by the time we conducted our last interviews with her in 2015. As of this writing, Daisy is 14 and thriving under Dawn’s care. Sixteen years free of alcohol and illegal drugs, Dawn still bears the scars of her previous life, walking with a cane and struggling with a variety of old injuries. However, she has an undetectable viral load, indicating minimal presence of HIV in her bloodstream, which she controls with only one prescribed pill daily, a far cry from her once 25 -pill daily regimen.

Since the turning point that she experienced at St. Mary’s, Dawn has embarked upon an extensive process of learning how to live with HIV, reluctantly but successfully weaving it into the fabric of her life. During one of our conversations, Dawn offered this challenging assessment: “If it weren’t for HIV, I’d probably be dead.”

REMAKING A LIFE AS A TRANSFORMATIVE PROJECT

Dawn’s statement represents the fundamental puzzle at the center of this book. The admission may sound shocking, fodder for those who would use Dawn’s words to dismiss or pathologize her. But it would be a mistake to

interpret her comment as evidence of intrinsic deviance or as romanticizing or downplaying the devastation of AIDS. Her statement calls for a nuanced analysis that reveals what underlies such a challenging assertion, contextualizes it, and gleans important lessons. Her words are also deeply ironic: how can a life-threatening illness, responsible for the deaths of millions around the world, actually help *prevent* a death?

In Dawn's assertion, she is reflecting on the asphyxiating chokehold of drugs. Addiction, with its roots in her history of childhood sexual abuse, was shaping every aspect of Dawn's life, from her tools of economic survival to her residential choices to how she formulated, sustained, or damaged relationships with friends, family, and intimate partners. Dawn's broader environment, lacking many opportunities and resources, also posed obstacles that she addressed through a variety of coping and survival strategies that were destroying her health. Over time Dawn came to see that HIV would require her to manage her health differently if she had any chance of surviving. But addressing the diagnosis would also demand new ways to navigate the economic psychological, and social hurdles that had previously hobbled her. HIV rendered Dawn's prior coping and survival strategies untenable. Acknowledging her past, Dawn nevertheless chose to create a future for herself by living another kind of life.

Talking with women living with HIV/AIDS (WLWHA) for more than a decade, I heard countless stories like Dawn's, the trauma and struggle perhaps not surprising given the devastation wrought by AIDS and the dynamics that fuel the epidemic. But I also heard stories of transformation. Women in my research talked about following a trajectory that began with *dying from* HIV/AIDS and took them to *living with* and even *thriving despite* HIV.¹¹ I became deeply curious as the number of transformation accounts grew. Were the women simply offering rationalizations and positive thinking to combat this potentially terminal disease? Was this merely a story about the effectiveness of highly active antiretroviral therapy (ART) and other medical discoveries? Or was something else happening—something that would shed light on the larger question of what it might take for us to ameliorate the wounds produced by social and economic disadvantage and psychological trauma?

Explaining transformation—what supports it, what obstructs it, and what happens when people are able to achieve it under difficult conditions—is the central goal of this book. We will bear witness to women's transitions

from severe and compounding crises—the body blow of a health diagnosis that is at once life-threatening and highly stigmatizing, sexual trauma, chronic unemployment, homelessness, and drug addiction—to major successes such as dramatic improvements in health, the rebuilding of familial ties, hard-won economic stability, civic engagement, and leadership that speaks truth to power. We will compare and contrast these stories against a broader array of experiences among WLWHA to consider how social and economic marginalization (and privilege) cast a unique frame around an HIV diagnosis. Notably, the HIV diagnosis on its own was seldom the direct catalyst for radical life changes and transformation: a surrounding set of social processes drove the more profound shift that Dawn and others experienced.

Alongside the women's stories of transformation, this book therefore presents a second, equally important narrative of change. The companion story to the remarkable life transformations experienced by many of the women I follow in this book is the transformation, over the same period, of the epidemic that threatened their lives. The extraordinary conversion of HIV/AIDS from an inevitable death sentence to a manageable chronic illness in well-resourced countries like the United States is not only one of the most noteworthy medical achievements of the past 35 years, it is also a significant social achievement. AIDS activists and advocates on the front lines of the domestic and global response have confronted a deadly disease and battled a political climate that ranged from unequivocally hostile to dangerously complacent. They pushed the medical community and governments around the world to invest significant dollars in research and shaped a public dialogue that increased awareness and pushed HIV/AIDS high up the list of societal concerns during some of the epidemic's most destructive periods.¹² Activists, advocates, and government officials drove important bipartisan policy gains, such as the Ryan White CARE Act, the AIDS Drug Assistance Program (ADAP), expansions of the Americans with Disabilities Act, the President's Emergency Plan for AIDS Relief (PEPFAR), and the National HIV/AIDS Strategy (NHAS). Perhaps one of the most important but under-recognized outcomes of this mobilization was the emergence of an extensive HIV safety net (HSN) of human service providers and other entities who would prove vital for individuals

confronting difficult circumstances by offering four things: access to healthcare, modest economic assistance, extensive social support, and a path to political and civic engagement.

“If it weren’t for HIV, I’d probably be dead.” In fact, what undergirds Dawn’s provocative comment is the community and infrastructure that afforded her the opportunities—and perhaps more importantly, the resources—to personally heal from, economically and socially navigate, and politically confront inequality, trauma, and their associated wounds. Dawn and many women like her had sustained so many blows throughout their lives that they were dying from their cumulative effects even before they were diagnosed with HIV. Rarely, if ever, had they been offered the kinds of openings that would give them the chance to repair these wounds. In the HIV/AIDS community, Dawn and others would find an unexpected place to create their lives anew.

Confronting Injuries of Inequality

Injuries of inequality—big and small wounds to personal, familial, and community well-being—represent the mental, physical, and social toll of acute inequity. They are the cumulative markers and scars of economic and social marginalization, the visible and invisible evidence of disadvantage.¹³ Injuries of inequality have dimensions shaped by gender, race, class, and sexuality, as the likelihood of occurrence is not random but shaped by where we are on the social hierarchy. The brutal truth deserves emphasis: *Injuries of inequality produce, and are produced by, a compromised ability to protect oneself from harm.*

Scholars of social inequality have extensively analyzed the mechanisms that inflict injuries on disadvantaged groups through processes such as mass incarceration, residential segregation, and chronic unemployment. We document the injuries themselves and their short- and long-term implications by examining experiences and outcomes related to education, health, housing, and economic well-being. Researchers also consider how individuals and communities respond to these injuries, identifying processes of identity formation, everyday survival, struggles for mobility, and political resistance in a context of constraint and confinement.

But how do women remake, not simply rebuild, their lives after traumas produced by injuries of inequality? Rebuilding suggests a return to a prior state. Remaking, however, is much more dramatic; it is transformational. We often think of significant life transformations as highly personal and perhaps even spiritual experiences. In this book I argue that life transformations are also deeply *social* events—negotiated processes influenced by the people, places, and public policies that we encounter.

By analyzing the lives of women living with HIV/AIDS as they grapple with their pasts while creating a future, this book delineates what I term the *transformative project*. I define the transformative project as a multidimensional process by which individuals *fundamentally shift how they interpret, strategize around, and tactically address struggles related to complex inequalities that affect their everyday lives*. It entails adopting a radically different set of approaches to negotiating questions of physical, social, economic, and political survival. To remake their lives, women alter how they engage in interpersonal interactions, with institutions and communities, and even with public policy, to create meaningful change over time. The transformative project typically incorporates several meaningful changes in multiple arenas of life and thereby generates a new *modus operandi*. The transformative project represents one's active and purposeful physical, psychic, economic, and social restructuring after being pummeled by some of the harshest blows of racism, poverty, sexism, and homophobia.

