Title
Changing the color of HIV/AIDS prevention: black community activism, U.S. Public Health, and the biopolitics of race, sexuality and citizenship

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in

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by

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2012
The Dissertation of Kevin Michael Moseby is approved and acceptable in quality and form for publication on microfilm and electronically:

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University of California, San Diego

2012
DEDICATION

To my beloved parents, Katie M. (Davis) Moseby and the late Cleveland Moseby, Sr. (1952-2007) whose miraculous support and love sustained me before birth; it never waivers

Thanks Mama and Daddy for allowing me to find and follow my dreams, even as they took me far away (physically, and at times it seemed, socially and culturally) from ya’ll—yet, home is always near
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ABSTRACT OF THE DISSERTATION


by

Kevin Michael Moseby

Doctor of Philosophy in Sociology

University of California, San Diego, 2012

Professor Steven G. Epstein, Co-chair
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The dissertation examines the salience of race over the course of the HIV/AIDS epidemic in the United States. In contrast to the first decade of the epidemic, AIDS is now increasingly seen as a disease of color; black Americans are central objects of U.S. public health efforts to prevent the spread of the disease. Additionally, black Americans' activism and advocacy is an important and influential feature in the contemporary configuration of the HIV prevention field. While it may be reasonable to assume that the changing racialization of the HIV/AIDS discourse and the prevention field was simply
inevitable given advancements in epidemiological and scientific knowledge of the disease, this explanation is insufficient. The dissertation focuses on the practices and politics of public health and biomedicine, media, sexuality and race that are intimately intertwined with producing and constructing responses to HIV/AIDS.

The dissertation finds that a discursive and bureaucratic shift prompted by multiple sources—including, black Americans’ activism and advocacy—occurred in the early 1990s. This shift is conceptualized as demarcating two disease regimes of HIV/AIDS in relation to black American experience: the regime of exclusion (1981-early 1990s) and the regime of inclusion (early 1990s-present day). Within the first regime, dominant images, practices and discourses of public health, biomedicine and the media constructed a representation of HIV/AIDS, which effectively rendered black Americans excluded or, virtually missing. Conversely, the regime of inclusion designates an ongoing period where black Americans are central actors, and black Americans’ concerns and cultural products are increasingly incorporated, within the HIV/AIDS discourse, and more specifically in the field of HIV prevention.

Building on a wide range of scholarship in the social and cultural studies of HIV/AIDS, race studies, science studies; and governmentality studies, the dissertation documents and analyzes a multiplicity of socio-political and cultural forces that helped to transform the HIV/AIDS disease regime of black American exclusion to one of black American inclusion. The dissertation is based on data derived from content and discursive analysis of public health publications, media and secondary scholarly sources; interviews with public health administrators and black American HIV/AIDS activists in Atlanta, Georgia; and participant observation at HIV/AIDS conferences.
Chapter 1

Introduction: How to Study and Theorize the Changing Color of HIV/AIDS Prevention

“In America today, AIDS is virtually a black disease, by every measure.”

Phil Wilson

“Silence is now suicide. The black American silence on this issue is suicidal.”

Reverend Eugene Rivers

These provocative statements regarding HIV/AIDS in “black America” are featured in the first few minutes of a one-hour special edition of the ABC News program, Primetime with Terry Moran, which aired in 2006. Entitled, Out of Control: AIDS in Black America, this news documentary—moderated by Moran and based in part on work conducted by esteemed TV journalist Peter Jennings, shortly before his death—is presented as an exposé that redresses the silence of the media on this health crisis in black America. As Moran puts it: “There are times in the news when we’re not watching or listening close enough, when we miss a story, a big important story that goes underreported and mostly ignored. This is one of those stories.”

While a humble admission of the media’s overall neglect of the story of AIDS in black America, Moran’s declaration, occurring approximately 3 minutes into the program, is somewhat surprising. It belies his earlier remarks, which render the overall narrative of

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1 Wilson is the founder and CEO of the Black AIDS Institute, and a long serving black American HIV/AIDS activist.
2 Reverend Rivers is Pastor of the Azusa Christian Community in Boston, Massachusetts.
*Out of Control* (hereafter *OOC*) as an admonishment to black Americas who fail to acknowledge the deadly toll of AIDS in their communities. As *OOC* opens, Moran’s off-camera narration—delivered over video footage displaying various scenes of black Americans worshiping at a religious convention in Atlanta, Georgia—including a recitation of “stunning statistics” to demonstrate the toll of the epidemic among blacks and to support a presumably obvious conclusion that: “AIDS is a topic that remains underground in black America.” Hence, even though *OOC* includes and identifies some important institutional and socio-political norms that cause HIV/AIDS in black America to be “mostly ignored” in the media, throughout the program there are persistent recurring references, by Moran and his black and white interview subjects, to the black community’s long-standing irresponsible and perilous inaction and inattention to AIDS.

Under-acknowledged in this orienting thesis of *OOC* is the contemporary presence of a significant network of black Americans and black American organizations, well established by 2006, working to combat HIV/AIDS in their communities. Indeed, the black American HIV/AIDS activists who I quote at the beginning of this chapter—quotes that are in fact interspersed throughout Moran’s introductory voice-over—represent, and are actors within, a significant and influential black health HIV/AIDS social movement. A central argument of this dissertation is that the story of black Americans’ inaction against HIV/AIDS is over-exaggerated in both popular representations, such as *OOC*, and, more importantly for the task at hand, the academic social science literature.