At its core, the transformative project does not target personal transformation as an end in itself, what we commonly think of as “self-help.” It is not about “fixing” alleged deficiencies. Nor is the transformative project a repackaged elixir of “bootstrapping” personal responsibility. Rather, the transformative project is about the integration of individual agency with environmental networks, institutions, and public policies. By charting that sociological process, including the resources women leverage and the barriers they confront, my work explicitly challenges the highly individualistic personal responsibility frame that dominates discourse about both HIV/AIDS and social/economic disadvantage. Therefore, this book analyzes how marginalized or stigmatized individuals use their power, however limited, to create dramatic and positive personal and social change while simultaneously engaging with the social, political, and economic conditions they seek to escape or alter.

The Launch of a Transformative Project

How did Dawn effect such a radical and dramatic change in the trajectory of her life? What accounts for her movement from *dying from*—a state of extreme physical, emotional, economic, and social distress—to *living with* and even *thriving despite*, in which she is taking a leadership role in her community, building a strong family, and significantly improving her physical and mental health? It would be tempting to say that once Dawn decided to change, her circumstances improved, but this explanation would be incomplete. Her story points instead to clear relationships among the cognitive shift that determined for Dawn that “something had to change,” a set of institutional relationships and public policies that anchored and supported that shift, and a fresh *modus operandi* comprised of newly adopted economic, social, and health strategies that are sustained over time. These factors together appear to have been necessary conditions for the success of Dawn’s transformative project, illustrated in figure 1.

Dawn suffered daunting injuries of inequality, from childhood sexual abuse to the frustrations and stresses of operating in a resource-deprived context in which her health, social incorporation, and economic prospects deteriorated with each dramatic turn of events. Life’s traumas had become embodied, coursing through Dawn’s mind, body, and spirit. Her cognitive shift came when she acknowledged that her coping and survival strategies—self-medicating and living on the streets—were killing her. Managing the pain and stress of living in a context of unrelenting injury had become exhausting:

I wanted to do something different. Drugs were flowing freely in the neighborhood when I started getting high. At some point, they stopped flowing as freely, and I had to get out and hustle for them. And that got old. I guess if I had not had the mindset to want to do better, I’d probably either be dead or still locked there in my addiction. Because there’s a lot of women who couldn’t handle the frustration or the pressure that being in a sober environment 24/7 would put on them, and they would just disappear. So you definitely have to have your mind made up.

Nevertheless, it took more than a change in mindset to transform Dawn’s situation. Along with the medical and pharmacological discoveries that evolved in the decades since Dawn’s initial HIV diagnosis, a safety net

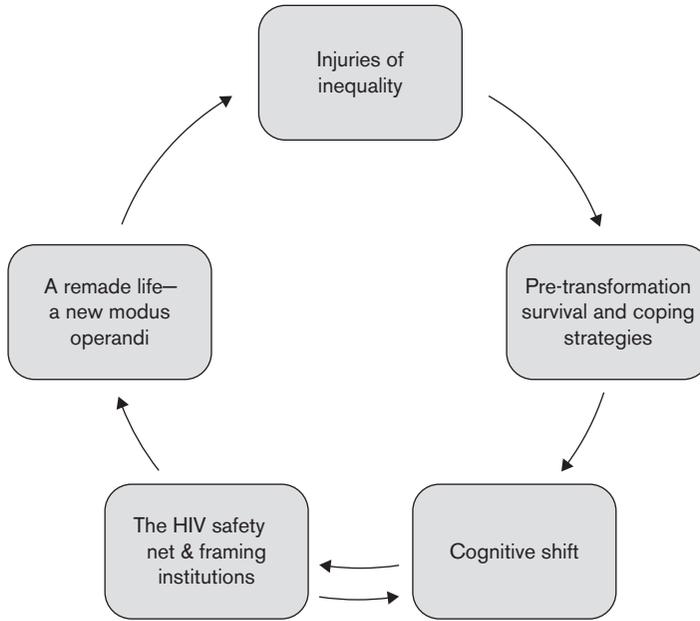


Figure 1. The transformative project.

emerged that offered Dawn new strategies and tools for confronting the deadly triad of sexual trauma, poverty, and HIV/AIDS that illegal drugs no longer helped her escape. Perhaps the deadly risk of AIDS created the final spark of urgency, but it was the institutional infrastructure that supported the change.

As a part of the HIV safety net, St. Mary's provided a roof over Dawn's head for two years as she embarked on her transformative project and reconstituted the pieces of her life. It surrounded her with people who were struggling through transformations of their own, allowing her to meet Raquel, who would become a major source of support. As an institutional broker, St. Mary's also connected Dawn with a network of HIV service providers who would help her survive physically by introducing her to a physician who perfected her HIV medication regimen, survive economically by assigning her a case manager who helped her access financial resources, and survive socially by connecting her to HIV support groups.¹⁴ Those relationships then facilitated her entrée into the city's

AIDS activist and advocate network, which she used to achieve a measure of political influence and economic opportunities.

Support from those institutional relationships gave Dawn the freedom she needed to explore different pathways, validate her newfound operating approach, and sustain it over time as her new *modus operandi*. Consider that when they left St. Mary's in 2001, Dawn and Raquel had to find a place to live. A local AIDS organization provided Raquel with a subsidized housing voucher via lottery and renewed the assistance for more than a decade, reducing their rent in 2015 from \$750 to \$375 per month. Dawn's case manager helped them find an apartment on the north side of Chicago, a short train ride from Boystown, home to many in Chicago's LGBTQ community and a cluster of AIDS service organizations. Residential migration from the far south and west sides of Chicago to the north and near south side of town occurs fairly commonly among the WLWHA in this book, as they gravitate toward their institutional support services.¹⁵ Dawn's relocation from her former neighborhoods would unfortunately take her away from her community just as she was beginning to thrive, yet it also meant moving away from memories of her life as an addict and those who did not necessarily support her new path.

After settling the issue of long-term housing, Dawn adopted additional health-management strategies. From their new apartment she and Raquel were able to move throughout the city using free bus and subway cards courtesy of Dawn's case manager at St. Mary's. This helped Dawn and Raquel make doctor's appointments, attend support group meetings, and buy groceries. The physician who prescribed a viable medication regimen when Dawn was at St. Mary's referred her to specialists to address some of her other health concerns, all of which were covered by Medicaid. Dawn then began seeing a therapist, working hard to repair the emotional injuries and process the sexual violence she had experienced.

As former participants in the drug economy, Dawn and Raquel next had to fashion less risky economic survival strategies. Raquel's health challenges qualified her for Social Security disability assistance. Dawn worked in several nonprofits until chronic and severe back and hip pain qualified her for Social Security disability benefits as well, albeit after a long fight to demonstrate her eligibility. Like many women we will meet in this book, Dawn also leveraged her experiential capital. She utilized the

knowledge and wisdom derived from traumatic events to lend her voice to the HIV/AIDS advocacy community, generating speaking engagements and volunteering to participate in research studies that offered stipends.

To be sure, Dawn describes her family even now as living “barely above the federal poverty level,” and life is by no means easy. Nevertheless, Dawn’s new financial strategies offered greater physical safety and a fundamentally new approach to managing economic stress:

It’s like my sponsor says, the devil tries everything to get you to come back to his way, but he doesn’t have any new tricks. I had my car repossessed last night. . . . That’s an old trick, I’m not falling for it. [Back then], I didn’t have money for rent, credit cards, light, gas, car note, any of that, and I just gave it all up to get high. Wander the streets and be homeless, but at least I had no responsibilities. But I also had very little contact with my children. So it’s just not worth it. I’m just not there today . . . been there, done that.

Notably we are not observing socioeconomic mobility here, marked by substantial gains in education, income, or wealth that sociologists typically count as legitimate mobility. Rather, Dawn’s mobility is animated by a transition from *dying from* to *living with* injuries of inequality, including HIV. The transformation enhanced Dawn’s social status through her community work. Most importantly, however, it generated improvements in well-being, with better housing, a consistent source of income, improved physical and psychological health, and socially supportive relationships. Once she reached this level of stability, Dawn was much better equipped not simply to cope with but also to confront injuries of inequality by supporting other marginalized women and by becoming politically active.

The area of Dawn’s life that seems the hardest to repair and remake, a place where her transformative project has its limits, involves her relationships with her biological children. She worked hard to reconnect with them after getting clean. Chyna, now 28, played an important role, serving as the family’s anchor by keeping in touch with her siblings while their mother struggled for all those years. As the child who had the most extensive contact with Dawn growing up, Chyna “saw a lot of stuff, and I had to explain a lot of stuff,” Dawn lamented. The family is just beginning to talk about the trauma—sexual and otherwise—that Dawn’s

children experienced as they were moved from home to home as children. Dawn cannot discuss the pain and guilt of that reality without becoming emotional.

Dawn's sons, now 35 and 33 years old, and her other daughter, now 22, each engage with her very differently. None of Dawn's children is HIV positive. When her oldest son Damon learned of Dawn's status from a gossiping relative, he dismissively told his mother that he could have gone his entire life without finding out. Her youngest son Devon is also unwilling to talk about it, but he will occasionally check in to ask if Dawn is taking her meds and will visit to see how she's feeling. Twenty-two-year-old Delisha lives in another state. During one of our last interviews in 2015, Dawn had just returned from visiting Delisha, who allowed her daughter Talia to travel with Dawn back to Chicago to visit the rest of the family in the city, an encouraging show of trust.

Dawn did not glean positive results from all of her institutional relationships. In some instances, institutions failed. For example, the prison where Dawn spent years knowing that she was HIV positive gave her little information about the illness, and the homeless shelter appeared to have no protocols in place to assist clients with HIV/AIDS. Later in the book we will explore how institutional failings threaten to undermine transformative projects.

We see in Dawn's case, however, many more instances in which institutions played pivotal and positive roles in her transformation. I once asked Dawn to recall a time in her life when she felt most accepted as a WLWHA. She described being elected to the city's HIV Planning Council, a federally mandated advisory group of service providers, public health officials, and affected community members that establishes service priorities for allocating Ryan White CARE Act Title I funds.¹⁶ These dollars provide medical and social support services for PLWHA: "With the planning council, it didn't really matter that I was HIV positive," she explained. "It was important, obviously, but not as important as who I was and what my capabilities were. Plus you get elected by the other people that are on that body, and they've got to think a lot about you to make you one of the spokespersons on HIV for the entire city." After surviving sexual abuse, homelessness, drug addiction, and sex work in a community struggling with its own trauma, Dawn has remade her life.

TOWARD A SOCIOLOGY OF THE
TRANSFORMATIVE PROJECT

Many narratives of the lives of the “truly disadvantaged” adopt the metaphor of being “stuck,” which is understandable given the massive structural forces that conspire against economic and social mobility for these individuals.¹⁷ The dynamic changes in life trajectory that people seek are not, however, confined to gains in education or income. What do we miss when we fail to account for other kinds of major shifts in the lives of those who have suffered massive injuries of inequality? The movement from *dying from* to *living with*, which entails radically reconfiguring physical, emotional, economic, political, and social survival strategies to grow and achieve a new level of stability, is not limited to WLWHA. Such a framework can help us understand how many individuals resist marginalization.

A growing body of social science literature captures life transformations in disadvantaged contexts, such as Edward Orozco Flores’s *God’s Gangs*, Laurence Ralph’s *Renegade Dreams*, Rob Sampson and John Laub’s “Desistance from Crime over the Life Course,” and Sharon Oselin’s *Leaving Prostitution*.¹⁸ While not yet explicitly advancing what I term a sociology of transformative projects, these texts nevertheless share several features that contribute to my framework. First, they identify significant environmental challenges that constrain everyday life and long-term opportunity and demonstrate how those forces inflict injuries of inequality upon those in their path. Next, they explicate the adaptations of individuals living under these conditions and explain how their adopted strategies further undermine quality of life and life opportunities. Some behaviors, such as gun violence and drug dealing, are illegal. Others, such as certain sexual behaviors, are not illegal but are high risk.¹⁹ These strategies prove threatening to individual health as well as to the overall health of families and communities.

This scholarship diverges from much of the urban poverty and inequality literature by focusing on the social processes through which these same individuals later seek out alternative strategies and ways of being after previously adopted practices become problematic. Orozco Flores documents, for example, the processes by which young Latino gang members—immigrants or the descendants of immigrants struggling to make it in

postindustrial Los Angeles—exit gang life by cultivating a reformed barrio masculinity through religiously oriented recovery programs. The men advance “redemption scripts,” describing their transformations in their own terms and carving out new spaces of legitimacy in a social context that often pushes them to the margins. To be sure, texts that document what I am calling transformative projects explicitly and implicitly challenge explanations that posit a pathology that must be “fixed.” Through nuanced ethnographic work, these authors show how transformation efforts—like the originally adopted strategies—are deeply embedded in context, and the authors emphasize both policies and conditions that marginalize and those that facilitate positive movement.

These studies documenting life transformations offer valuable evidence of their potential to improve lives, but we lack an overarching theory or conceptual framework that captures this process of transformation across injuries of inequality. Although the “crisis points” may differ—an HIV diagnosis, incarceration, a life-threatening gunshot wound—the similarities between the underlying causes and the dynamic process of dramatically changing one’s strategies after a life-altering and traumatic event beg for a more systematic explanation. More specifically, we must shift away from life transformation narratives that focus solely on the individual. From the truly disadvantaged to the “one percent,” the structural scaffolding on which transformations are built is too often masked, providing the false impression that the individual is the sole architect of the change we witness.

I believe that the transformative project framework can help us understand many situations in which individuals radically restructure their lives. These undertakings represent the integration of agency—beliefs, strategies, and action to inspire radical life change—with environmental networks, institutions, and public policies that support these efforts. Yet we can distinguish transformative projects from other major life shifts insofar as the restructuring alters how one responds to and navigates complex inequality. The framework is therefore a theory about power relations, revealing how individuals shift their responses to social marginalization at the societal, institutional, and interpersonal levels.

Is a life-threatening condition a necessary antecedent to a transformative project? No, as any individual who embarks on a deliberate effort to improve upon the strategies they have used in the past to confront

inequality is engaged in a transformative project as long as we see evidence of a cognitive shift; engagement with people, institutions, and policies that provide new strategies, networks, and resources; and a fresh *modus operandi*. It is likely, however, that a life-threatening issue heightens the urgency and stakes involved in such a transformation.