This dissertation is a study of how black American experience and mobilization within the field of HIV prevention have changed, as has the notions and currency of race,
over the course of the epidemic in the United States. In highlighting the role of black
American activism and advocacy, I seek to intervene in the official histories of
HIV/AIDS that center white gay men experiences and subjectivities. That is, this
dissertation systematically examines the evolving experiences of black Americans in the
field of HIV prevention since 1981, simultaneously as objects of public health
interventions and as active subjects in the creation of knowledge within the field.
Throughout the dissertation, my analysis focuses on the institutional practices and
discourses that assist in dynamically constituting black Americans’ subjectivity and
mobilization in relation to the disease. I argue that a discursive and bureaucratic shift,
originating in the early 1990s, significantly affected the HIV/AIDS discourse and
prevention policy as it related to black Americans. In addition to exploring how this shift
matters to contemporary black Americans, I explore the ways in which both social
movement and state actors were involved in making this shift come to pass.

I am dedicated to writing a sociological informed history of the racialization of
the U.S. HIV/AIDS epidemic. This dissertation is a “history of the present” in such that
a central goal is to highlight how contemporarily the HIV prevention field—in which
over time black Americans have become increasingly visible and active actors—is a
construction contingent on power relationships of the past.3 Importantly, as Cindy
Patton argues, “representations of AIDS at every level—in the media, in the science[s], in
the cultural assumptions manifest in the effects of institutional process—are multiple and

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discontinuous [and, I would add, incomplete]...the terms of AIDS discourse also relate to different already-inscribed relations of power.4 Thus, in this dissertation I recognize the strengths and weakness of media coverage and prior social scientists’ accounts of HIV/AIDS, locating such work within the domain of necessarily partial and problematic representation of HIV/AIDS and race.

Particularly, the narrative of this dissertation builds upon the social and cultural studies of HIV/AIDS through a critique that employs a sustained racial analysis that is consistently absent in prior scholars’ accounts of HIV/AIDS activism. I bring attention to practices of racialization involved in producing the social relations of the disease: I argue that institutional practices and discourses assist in differentially shaping experience and enabling mobilization along racial lines within the HIV prevention field. My argument is based on my belief that scholars have over-emphasized, the conservatism of black institutions, as well as the role of homophobia and gay and drug stigma—both often problematically conceived as a product of the culture of blacks—as a significant barrier to black American HIV/AIDS mobilization. In line with the late sociologist Lionel Cantú's warning that scholars who place analytical emphases on the culture of marginalized people “often obfuscate the structural power dimensions that shape...lives,” and thereby run the risk of pathologizing that culture, this dissertation centers the role of dominant or mainstream institutional discourses and practices in constraining or enabling black American’s HIV/AIDS activism.5

Additionally, starting from and extending Patton’s insight that there is significant

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“amnesia surrounding the history of [HIV/AIDS] activism,” this dissertation identifies a legacy of black American HIV/AIDS activism from the earliest days of the epidemic.\(^6\) In *Inventing AIDS*, Patton’s analysis focuses on how the dual emergence of the professionalized “AIDS industry” and the direct-action group ACT UP (AIDS Coalition to Unleash Power) in late 1980s rendered invisible the earlier organizing and activism between 1981-1985. A primary goal of this dissertation is to begin to uncover and make visible earlier instances of black American HIV/AIDS activism, while also identifying some of the pathways and events that led black Americans to establish community based organizations and advocacy groups. I demonstrate that the institutionalization of black American mobilization directed toward combating HIV/AIDS began in the late 1980s, gathered momentum throughout the 1990s and matured in the 2000s.

At the same time, a central task of this dissertation is to track the emergence of the black American community as a primary object of public health policy and intervention. It is well established in the social science literature that institutions of public health were detrimentally slow in mounting a defense against HIV/AIDS directed toward black Americans and their communities. Conversely, since the early-mid 1990s, black Americans and their communities increasingly have become central objects of concern on the part of public health institutions. For instance, black Americans are currently primary targets of HIV prevention initiatives, policies, and surveillance technologies that are produced or conducted by the U.S. federal agency mandated to ensure the public safety against disease, i.e. the Centers for Disease Control and Prevention (CDC). The CDC now unequivocally acknowledges that black Americans are

disproportionately burden by HIV/AIDS.

For example, the CDC’s fact-sheet *HIV among African Americans*, most recently updated in September 2010, opens with the ominous unambiguous statement: “By race/ethnicity, African Americans face the most severe burden of HIV in the United States.” The fact-sheet goes on to detail surveillance data and other statistical information that gives credence to black American activist Phil Wilson's declaration that “in America today, AIDS is virtually a black disease by every measure.” The following are some of the facts presented on the fact-sheet: 

- In 2006, black men accounted for two-thirds of new infections (65%) among all blacks. The rate of new HIV infection for black men was 6 times as high as that of white men, nearly 3 times that of Hispanic/Latino men, and twice that of black women.

- In 2006, black men who have sex with men (MSM) represented 63% of new infections among all black men, and 35% among all MSM. HIV infection rates are higher among black MSM compared to other MSM. More new HIV infections occurred among young black MSM (aged 13–29) than among any other age and racial group of MSM.