Remaking a Life therefore addresses central questions in sociology, public policy studies, public health, African American Studies, social work, and gender and sexuality studies by exploring the complex relationship between social, economic, and political inequality and health; the emergence of effective safety nets in sometimes unexpected places; and the radical possibility that those suffering from marginalization might imagine and experience their lives anew after devastating and multiplicative injury. It is often through this reimagining and reshaping process that some of the most effective organizers, thoughtful critics, and energized community leaders emerge.

As I explicate the sociology of transformative projects and unpack the mechanisms that drive this process, I use an intersectional lens.²⁰ Black feminist and legal scholar Kimberlé Crenshaw is widely credited with coining the term *intersectionality*, building on the work of feminists of color who challenged single-category thinking about identity and group status and emphasized how race, class, gender, sexuality, and other social identities operate simultaneously to shape individual social experiences and large-scale societal dynamics.²¹ An intersectional approach reveals interlocking power dynamics and demonstrates how they are shaped by our societal approach to sameness (embrace) and difference (hostility).²²

Scholars have conceptualized intersectionality as a theory of power relations, a methodological imperative to uncover interlocking inequalities, and a political perspective that resists oppression in all forms.²³ With its roots in black feminist scholarship and activism, intersectionality allows us to present robust theoretical and empirical analyses of identity, representation, and narrative, especially as they manifest in the lives of marginalized populations.²⁴ These three themes will arise often here, as a common goal of intersectional work is to critique powerful public discourses and stereotypes that limit and distort the realities of women, people of color, LGBTQ individuals, low-income people, PLWHA, and any others who inhabit multiple marginalized statuses. The concept operates in several disciplines, including legal

studies, sociology, public health, ethnic studies, gender studies, queer studies, history, psychology, social work, and anthropology. It is also a driving principle of feminism and other forms of activism and will emerge in this book as an important value and tension point within AIDS mobilization.

While this book documents and analyzes several impressive transformative projects, it also highlights the hurdles and obstacles associated with these transformations. In spite of the agency that the women with whom I spoke exercised, racism, sexism, poverty, homophobia, and HIV stigma remain powerful forces, shaping their opportunities and experiences. Women's progress in transforming their lives does not inoculate them from the punishing hurdles that continue to confront them. Moreover, they continue to cope with a serious health issue that can kill them if not appropriately managed. For all these reasons, the process of remaking a life is not rapid or linear. Rather, it is best characterized by fits and starts, periods of marked improvement followed by crushing setbacks. In this book, I demonstrate the hard work involved in testing and struggling with new strategies. Moreover, some women we will meet were unable to move beyond the shock of diagnosis and other traumas to launch successful transformative projects. In those cases, I attempt to explain why they remained locked in destructive and heart-wrenching patterns.

Notably, therefore, *Remaking a Life* is not a story about upward mobility, a well-trod area in sociology and other disciplines. The women in this book by and large do not experience major leaps in socioeconomic status. But many *do* experience a noteworthy and radical movement from social, and in many cases almost physical, *death to a life* in which they are much more stable and better positioned to confront structural barriers in their paths. Their survival represents a form of resistance as they have cheated a presumed "death sentence" and withstood additional traumas that threatened to destroy them. Such movements in life trajectories are grossly under-analyzed in the sociological literature despite their fairly frequent occurrence. With my theory I therefore attempt to recognize the agency of social actors living in difficult contexts, highlight and account for the possibility of dynamic and significant change in the lives of stigmatized individuals that disrupts the narrative of stasis, and analyze the policy and institutional infrastructure that facilitates (and sometimes undermines) these transformations.

STUDYING THE HIV/AIDS EPIDEMIC

For years, I have been intellectually and socially engaged in the continuing struggle against the AIDS epidemic. In the late 1990s, I was working on a project exploring the effects of the 1996 welfare reform legislation on the lives of low-income women, and one of the women whom I interviewed several times was living with HIV. Although I would develop the terminology to describe what I was observing later, I immediately understood HIV/AIDS as an injury of inequality, as those most affected were often already marginalized. But I was also struck by how her social networks, institutional ties, and access to resources differed so markedly from those of other low-income women in our sample. The seed was planted that I might be observing a safety net in action that was very different from the weakening welfare system, one that represented an alternative approach to offering support to vulnerable populations.

In 2005, while completing my book on the welfare system (*The New Welfare Bureaucrats*), I began conducting interviews and participant observation with black cisgender women living with HIV/AIDS (WLWHA) in Chicago. Over the course of a decade, my research team and I expanded this work, culminating in interviews with over 100 WLWHA of diverse racial, ethnic, class, and sexual identities and backgrounds in Chicago. We also conducted interviews with over 75 AIDS activists, advocates, policy officials, and service providers working at both the local and national levels.

By analyzing a series of transformative projects, this book captures how women have fought for survival in the epidemic and claimed their space in the organized AIDS response. Although the virus was understood in the beginning as a “gay man’s disease” in places like the US, women constitute *more than half* of all adults living with HIV/AIDS worldwide.²⁵ Yet, historically, they have not been centered in global research, prevention and treatment initiatives, or AIDS policy. This is especially so in the United States, where women currently account for one in five new HIV diagnoses and deaths caused by AIDS.²⁶ I focus on women to highlight and analyze their role and significance, not only as PLWHA but also as steadfast and effective (but largely unacknowledged) advocates, activists, policy officials, and service providers in the epidemic from the earliest recognition of the disease.

Black women have been disproportionately affected by the HIV/AIDS epidemic. In January 1983, when the Centers for Disease Control and Prevention (CDC) documented the first two cases of AIDS in women, one woman was black and the other was Latinx.²⁷ When I began this research in 2005, black women comprised 37 percent of Chicago's female population, but they accounted for 80 percent of female HIV diagnoses; and HIV/AIDS was the number-one cause of death for black women aged 25 to 34.²⁸

More than a decade later, racial disparities persist. Among all US women with HIV diagnoses in 2015, 61 percent (4,524) were African American, 19 percent (1,431) were white, and 15 percent (1,131) were Latinx. That year, HIV/AIDS was the fourth leading cause of death among black women ages 35 to 44, before diabetes, stroke, and homicide. Younger generations of black women continue to be affected, as HIV/AIDS remains one of the leading causes of death among those in their twenties and early thirties, while women from other racial backgrounds have fortunately seen the illness drop below their top ten leading causes of death.²⁹ Black women have also been unsung leaders and foot soldiers in HIV/AIDS activist and advocacy work. For these reasons, their experiences constitute a central part of this analysis. *Remaking a Life* takes readers deep into the lives of four black women to trace the what, why, and how of transformative projects using data collected through more than ten years of engagement, from 2005 into 2015. Dawn's story is presented in this chapter; in subsequent chapters I present the stories of Keisha, Beverly, and Yvette.

Many women living with HIV/AIDS have experienced multiple injuries of inequality. For them, the diagnosis was unceremoniously added to a long list of urgent concerns. For other women, the HIV diagnosis is a stunning setback, an experience that contradicts the relatively smooth trajectory they believed they were following. They come from a range of racial and ethnic backgrounds. Many do not have histories of drug use or sex work. Some are quite well-off economically, with high levels of education and white-collar jobs. Others contend with the added dimension of immigration status as they seek assistance to address health concerns. Hearing from a diverse group of women enables us to consider what it means to confront HIV and other difficult life events from multiple vantage points.

Therefore, in addition to Keisha, Beverly, and Yvette, we will also follow Trisha, a white Canadian immigrant who launched a transformative project

after the trauma of childhood sexual abuse, and Rosario, a Latina whose experiences were also shaped by her engagement with the HIV safety net. Alongside these central storytellers, I present the words of other interviewed women throughout the book. I also offer my observations as I accompanied some interviewees to medical appointments and support group meetings, sat in the audience during speaking engagements when they told their stories, and visited them in their homes. All of these women had to consider whether and how to transition from believing and behaving as though they have been given a death sentence at diagnosis to interpreting and coping with HIV as a chronic but manageable illness. As they reflect on the physical, social, economic, and political impact of HIV/AIDS on their lives, we will see how the disease's imprint extends well beyond the issue of health.

Remaking a Life uses the case of HIV/AIDS to advance a conceptual and policy framework for improving women's social well-being. The creation of what I call the HIV safety net, as a political and institutional response to human crisis, is noteworthy for the lessons that it offers. The HIV safety net funnels medical care, social services, and opportunities for political engagement to people living with HIV/AIDS and those at higher risk of contracting the disease. Undergirded by the initial mobilization and support of activists, the HIV safety net now functions through a three-sector partnership (public, private, and nonprofit) and provides a supportive infrastructure to combat the disease. My research therefore would not be complete without talking to some of the people who constitute the safety net, with a special focus on those fighting the epidemic among women. In addition to their interviews, I also conducted participant observation by attending HIV/AIDS conferences, meetings, and public presentations in which members of this community were actively discussing and shaping the AIDS policy agenda. These interviews and observations locate the experiences of WLWHA within a broader institutional and policy context. I regret that I could not speak to every activist, advocate, policy official, and service provider who played a crucial role in the development and growth of the HIV safety net.³⁰ My hope is, however, that this book, through the stories represented, offers a sense of the collective that built the AIDS response. Further, while the HIV safety net operates all over the world as part of the global fight against the epidemic, this book focuses on the US context, with its unique political, social, and economic specificities.

It is important to note that both cisgender and transgender women have historically struggled to have their voices and needs included in the AIDS response. Cisgender women are women whose sense of personal identity and gender corresponds with their birth sex. Transgender women are women whose sense of personal identity and gender does not correspond with their birth sex. Estimates suggest that transgender women have an overall HIV seroprevalence rate of 28 percent, with extremely high occurrence rates (56 percent) among black transgender women.³¹ Transgender women, when included, have often been grouped with gay men in the research, service provision, and political activism related to the epidemic.³² This approach clearly suffers from limitations, as it does not address the unique struggles of transgender women and conflates sexual and gender identity. This can elide the ways in which the benefits of advances in AIDS services, information, and treatments have eluded transgender women as compared with gay men.

In recent years, we have witnessed a seismic shift in societal understandings of transgender individuals, due in no small part to their growing media presence and political activism.³³ For example, when I began this project in 2005, it was not uncommon to focus a study of women living with HIV/AIDS exclusively on cisgender women. I followed that convention when I conducted interviews with Chicago WLWHA. However, during the later stages of my data collection, I interviewed transgender activists to ask whether and how the HIV/AIDS safety net has evolved to become more responsive to the needs of transgender women.

My multilayered approach enables us to examine women's stories of transformation (with their successes and limitations) against the backdrop of the transformation of the AIDS epidemic and the organized AIDS response (with its successes and limitations). To preserve confidentiality, I use pseudonyms for all Chicago WLWHA and the people who appear in their narratives, but in discussions of the social history of the AIDS response, I use real names to reference the activists, advocates, policy officials, and service providers with national profiles in the AIDS community. I present additional methodological details in appendix A. Tables capturing the book's featured storytellers and additional demographic information about the Chicago women can be found in appendix B. Photos of several referenced activists and advocates are at remakingalife.org.

OVERVIEW

The chapters of *Remaking a Life* move between the perspectives and personal lives of the Chicago women and those of advocates, activists, policy-makers, and service providers who work on the issue of HIV/AIDS at the national, state, and local levels. In chapter 1, I explain the context that creates the impetus for women's transformative projects, the state of extreme distress that I have termed *dying from*. Women with this status are destabilized in multiple areas of their lives—physical and mental health, family, finances, housing, intimate relationships, self-esteem, and so on—and have suffered to the point that these life domains are interdependently undermining one another. An HIV diagnosis can both initiate and serve as an indicator of this state of *dying from*, and WLWHA believe and behave as though they have death sentences.

In this chapter, I also trace the epidemiological history of the AIDS epidemic in the United States to help us understand the women's health risks. The women in my study describe a variety of events that might have exposed them to HIV, including sexual activity, intravenous drug use, and blood transfusions that were received before the advent of protocols for screening the nation's blood supply for HIV. For an alarming number of women, experiences with early sexual trauma likely contributed to pathways that later increased their risk for HIV infection. I also examine HIV's continuing devastating and disproportionate impact on women entangled in, or in close geographic or social proximity to, the sexualized drug economy. Legal and illegal drugs, in conjunction with an unevenly applied spike in incarceration, increase women's exposure to sexual and social networks that put them at higher risk for contracting HIV. In Chicago, the sexualized drug economy has arguably had the most devastating and visible impact on black and Latinx communities; however, a growing opioid drug epidemic in the United States, including and especially within white rural and suburban communities, demonstrates that economically depressed communities in general are especially vulnerable to this threat.

Chapter 2 charts the rise of the safety net that emerged in response to the AIDS epidemic in the 1980s. I consider how multiple stakeholders eventually coalesced after initial conflicts to create an infrastructure targeted toward HIV/AIDS prevention and treatment. Adopting an intersectional

approach in chapter 2 helps to explain why the institutional response to HIV has taken form as it has. In light of the growing economic, cultural, and political clout of white, middle-class gay men, I point to how the AIDS response was powerfully fueled by both the privilege and marginalization experienced by this group. They passionately demanded and received resources, with their status as white men bolstering their claims and opening doors that were clearly shut to black and brown people suffering from the same disease. Simultaneously, the need to offer safe spaces that provided respite from crushing homophobia and other forms of stigmatization was programmed into the DNA of many institutions that emerged from AIDS activism, and this ethos would prove extremely attractive to many women seeking to address their own injuries. Challenges facing women, poor people, gay men of color, and transgender individuals pushed the ethos surrounding AIDS mobilization even further as these segments of the community demanded racial, gender, and class diversity, inclusivity, and parity in the plans, policies, practices, and spokespeople that constituted the growing safety net. I therefore argue that part of the success and the struggle of the AIDS response is that social privilege and marginalization are embedded in the movement in a constant collaborative tension. Emerging from these contests and confrontations, the AIDS community has produced a structure and culture of care that differs markedly from many other models of human service delivery and creates a space for women to remake their lives.

Chapter 3 returns to the Chicago women and begins to chart the specific components of the transformative projects that my research team and I observed. I illustrate how framing institutions within the HIV safety net are vital to the process of remaking a life.³⁴ These organizations can positively or negatively frame what it means to live with HIV by offering critical information about HIV as a medical diagnosis and social status; language with which to talk about HIV and its implications for women's lives; and resources and networks that help or hinder women in restructuring post-diagnosis life. As institutional brokers, framing institutions are often invisible to those who do not rely on them but critically important to those who do. In addition to implementing programs, distributing resources, and facilitating everyday social encounters that may not otherwise occur, the most effective institutional interactions help women generate new thinking about their lives, a cognitive shift that helps them realize that "something has to change."