- In 2006, the rate of new HIV infection for black women was nearly 15 times as high as that of white women and nearly 4 times that of Hispanic/Latina women.

- At the end of 2007, blacks accounted for almost half (46%) of people living with a diagnosis of HIV infection in the 37 states and 5 US dependent areas with long-term, confidential, name-based HIV reporting. In 2006, blacks accounted for nearly half (45%) of new infections in the 50 states and the District of Columbia. Even though new HIV infections among blacks overall have been roughly stable since the early 1990s, compared with members of other races and ethnicities they continue to account for a higher proportion of cases at all stages of HIV—from new infections to deaths.

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7 This list is taken from the fact-sheet located at http://www.cdc.gov/hiv/topics/aa/index.htm, retrieved 12/22/2010.
Although new HIV infections have remained fairly stable among blacks, from 2005–2008 estimated HIV diagnoses increased approximately 12%.

From 2005–2008, the rate of HIV diagnoses among blacks increased from 68/100,000 persons to 74/100,000. This increase reflects the largest increase in rates of HIV diagnoses by race or ethnicity.

By the end of 2007, an estimated 233,624 blacks with a diagnosis of AIDS had died in the US and 5 dependent areas. In 2006, HIV was the ninth leading cause of death for all blacks and the third leading cause of death for both black men and black women aged 35–44.

At some point in their lifetimes, 1 in 16 black men will be diagnosed with HIV infection, as will 1 in 30 black women.

Such disquieting and sobering statistics underscore a prominent feature of the changing racialization of HIV/AIDS in the U.S.: The crisis of HIV/AIDS in white gay males living in urban communities on the East and West coasts in the 1980s has transferred to the urban and rural communities of black America. At first glance there may appear a seemingly unproblematic ready answer to the question of how black Americans came to be primary objects of public health HIV/AIDS purview; is it not reasonable, after all, to assume: Where the HIV virus traveled the CDC, and other public health institutions, would soon responsively follow? Such an assumption, however, to use a familiar idiom, “does not hold water.” CDC administrators and researchers themselves now acknowledge, “blacks and Hispanics in the United States have been disproportionately affected by HIV and AIDS, compared with non-Hispanic Whites, since the early years of the epidemic.” Yet, as the political scientist Cathy Cohen demonstrated in her foundational study, black Americans were substantially “invisible to

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the CDC” well into the early 1990s. Thus, it behooves us to offer a sociological explanation and analysis of how the black American community became visible to the CDC. Relying on pathbreaking insights from science and technologies studies (STS), I hold that it is insufficient to explain the evolving racialization of the HIV/AIDS discourse and the prevention field as simply inevitable given shifts in the epidemiology of the disease in the U.S. Instead, in analyzing the changing relationship—with regard to HIV/AIDS—between black Americans and the CDC, this dissertation zeroes in on the politics of science, public health, and media that is intimately intertwined with producing and constructing responses to HIV/AIDS.

In the remainder of this Introduction, I more concretely define the guiding questions and assumptions of this project, and enumerate each with commentary that further contextualizes my research within relevant literature. Next, I further articulate the significance of this research within the context of relevant substantive and theoretical traditions. I then follow with a survey of the theoretical perspectives that serve as the framework to my analysis, including health social movements, critical race theory, and governmentality studies. I then detail the research design, including the diverse qualitative methods of data collection and the methodological and analytical tools I

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The HIV Prevention Field

A fundamental organizing principle of this dissertation is the conceptualization of the “HIV prevention field.” My use of the concept of field is greatly influenced by the works of sociologists Steven Epstein (1996), Raka Ray (1998 & 1999) and Nick Crossley (2006), each of whom in turn, more or less, extends and improvises on the notion of “field” as develop by Pierre Bourdieu (1990 and Bourdieu & Wacquant 1992).12 In his foundational study of HIV/AIDS treatment activism and the politics of scientific knowledge regarding the disease, Epstein’s object of study was “a field that generates knowledge about AIDS” which emerges in interactions between vested actors and groups.13 Following Epstein’s example, my conception of the field of HIV prevention specifically refers to a domain of social action engaged in developing and implementing HIV prevention technologies. The HIV prevention field should thus be considered a particular subset or sub-field of the greater “AIDS field” that Epstein identifies.

Within the field of HIV prevention, this dissertation chiefly considers two sets of organizational actors: black American community based organizations (BCBOs), and

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institutions of public health, namely the CDC. In my emphasis on actors and their organizationally embedded activity, I am particularly influenced by Ray, who saw “a field as a structured and socially constructed environment within which organizations are embedded and to which organizations constantly respond.” Ray’s notion of “political field” is also relevant in my analysis, albeit with important qualifications discussed later. The HIV prevention field is a “political field” in as far as it “involves actors such as the state, political parties, and social movement organizations.”