I capture how the women then begin to generate alternative strategies for navigating the entrenched environmental hurdles and widening social inequalities that initially put them at risk for acquiring HIV. This chapter and the next also consider which characteristics, of both individuals and organizations, are more likely to anchor (or undermine) a transformative project.

In chapter 3 I also address the limitations of framing institutions within the HIV safety net. For example, engaging with the HIV/AIDS community has varying class-based implications for women, as public association often improves the social status of impoverished and working-class women while diminishing that of middle-class women, who are deeply concerned about the stigma of identification. Overall, middle-class women report less engagement with the HIV safety net, and they possess fewer social ties with service providers and other PLWHA on whom they can rely for HIV-related information and support. Ironically, this renders middle-class WLWHA more vulnerable to HIV-specific social isolation than their poorer counterparts who engage with the HIV safety net.

Recent findings from three major studies play a major role in informing HIV service delivery: continuous antiretroviral treatment is superior to episodic ART, early ART take-up reduces HIV transmission to uninfected sexual partners by 93 percent, and early ART take-up reduces serious illness and death among PLWHA by 57 percent.³⁵ This wave of research led the CDC to announce in 2017 that “people who take ART daily as prescribed and achieve and maintain an undetectable viral load have effectively no risk of sexually transmitting the virus to an HIV-negative partner.”³⁶ In chapter 4, I argue that the HIV safety net plays an important, if underappreciated, role in our ability to fully exploit these discoveries and curb the epidemic through this test-and-treat revolution. I demonstrate that women’s ties to the HIV safety net are vital to the effective implementation of test-and-treat in health care settings, and I highlight opportunities at the individual, institutional, and structural levels that could further maximize our substantial financial and social investments in treating and preventing HIV/AIDS. In short, investing in the HIV safety net not only encourages and supports women’s transformative projects, it could also facilitate the end of the epidemic.

A successful transformative project is sustainable over time. Women often confront their greatest challenges after they have left the supportive and protective setting of framing institutions within the HIV safety net. In

chapter 5, we return to the central storytellers—Beverly, Keisha, Yvette, Trisha, and Rosario—to examine the longer-term reconstruction and maintenance of their remade lives. WLWHA often produce new identities and self-narratives after undergoing change that they then operationalize. They must grapple not only with the difficult work of HIV-status disclosure but also decide how they will answer questions about past relationships, behaviors, and struggles. Sexual relationships take on new significance, and many women still grapple with the afterlife of sexual trauma and the symbolic labeling of their bodies as “contaminated” with an HIV diagnosis, despite the clear medical advances. Some have assumed leadership roles in families, organizations, and communities and must navigate these new dimensions of their social and political lives even while reconciling with the stigma and “status” that result from being HIV positive. Overall, this chapter analyzes how individuals attempting transformation renegotiate their social roles as women, mothers, intimate partners, family members, friends, political actors, and economic providers over time.

In the final chapter of *Remaking a Life*, I contemplate the implications of changing policy environments, advances in the treatment of HIV/AIDS, and other potential shifts in the epidemic for the political and social viability of the HIV safety net. With medical developments that have transformed HIV/AIDS from a terminal to chronic illness, stabilizing infection rates among certain populations, declining political mobilization, and waning public interest, many have questioned why the HIV safety net should continue to enjoy access to government resources through the Ryan White CARE Act and other policies. But the public’s sense of crisis that helped define the 1980s and 1990s has subsided in part because of the gains that have been achieved. I make the case in this chapter that we must ensure that the HIV safety net continues to receive resources to sustain the successes and address ongoing challenges that allow the epidemic to stubbornly persist in some of our most vulnerable communities. Moreover, the infectious nature of the disease requires vigilance from all of us. The AIDS response therefore must be tenacious and robust, sensitive to both the inequality and the universality that drive the epidemic.

In the book’s concluding chapter, I also grapple with the unfortunate irony of my analysis and its policy implications. Access to the safety net that enabled women to achieve significant and sustained life change

depended on their being HIV positive. This is a sobering reality. It suggests that our societal safety net has been perversely shaped to intervene only when people are already deeply injured or assumed to pose a threat to public health, rather than playing a preventive role, insofar as the determining factor allowing women to access the social safety net was not need but a serious, transmittable, and perhaps deadly health threat.³⁷ The fire had to be raging before we installed the fire extinguisher.

Nevertheless, the HIV/AIDS safety net should be viewed as a model for confronting rising inequality through multidimensional and empathetic public policy. AIDS activists and advocates deserve a great deal of credit for creating a life-saving infrastructure in several major cities and helping to transform the AIDS epidemic in the United States. I conclude my analysis by underscoring its potential as a prototype for how we might assist a broader segment of the public—not just those living with HIV/AIDS—by highlighting the most important lessons from the AIDS response. We would never imagine creating a system that perversely incentivizes having HIV, and I note at the outset that none of the more than 100 women interviewed by my team over 15 years of conducting this research stated that she acquired HIV to access the HSN. The key nonetheless is to offer services to a broader array of individuals as a preventive strategy against injuries of inequality like HIV. The combination of access to healthcare, modest economic assistance, extensive social support, and an on-ramp to political and civic participation offered by the HIV safety net offers powerful lessons regarding how we can help individuals recover from some of inequality's harshest blows. Implemented in tandem with approaches that seek to reduce economic and social inequities and prevent their related injuries, effective safety nets can create opportunities that enable individuals to successfully launch transformative projects. The AIDS response demonstrates that the chance to remake our lives following tragedy and trauma should not be reserved for the most privileged among us.

C O D A

Ten years after we first met her and 30 years since her initial HIV-positive diagnosis, Dawn continues remaking her life. She was recently approved

through Medicare for back surgery that she hopes, if successful, will return her to the world of paid employment. Daisy is starting high school. Raising the girl as she approached her teenage years encouraged Dawn to draw on her own traumatic experiences and to use them constructively in her parenting practices. Dawn carefully manages where Daisy goes and with whom she socializes, reducing sleepovers to the homes of only a select few friends and monitoring Daisy's cell phone communication.

Dawn knows that her life as a WLWHA could have turned out much differently. Consider a story that she shares during her speaking engagements as she tells listeners what became of Jackie, the favorite stepsister who first introduced Dawn to intravenous drugs: "There are many things that you can do with your family. . . . My stepsister and I used to get high together, and we were both intravenous drug users. We shared a lot, including the HIV virus." Sadly, Jackie lost her battle with AIDS. She participated in the AIDS community with Dawn for a while, forging her own attempt at a transformation. "But, I guess it just wasn't enough for her," Dawn stated, her eyes lowering, "so she went back out there. And she didn't make it back."

When we first spoke in 2005, Dawn shared her biggest concern: the transformed lives that she and Raquel had built depended heavily on the support they offered each other. "I told Raquel time and time again, she relies on me too much. And I've asked her, 'What are you going to do if something happens to me? You need to become more independent.'"

Tragically, it would be Dawn who would hold the hand of a dying loved one. Raquel started having headaches in 2012. A CAT scan revealed stage IV cancer. "They gave her six months, and we're like, 'Yeah, right, y'all don't know Raquel,'" Dawn explained as she fought back tears. "She made it a year and a half. She fought until we told her, 'You know, you really don't have to do this for us, we got this. . . .' We don't. But we told her that we could manage."

Losing the love of her life would be the ultimate test of Dawn's transformative project. "When she died, I was like, what will I do now? I felt lost. I understand what it means to feel lost and broken." She withdrew from much of her AIDS work, in part because raising Daisy consumes more and more of her time. Yet she still maintains a connection to that community, holding a seat on an AIDS community advisory board. She

also gives back to those just starting their transformative journeys: “In my old HIV support group, [I keep in touch with] ten of us left from the original batch who started our services at that agency. So, once a year, we all just converge on the HIV support group meeting and let folks know that we’ve been around since the mid-80s, and don’t give up. It’s kind of like reunion time.” Dawn has never forgotten the role that those institutional ties played, including introducing her to the love of her life and helping her anchor a new life for herself.

In the decade during which I followed her, Dawn not only maintained her strategies for negotiating challenges but also took additional steps in her transformative journey. This includes a very special one. She started the process of legally adopting Daisy: “She is my daughter. I raised her. Unfortunately, she has my and Raquel’s attitude [laughs]. And she is highly sensitive to people who are ignorant about HIV/AIDS. So yeah, she’s our daughter, mine and Raquel’s.”

Notes

INTRODUCTION. INJURIES OF INEQUALITY AND THE TRANSFORMATIVE PROJECT

1. Douglas S. Massey and Nancy A. Denton, *American Apartheid: Segregation and the Making of the Underclass* (Harvard University Press, 1993); Mary Pattillo, *Black Picket Fences: Privilege and Peril among the Black Middle Class* (University of Chicago Press, 2013); William Julius Wilson, *The Truly Disadvantaged: The Inner City, the Underclass, and Public Policy* (University of Chicago Press, 2012).

2. Michelle Alexander, *The New Jim Crow: Mass Incarceration in the Age of Colorblindness* (New Press, 2012); Todd R. Clear, *Imprisoning Communities: How Mass Incarceration Makes Disadvantaged Neighborhoods Worse* (Oxford University Press, 2007); Mary Pattillo, Bruce Western, and David Weiman, *Imprisoning America: The Social Effects of Mass Incarceration* (Russell Sage Foundation, 2004).

3. Routes of HIV transmission include sexual intercourse; exposure to blood (via transfusion of blood or blood products; sharing injection needles, syringes, or “works”; or an occupational needlestick); or perinatally (from mother to child during pregnancy or breast feeding).

4. CD4 cell counts below 200 cells per cubic millimeter of blood (200 cells/mm³) indicate that HIV has progressed to AIDS. Normal CD4 counts are between 500 and 1,600 cells/mm³. One can also be diagnosed with AIDS after

developing one or more opportunistic infections, regardless of CD4 count (see www.aids.gov).

5. AmfAR, “Statistics: Worldwide,” www.amfar.org/worldwide-aids-stats/.

6. Cathy J. Cohen, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics* (University of Chicago Press, 1999); Robert Fullilove, “Mass Incarceration in the United States and HIV/AIDS: Cause and Effect,” *Ohio State Journal of Criminal Law* 9 (2011): 353–61; Jacob Levenson, *The Secret Epidemic: The Story of AIDS and Black America* (Anchor, 2005).

7. Merrill Charles Singer et al., “Syndemics, Sex and the City: Understanding Sexually Transmitted Diseases in Social and Cultural Context,” *Social Science & Medicine* 63, no. 8 (2006): 2010–21.

8. Kristine A. Johnson and Shannon M. Lynch, “Predictors of Maladaptive Coping in Incarcerated Women Who Are Survivors of Childhood Sexual Abuse,” *Journal of Family Violence* 28, no. 1 (2013): 43–52.

9. Lawrence K. Altman, “AIDS Is Now the Leading Killer of Americans from 25 to 44,” *New York Times*, January 31, 1995, C7.

10. Dawn was interviewed by three members of the study team over a decade. In 2005, the original project coordinator interviewed her twice and conducted an observation session with her. A graduate research assistant interviewed Dawn in 2010, and I conducted interviews with Dawn in 2014 and 2015. Having multiple interviewers allowed us to verify the consistency of Dawn’s account and to follow her over a ten-year period.

11. Celeste Watkins-Hayes, LaShawnDa Pittman-Gay, and Jean Beaman, “Dying from’ to ‘Living with’: Framing Institutions and the Coping Processes of African American Women Living with HIV/AIDS,” *Social Science & Medicine* 74, no. 12 (2012): 2028–36.

12. Jennifer Brier, *Infectious Ideas: US Political Responses to the AIDS Crisis* (University of North Carolina Press, 2009); Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (University of California Press, 1996); Patricia D. Siplon, *AIDS and the Policy Struggle in the United States* (Georgetown University Press, 2002); Raymond A. Smith and Patricia D. Siplon, *Drugs into Bodies: Global AIDS Treatment Activism* (Greenwood, 2006).

13. Anthropologist Laurence Ralph explores the depths and forms of injury in a west Chicago neighborhood, defining it as, “a vast spectrum . . . of encumbrances that followed [residents] through life, weighed them down, and affected their future prospects.” Laurence Ralph, *Renegade Dreams: Living through Injury in Gangland Chicago* (University of Chicago Press, 2014), 5.

14. Mario Luis Small, *Unanticipated Gains: Origins of Network Inequality in Everyday Life* (Oxford University Press, 2009).

15. Scott W. Allard, *Out of Reach: Place, Poverty, and the New American Welfare State* (Yale University Press, 2009).

16. The Ryan White CARE Act is the largest federally funded program in the United States for PLWHA. The act provides funding to improve care availability for low-income, uninsured, and under-insured PLWHA and their families. I present more information about the history and implementation of the act in chapter 2.

17. Patrick Sharkey, *Stuck in Place: Urban Neighborhoods and the End of Progress toward Racial Equality* (University of Chicago Press, 2013); Wilson, *The Truly Disadvantaged*; William Julius Wilson, *When Work Disappears: The World of the New Urban Poor* (Vintage, 2011).

18. Edward Flores, *God's Gangs: Barrio Ministry, Masculinity, and Gang Recovery* (New York University Press, 2013); Sharon S. Oselin, *Leaving Prostitution: Getting Out and Staying Out of Sex Work* (New York University Press, 2014); Ralph, *Renegade Dreams*; Robert J. Sampson and John H. Laub, "Desistance from Crime over the Life Course," in *Handbook of the Life Course*, ed. Jeylan T. Mortimer and Michael J. Shanahan (Kluwer, 2003), 295–309. See also Shadd Maruna, *Making Good: How Ex-convicts Reform and Rebuild their Lives* (American Psychological Association, 2001); and David J. Brown, "The Professional Ex-: An Alternative for Exiting the Deviant Career," *Sociological Quarterly* 32, no. 2 (1991): 219–30.

19. Dexter R. Voisin, "The Relationship between Violence Exposure and HIV Sexual Risk Behaviors: Does Gender Matter?" *American Journal of Orthopsychiatry* 75, no. 4 (2005): 497–506.

20. Celeste Watkins-Hayes, "Intersectionality and the Sociology of HIV/AIDS: Past, Present, and Future Research Directions," *Annual Review of Sociology* 40, no. 1 (2014): 431–57.