The HIV prevention field, after all, is also a sub-field of the greater field of U.S. public health—institutionally governed by the Department of Health and Human Services (DHHS), which is an integral component of the federal government’s organizational structure. The CDC is "the primary Federal agency for conducting and supporting public health activities in the United States," and as such contingently holds many of the influential cards in the ‘game’ of HIV prevention. Particularly from the perspective of HIV/AIDS CBOs, to a significant extent, the CDC occupies a central position in the field. For example, specifically through the Division of HIV/AIDS Prevention (DHAP), the CDC oversees the development of interventions and control the distribution of funds much needed by BCBOs. Thus, the CDC is a central character in

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15 Ibid.
16 This project is built upon a 'Foucaultian' understanding of public health as a central feature in U.S. state regulatory regimes. Public health is an exemplar of the state governing power of which, according to Michel Foucault, “[does] not refer only to political structures or to the management of states” (Foucault, Michel. 1983. "The Subject and Power." Pp. 221-228 in *Michel Foucault, Beyond Structuralism and Hermeneutics*, edited by Hubert L. Dreyfus and Paul Rabinow. Chicago: University of Chicago Press 221). As an official arm of the state, the CDC is an expression of state power. A later section in this introduction will be devoted to explaining in more detail the influence of Foucault and his followers on this project.
17 CDC Fact Sheet found online at http://www.cdc.gov/about/resources/facts.htm (retrieved 11/12/2007).
this dissertation primarily because it is the federal organization with which BCBOs directly interact. However, the CDC is only one of the entities of “the national medical-scientific-public health establishment” that will play a part in the analysis presented within this dissertation. The Congressional Black Caucus, the National Institute of Health and the Office of the U.S. President are a few other examples of political actors relevant to the production of discourses and practices within the HIV prevention field.

BCBOs are social movements organizations (SMOs) within ‘the political field of HIV prevention.’ I use the term BCBOs as shorthand to refer to black HIV/AIDS SMOs that have various missions, services and objectives within the HIV prevention and treatment fields. Black HIV/AIDS activism is institutionalized in a number of national and local organizations, lobbying groups and research coalitions that specifically focus on HIV/AIDS in black communities and directly interact on various levels with the CDC. BCBOs are diverse and sophisticated, offering, for example, client services such as case management and transitional housing for individuals who are HIV positive or who are living with AIDS. These community organizations also develop and employ, alongside the federal designated effective behavioral interventions (EBIs), “homegrown” interventions to prevent further HIV infections in the community (those interventions

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19 In my conception, black community organizations, or (BCOs), are those organizations that are founded by black Americans and that are predominately administered by and for black Americans.

20 Examples of nationally oriented groups include The Black AIDS Institute, The National Gay Black Men Advocacy Coalitions, the Black Gay Research Group and the National AIDS Education & Service for Minorities. Local HIV/AIDS BCBOs are found in nearly every major city and increasingly in smaller cities of the US South.
black American activists refer to as “For Us and By Us,” or FUBU). HIV/AIDS BCBOs thereby run the gamut from being a part of the so-called “AIDS service industry” to being innovative centers where technologies of HIV prevention are researched and developed, to patient groups and health movement organizations focused on advocacy at the federal and local policy levels (see chapter 3 and 4).

In addition to my use of field, I refer to the related concept of “social worlds” throughout the dissertation. In my use, the CDC is part of the public health social world, whereas BCBOs are another distinct social world. The social world of public health and BCBOs both are located within the larger field of HIV prevention. To reiterate, I understand a field to be a socially constructed site of struggle where social relations are configured and transformed. Hence, BCBOs are active, though not necessarily equal participants within the field of HIV prevention. Given that power and resources, generally speaking, are unequally distributed across social worlds that populate the prevention field, one may expect significant conflict as a prominent feature within it.

Indeed there will be episodes of conflict within this dissertation; however, I also highlight and analyze instances and ways that institutions of public health, especially the CDC, and BCBOs cooperate with and inform each other within the field of HIV prevention. To that end, the British sociologist Nick Crossley’s concept of field of

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21 Clarke, Adele. 1990. "Social Worlds Research Adventure: The Case of Reproductive Science.” Pp. 15-42 in *Theories of Science in Society*, edited by Susan E. Cozzens and Thomas F. Gieryn. Bloomington, Ind.: Indiana University Press. Clarke identifies three major types of social worlds: 1) production worlds, “where the activities produce something” (e.g. scholarly and scientific worlds producing knowledge); 2) communal worlds, “where the activities focus on the establishment and maintenance of communities of people committed to each other and to their shared goals (e.g., ethnic communities);” and, 3) social movements, “where the activities focus on shared commitments to alter the larger world in which they are embedded” (Ibid., 19). As we shall see, the social worlds constitutive of the HIV prevention field are “mixed social worlds” with features of each of the three types defined by Clarke.
contention is useful. In his research on the field of psychiatry in the UK, Crossley defined field as “a cultural and material space of contention...which is populated by competing social movement organizations whose identities and actions are closely interwoven, if as much by way of distinction and opposition as alignment.”

He further explained that the concept of field of contention is “intended to capture the multiple interactions, relationships and interdependencies in which agents and particularly organizations who elect to contest an area of life...find themselves enmeshed.”

Prior scholarly accounts of HIV/AIDS have more than adequately established the fact that HIV/AIDS prevention and treatment fields—as increasingly are other health research/policy domains—are characterized by multiple interactions and interdependences between scientists, the state and social movements. For example, Epstein described his aforementioned research, as “a study of how varied classes of AIDS experts [including “lay” AIDS activists], diverse conceptions of scientific practice, and distinct claims of knowledge about AIDS have all been generated out of relationships of conflict and cooperation in the United States since the early 1980s.” Thus, Epstein's conception of the field of AIDS research is itself similar to Crossley’s notion of field of contention, as Epstein argued that a field “…has an emergent logic—itself the product of

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23 Ibid., 562.
24 For two other examples of scholarship that also address the interdependence of activists, social movement organizations and the state with specific regard to HIV/AIDS knowledge production and to the construction of responses to the disease, see (Patton, Cindy. 1990. Inventing AIDS; Stoller, Nancy E. 1998. Lessons from the Damned: Quers, Whores, and Junkies Respond to AIDS. New York: Routledge. For an analysis of the interdependence of the state, social movements, and public health domains in regards to the fight against tobacco in the U.S. see (Wolfson, Mark. 2001. The Fight Against Big Tobacco: The Movement, the State, and the Public’s Health. New York: Aldine de Gruyter). Additionally, as I will discuss at some length in Chapter, Epstein traces the similar interdependence of actors and groups who were successful in bringing about broad institutional change in U.S. biomedical research and policy (2007. Inclusion: The Politics of Difference in Medical Research. Chicago: University of Chicago Press).
negotiation and cooperation—that conditions the practices of the diverse actors within it.”

In following such a conceptual understanding, I remain cognizant of the ways in which the HIV prevention field, especially in specific regard to the relationship between the social worlds of public health and BCBOs, is arguably a quintessential field of contention. To put it another way, the analysis presented within this dissertation focuses on the ways in which BCBOs and the CDC contend with each other within the prevention field. It will be evident throughout this dissertation, that the dual meaning of “contention” characterizes the field of HIV prevention. In working to combat HIV/AIDS in black American communities, actors are earnestly striving to endeavor together, and at times in opposition—but yet, always in relation to each other. This will be especially evident in Chapter 3 and 4 of this dissertation.

The HIV Prevention Field in Two Regimes

In this dissertation, I track the HIV/AIDS discourse and field of HIV prevention over the course of epidemic in the U.S. In doing so, I address these questions: What social and political factors have shaped the racialization of HIV/AIDS, transforming the dominant conceptualization from a white to a black disease in the US? How have black American experiences in the HIV prevention field changed over time? And, what social

26 Ibid., 18
27 I am playing on the first two definitions of contention as defined by the Oxford English Dictionary (online edition, retrieved 01/08/2011): (1) the action of straining or striving earnestly; earnest exertion, effort, endeavour; and (2) the action of contending or striving together in opposition; strife, dispute, verbal controversy.
and political factors have enabled or constrained the emergence of a prominent black community HIV/AIDS mobilization in the 1990s? Providing answers to these questions require conceptual tools that enable a critical socio-historical analysis that accounts for how discourses, practices and activisms around the epidemic have evolved. Such a concept must provide analytical leverage to counter the curious fact that “few scholars systematically have tracked patient groups and health movements through distinct phases of their evolution.”

The sociologist Maren Klawiter development in recent publications of the concept of disease regime offers such a tool that fruitfully assists my analysis of the HIV/AIDS activism over time.

Klawiter characterized disease regimes as being “comprised of the institutionalized practices, authoritative discourses, social relations, collective identities, emotional vocabularies, visual images, public policies and regulatory actions through which diseases are socially constituted and experienced.” The analytic focus of the concept is on the evolving practices that discursively and materially render diseases knowable, and that socially constructs and structures people's experiences with a given disease. It brings critical attention to the systems of practices that undergird the public administration of disease or, in other words, the discourses and practices of public health. This dissertation demonstrates the concept's relevance and its generative capacity for a socio-historical analysis of the politics of race in the HIV prevention field.

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Drawing heavily from Michel Foucault—specifically his theorization of biopower and his influential investigations of “regimes of practices” and “regimes of truths”—Klawiter developed and employed the concept of disease regime to analyze the changing cultures of breast cancer and breast cancer activism in the U.S. from the 1970s through the 1990s. Klawiter argued that breast cancer was medically managed and publicly administered across the regimes of medicalization and biomedicalization, and highlights the content, character, and consequence of social movement activity enabled within each regime. Klawiter maintained that earlier scholars who followed Foucault in analyzing regimes of public health and medicine tended to portray regimes “in rather totalizing terms.” Klawiter, however, insisted that paying due attention to “the lived experience of health and illness” and adequately foregrounding how “social movements and other forms of collectively organized resistance” may bring to light significant challenges to regimes. Thus, in contrast to earlier Foucaultian inspired analysts, Klawiter employment of the concept made evident that “although they are relatively structured and stable...[disease regimes] are subject to a wide variety of cross-cutting pressures.”