21. Frances Beal, "Double Jeopardy: To Be Black and Female," in *Words of Fire: An Anthology of African-American Feminist Thought*, ed. Beverly Guy-Sheftall (New Press, 1995), 146–55; Patricia Hill Collins, *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment* (Routledge, 1990); Combahee River Collective, "A Black Feminist Statement," in *Home Girls: A Black Feminist Anthology*, ed. Barbara Smith (Rutgers University Press, 1983), 264–74; Anna Julia Cooper, *A Voice from the South* (Oxford University Press, 1988); Kimberlé Crenshaw, "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color," *Stanford Law Review* 43, no. 6 (1991): 1241–99; and Deborah K. King, "Multiple Jeopardy, Multiple Consciousness: The Context of a Black Feminist Ideology," *Signs: Journal of Women in Culture & Society* 14, no. 1 (1988): 42–72.

22. Sumi Cho, Kimberlé Crenshaw, and Leslie McCall, "Toward a Field of Intersectionality Studies: Theory, Applications, and Praxis," *Signs: Journal of Women in Culture & Society* 38, no. 4 (2013): 785–810.

23. Hae Yeon Choo and Myra Marx Ferree, "Practicing Intersectionality in Sociological Research: A Critical Analysis of Inclusions, Interactions, and

Institutions in the Study of Inequalities,” *Sociological Theory* 28, no. 2 (2010): 129–49; Brittney Cooper, “Intersectionality,” in *The Oxford Handbook of Feminist Theory*, ed. Lisa Disch and Mary Hawkesworth (Oxford University Press, 2016); Leslie McCall, “The Complexity of Intersectionality,” *Signs: Journal of Women in Culture & Society* 30 (2005): 1771–800.

24. Ange-Marie Hancock, “Intersectionality as a Normative and Empirical Paradigm,” *Politics & Gender* 3, no. 2 (2007): 248–54; Jennifer Nash, *Black Feminism Reimagined: After Intersectionality* (Duke University Press, 2019).

25. amfAR, “Statistics: Women and HIV/AIDS,” www.amfar.org/about-hiv-and-aids/facts-and-stats/statistics--women-and-hiv-aids/.

26. US CDC, “HIV/AIDS among Women.”

27. Black Women’s HIV/AIDS Network and National Black Gay Men’s Advocacy Coalition, “Joint Statement from the Leadership Meeting of Black Women and Black Gay Men,” 2007.

28. US CDC, WISQARS Leading Causes of Death Reports, 1999–2004; Demian Christiansen, Nanette Benbow, and Carrie Kempler, “The HIV/AIDS Epidemic in Chicago: Chicago HIV/AIDS Brief” (Office of AIDS Surveillance, Chicago Department of Public Health, 2006). All data for blacks and whites reflect non-Hispanic racial categories. All data are based on HIV/AIDS Reporting System (HARS) reports to the Chicago Department of Public Health as of September 30, 2006.

29. US CDC, “Leading Causes of Death in Females, United States.”

30. I use the term *advocate* to refer to those who engage in “interventions such as speaking, writing or acting in favor of a particular issue or cause, policy or group of people. In the public health field, advocacy is assumed to be in the public interest, whereas lobbying by a special interest group may or may not be in the public interest.” Activists can be thought of as those taking direct action to achieve a political or social goal. Public Health Agency of Canada, “Glossary of Terms,” www.canada.ca/en/public-health/services/public-health-practice/skills-online/glossary-terms.html.

31. US CDC, “HIV among Transgender People.”

32. Tonia Poteat, Danielle German, and Colin Flynn, “The Conflation of Gender and Sex: Gaps and Opportunities in HIV Data among Transgender Women and MSM,” *Global Public Health* 11, no 7–8 (2016): 835–48.

33. Julian Kevon Glover, “Redefining Realness? On Janet Mock, Laverne Cox, T. S. Madison, and the Representation of Transgender Women of Color in Media,” *Souls* 18, no. 2–4 (2016): 338–57.

34. Watkins-Hayes, Pittman-Gay, and Beaman, “‘Dying from’ to ‘Living with.’”

35. “Ryan White 2016: Scientific and Programmatic Accomplishments,” TargetHIV, <https://targethiv.org/blog/ryan-white-2016-scientific-and-programmatic-accomplishments>.

36. US CDC, “Dear Colleague: Information from the CDC’s Division of HIV/AIDS Prevention,” September 27, 2017.

37. Johanna Crane, Kathleen Quirk, and Ariane Van Der Straten, “Come Back When You’re Dying’: The Commodification of AIDS among California’s Urban Poor,” *Social Science & Medicine* 55, no. 7 (2002): 1115–27; Alyson O’Daniel, *Holding On: African American Women Surviving HIV/AIDS* (University of Nebraska Press, 2016); John A. Updegraff et al., “Positive and Negative Effects of HIV Infection in Women with Low Socioeconomic Resources,” *Personality & Social Psychology Bulletin* 28, no. 3 (2002): 382–94.

CHAPTER 1. DYING FROM

1. Indiana Department of Health, “Scott County Public Health Emergency Declaration Extended,” 2016, www.in.gov/isdh/files/May_2_2016_SCOTT_COUNTY_PUBLIC_HEALTH_EMERGENCY_DECLARATION_EXTENDED.pdf.

2. US CDC, “Community Outbreak of HIV Infection Linked to Injection Drug Use of Oxycodone—Indiana, 2015,” *Morbidity and Mortality Weekly Report* 64 (2015): 443–44.

3. Jeffrey S. Crowley and Gregorio A. Millett, “Preventing HIV and Hepatitis Infections among People Who Inject Drugs: Leveraging an Indiana Outbreak Response to Break the Impasse,” *AIDS & Behavior* 21, no. 4 (2017): 968–72; Colleen Nguyen, “HIV in Indiana: 81 Cases and Counting,” *Health Map: The Disease Daily: Outbreak News* (blog), April 5, 2015, www.diseasedaily.org/diseasedaily/article/hiv-indiana-81-cases-and-counting-4515; Steffanie A. Strathdee and Chris Beyrer, “Threading the Needle: How to Stop the HIV Outbreak in Rural Indiana,” *New England Journal of Medicine* 373, no. 5 (2015): 397–99.

4. Shari Rudavsky, “An Indiana Town Recovering from 190 HIV Cases,” *IndyStar*, April 8, 2016.

5. US CDC, “Injection Drug Use and HIV Risk,” 2018.

6. F. I. Bastos and S. A. Strathdee, “Evaluating Effectiveness of Syringe Exchange Programmes: Current Issues and Future Prospects,” *Social Science & Medicine* 51, no. 12 (2000): 1771–82; Don C. Des Jarlais, “Research, Politics, and Needle Exchange,” *American Journal of Public Health* 90, no. 9 (2000): 1392–94; “HIV and AIDS Information: Injecting Drug Use—Why Is Injecting Drug Use a Risk for HIV Transmission?” *AIDSmap*, 2016; David Vlahov et al., “Needle Exchange Programs for the Prevention of Human Immunodeficiency Virus Infection: Epidemiology and Policy,” *American Journal of Epidemiology* 154, no. 12 (2001): S70–S77; Alex Wodak and Annie Cooney, “Do Needle Syringe Programs Reduce HIV Infection among Injecting Drug Users: A Comprehensive Review of the International Evidence,” *Substance Use & Misuse* 41, no. 6–7 (2006): 777–813.