More specifically, I use the concept of disease regime to highlight the ways in which racialized and racializing institutional practices and discourses that are constitutive

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33 Ibid.
of the HIV prevention field have changed over time in relation to black Americans. In following Klawiter, I rely on three features of disease regimes that are especially important to understanding the dynamic politics of race throughout the years of the HIV prevention field. First, “different regimes of practices produce different subjects and social relations of disease.” Second, “disease regimes can both enable and inhibit the formation of diseased-based identities, social networks, and solidarities.” And, third, subjects of disease regimes have agency but “agency that is shaped and bounded by the regime's discourses and practices.” These three features enable my account of black’s experiences and mobilizations within the HIV/AIDS prevention field throughout the U.S. epidemic. I argue that in relation to black Americans we can identity two disease regimes of HIV/AIDS: the regime of black American exclusion (1981-early 1990s) and inclusion (early 1990s-present day). The analytical story at the heart of this dissertation centers on the discursive and bureaucratic shift between the first and second regimes; and, it highlights the dialectical interplay between social movement and state actors and the systems of practices and meanings constitutive of each regime, which are fundamental in structuring experience in each regime and in bringing about the regime shift.

34 The explication of the ‘multi-institutional politics’ model for understanding social movements provided by Elizabeth Armstrong and Mary Bernstein further clarifies the notion of disease regime. They describe society as being “composed of multiple and contradictory institutions with each institution viewed as mutually constituted by classificatory systems and practices that concretize these systems” (2008. "Culture, Power, and Institutions: A Multi-Institutional Politics Approach to Social Movements." Sociological Theory 26: 74-99, 87). In my conceptualization, the HIV prevention field is part of the social institution of public health. The concept of disease regime denotes the “classificatory systems and practices that concretize” the institution of public health as it relates to HIV/AIDS. The multi-institutional politics model is adopted to analyze specifically health social movements in (Banaszak-Holl, Jane, Sandra Levitsky and Mayer N. Zald (eds.). 2010. Social Movements and the Transformation of American Health Care. New York: Oxford University Press.


36 Ibid.

37 Ibid., 34.
Health Social Movements

I follow Klawiter’s lead on the role of social movements in transforming disease regimes. She wrote, “social movements are capable of affecting each and every one of…the dimensions of a disease regime, and thus] they can have profoundly transformative effects on disease regimes.”38 My dissertation conceptualizes Black Americans’ mobilization in response to HIV/AIDS as a health social movement (HSM). Phil Brown and Stephen Zavestoski defines HSMs as “collective challenges to medical policy, public health policy and politics, belief systems, research and practice which include an array of formal and informal organisations, supporters, networks of cooperation and media.”39 Brown and Zavestoski identify three conceptual categories of HSMs, distinguishing between health access movements concerned with “equitable access to health care and improved provision of health care services;” embodied health movements that “address disease, disability or illness experience by challenging science on etiology, diagnosis, treatment and prevention;” and constituency-based health movements that “address health inequality and health inequity based on race, ethnicity, gender, class and/or sexuality differences.”40

Though in general agreement with Brown and Zavestoski’s definition of HSM, I understand HSMs as not necessarily involved in agonistic challenges to medical science or biomedical policy. As David Hess maintains, HSMs are “both critical and generative”

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40 Ibid., 686-687.
and are increasingly incorporated, however tentatively, into official biomedical research domains. Therefore, in line with my understanding of the dynamics of a field, I emphasize the fact that HSMs are often engaged in complicated “give and take” relationships characterize by both cooperation and conflict. Furthermore, I suspect that most, if not all, HSMs when studied over time are not easily categorized as health access movements, embodied health movements or constituency-based health movements. Certainly, the case of Black American HIV/AIDS activism resists easy classification as they cut across Brown and Zavestoski ‘s ideal types.

However, the broader AIDS movement, as past scholars have indicated, is arguably the quintessential example of an embodied SM in health care. As Epstein documents, the mobilization of activists often occurs among those suffering from the disease or intimately related to people who are. AIDS activism in the U.S. has exerted a phenomenal challenge to the credibility of scientific claims and knowledge production about AIDS. This unique interaction and confrontation with health policy and biomedical research arose during the earliest years of the epidemic, due, in part, to the high stakes involved—the difference between life or death—at a time when AIDS treatments were scarce, or nonexistent and AIDS policy deficient.

Epstein, like scholars since him also highlights the multiple arenas and social

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institutions with which activists working to fight HIV/AIDS must contend. Thus, I adhere to the *multi-institutional politics model* of understanding the black American HIV/AIDS HSM goals, membership, tactics, etc. The multi-institutional politics (MIP) approach “offers the theoretical tools with which to investigate the shifting nature of domination (both material and cultural) in both governmental and nongovernmental institutions and collective efforts that arise in response to different types of domination.” This approach to social movements is a recent development emerging out of critiques of earlier theoretical interventions—i.e. political opportunity and political process theory—that are still dominant in analyzes of social movements.

Political opportunity and political process theory approaches continue to assume that the nation-state plays a primary and determining role in social movements. As Levitsky and Banaszak-Holl explained in the introduction to the edited volume, *Social Movements and the Transformation of American Health Care*, “[I]n these accounts, the primary goal of social movements is to achieve changes in public policy[,] to grant new benefits for constituents[,] or recognition by authorities.” In contrast, HSMs call attention to how movements may challenge institutions beyond the state, “including the political

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logics, organization, and systems of meanings that sustain and reproduce dominant health paradigms and systems of health care provision.”

I have previously stated that the nation-state, in the form of public health organizations—most notably, the CDC—is a significant actor in my analysis. We shall see the state at times in this social-history of the black American’s HIV/AIDS activism functioning as it is conceptualized in classical understandings of social movement activity. Yet, in analyzing the general black American HIV/AIDS HSM, I argue that the MIP model offers numerous, generative advantages over political opportunity and political process theory. For example, of particular importance to this study, it expands our notion of “who counts” as a social movement actor. Rather than seeing state actors as necessarily separate from social movement actors, the MIP framework holds that the position of a state actor role vis-à-vis the social movement is variable across institutions and change efforts addressing them; it is a question of empirical investigation. My analysis highlights the way in which, within the context of the HIV prevention field, actors transverse the demarcations between the state and social movement.

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48 Ibid., 4.
Critical Race Studies

Throughout this dissertation, my analysis is grounded within a tradition of scholarship that treats racial categories and meanings as an outcome of social processes, rather than an inherent characteristic naturally and unproblematically imbued with meaning and consequence. I identify such scholarship under the general heading of critical race studies. More specifically, this dissertation relies on and contributes to two distinct—yet easily relatable—theoretical streams greatly influential in critical studies of race: racial formation theory and intersectional theory.50

Racial Formation Theory:

Michael Omi and Howard Winant defined racial formation as “the sociohistorical process by which racial categories are created, inhabited, transformed, and destroyed.”51 They further clarified that racial formation is “a process of historically situated projects” that make linkages “between structure and representation and that these “racial projects” are “simultaneously an interpretation, representation, or explanation of racial dynamics, and an effort to reorganize and redistribute resources along particular racial lines.”52 I argue in this dissertation that black Americans’ HIV/AIDS activism and other

52 Ibid., 55-56.
organizational actors efforts within the general HIV prevention field—as configured both in the past and more contemporarily—are racial projects.

That is, racial formation theory provides a framework for analyzing the constructions and articulations of race within and across the regimes of black American exclusion and inclusion, as well as the representations of race in the US HIV/AIDS epidemic over time. I take seriously Omi and Winant’s admonishment that “we should think of race as an element of social structure rather than as an irregularity within it.”53 I am thus compelled to examine the ways in which scientific and public health knowledge about HIV/AIDS, from its emergence, has been intertwined with representations and formations of race (and obviously and just as importantly: gender, sexuality, and class). Therefore, racial formation theory serves as a useful conceptual apparatus to assist me in thinking through the ways in which, over time, the institutional practices and discourses constitutive of the HIV/AIDS disease regimes enable various racial subjectivities and activism within the HIV prevention field.

My employment of racial formation theory addresses an analytical shortcoming of the concept of disease regime as developed and used by Klawiter. As I explained earlier, the concept of disease regime calls attention to practices that discursively and materially render diseases knowable, and that socially constructs and structures people’s experience with a given disease. However, Klawiter does not explicitly define or explore how practices constitutive of disease regimes relate to or signify race, or how the practices themselves are embedded within a broader politics of race. Conversely, since its original formulation in the mid-1980s, Omi and Winant’s racial formation theory is

53 Ibid., 55.
implicitly and explicitly employed by a host of scholars who analyze various arenas within which meanings and representations of race are constructed and debated. Yet, few social scientists have offered studies of how domains of health and biomedicine are involved in processes of racial formation as I do within this dissertation. Hence, the approach I take with this dissertation is, perhaps, more in line with humanities scholars, particularly historians, who in relatively recent work have begin to trace how meanings and practices attributed to diseases and diseased populations contribute to processes of racialization or racial formation.

Intersectionality Theory:

As suggested above, I understand the field of HIV prevention as being implicated in representations and formations of not only race, but also gender, sexuality and class. I follow an intellectual tradition promoted most prominently by women of color feminists

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and apply an analysis that reveal the intersecting salience of race, gender, sexuality, and class within the HIV prevention field. Patricia Hill Collins, an eminent sociologist and black feminist, described analytical advantages of what is now known as intersectional theory, in her foundational manuscript, *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment.* In demonstrating “Black women’s emerging power as agents of knowledge” and explicating an Afrocentric feminism goal of empowering oppressed people, Collins argued, “Black feminist thought fosters a fundamental paradigmatic shift that rejects additive approaches to oppression.” Instead of viewing race, gender, sexuality and class as simply similar yet distinguishable social institutions, she advocated for the importance of examining them as an interlocking system and applying due analytical attention to how race, gender, sexuality and class interconnect.

I follow the insights of Collins and other women of color feminists who employ intersectional analysis and/or generate intersectional theory in two specific ways. First, throughout the chapters of this dissertation I highlight how the intersections of race, gender, sexuality and class formations are implicated in the field of HIV prevention. Secondly, a goal in this dissertation is to center the intersections of

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57 Ibid., 221.
58 Ibid., 222.
race/gender/sexuality/class formations in my analysis, as I also apply intersectional
theory as an interpretive framework.

Such an approach has much in common with what Roderick Ferguson terms a
“queer of color critique.” Similar to Collins’ insistence on the relief that intersectional
theory provided from the “either/or dichotomous thinking of Eurocentric, masculinity
thought,” Ferguson maintained, “that liberal ideology occludes the intersecting saliency
of race, gender, sexuality, and class in forming social practices.” He continues:

“Approaching ideologies of transparency [i.e.: Marxism, revolutionary nationalism, and
liberal pluralism] as formations that have worked to conceal those intersections means
that queer of color analysis has to debunk the idea that race, class, gender, and sexuality
are discrete formations, apparently insulated from one another. As queer of color critique
challenges ideologies of discreteness, it attempts to disturb the idea that racial and
national formations are obviously disconnected.”

My dissertation employs a queer of color analysis, as the concept is defined by
Ferguson, in the sense that I too am concerned with both racial and national formations
and interconnections between the two. Specifically, I conceptualize black health

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63 Ibid.
64 From my perspective, in formulating the queer of color critique Ferguson understates the substantive and theoretical reach of women of color feminists’ interventions. For example, Ferguson writes: “We may say that women of color feminism names a crucial component of...[the] genealogy of queer of color analysis as women of color theorists have historical theorized intersections as the basis of social formations. Queer of color analysis extends women of color feminism by investigating how intersecting racial, gender, and sexual practices antagonize and/or conspire with the normative investments of nation-states and capital” (Ibid.). Yet, what Ferguson identifies as the innovation of the queer of color analysis, I identify as a long-standing project of women of color feminists (c.f., Collins, Patricia H. 1998. "It's all in the Family: Intersections of Gender, Race, and Nation;" Collins, Patricia H. 2000. "Gender,
activism to prevent HIV/AIDS in black America as a part of the ongoing citizenship struggles of black Americans. And, additionally I understand modes of governance in the U.S. as deeply implicated in how black Americans experience(d) exclusion and inclusion within the HIV prevention field.

**Governmentality Studies**

My focus on the mobilization of institutions of U.S. public health—i.e. the state—and black Americans to combat HIV/AIDS in black communities also leads me to locate my analysis within domains of scholarship concerned with issues of governance and citizenship. In particular, I rely on—and contribute to—a tradition of scholarship inspired by the late writings of Foucault known as *governmentality studies/theory*. The concept of governmentality developed from Foucault’s definition of government as “the conduct of conduct.” As used in this phrase, conduct calls attention to how government “entails any attempt to shape with some degree of deliberation aspects of our behaviour according to particular sets of norms and for a variety of ends.” The term governmentality refers to the “art of government” and directs our analytical attention to “the organized practices through which we are governed and through which we govern ourselves.” It assumes that expertise, and the general production of truth and

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67 Ibid. 18.
knowledge, is of great significance to the regimes of practices, or regimes of government, constituting governance.68

I argue that HIV prevention makes readily apparent and exemplifies the practices and ethos of (post)modern modes of governance that the notion of governmentality is meant to evoke. The field of HIV prevention—at its core—is focused on developing techniques and programs that change the conduct and behavior of individuals and groups at risk of contracting or spreading HIV.69 Preventing HIV in ‘black America’ is thus, especially from the perspective of the CDC, dependent upon scientifically produced knowledge and best-demonstrated practices to develop effective prevention programs. Scholars such as historian Nayan Shah have demonstrated that throughout the 19th and 20th century public health has operated through strategies “of both state regulation and bourgeois self-regulation that linked the conduct and consciousness of the individual self with the vitality of society overall.”70 This fact has been particularly studied with regard to both local and federal public health jurisdictions relationships with their racial or ethnic minorities communities.71

My focus on black American activists and BCBOs as consequential actors in the

HIV prevention field allows me to provide a corrective to studies that highlight public health’s regulative functions and intervention within racial and ethnic minority communities. A predominate concern of this scholarship is with delineating and critiquing practices of official institutions of governance and arms of the state as public health without due attention to activities and knowledge production practices within the racial and ethnic minority communities targeted by public health practices. The history of HIV/AIDS epidemic and the responses to it, I argue, exemplify a central tenet of governmentality theory: “[T]here is no simple distinction between those who have power and those who are subject to it.”72 Hence, my goal is to document and examine black Americans’ experiences in the field of HIV prevention as both objects of public health intervention and as active subjects and knowledge producers within the field.

The dynamics of the field of HIV prevention also expose another aspect of the concept of governmentality. Governmentality also marks the emergence of a new form of politics in the 18th century, surviving to this day, that “focus on the life processes of the population.”73 Foucault and his follows have addresses this biopolitics across three regimes of government: (a) liberalism or classical liberalism; (b) the welfare state; and (c) neoliberalism or advanced liberalism.74 My analysis of the HIV prevention field reveals it to be is a site where the continuities, discontinuities and particularities of the welfare and

neoliberal modern state are rendered discernible. Most significantly, applying
governmentality theory to the case of black American mobilizations and experiences
within the HIV prevention field enables, I argue, an analysis of the ongoing constructions
and particularities of black American citizenship.

Starting from a position that citizenship is not only a matter of formal legal status,
but also an ongoing contingent process, I show how black health activism to prevent
HIV/AIDS in black America is part of the ongoing citizenship struggles of black
Americans.75 Our history and present confirms that black Americans have had an uneasy
and precarious relationship with citizenship. For example, as the mass incarceration of
black males and the valence of racism within debates over social welfare demonstrates,
black Americans inclusion and incorporation within the US welfare state has and
continues to be very tenuous and fraught in the last few decades.76 The HIV prevention
field is another site where the everyday processes and practices of belonging and being-
made “American,” as well as struggles to claim the rights of legal, political and social U.S.
citizenship, are staged. Within and across the two disease regimes of HIV/AIDS defined

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75 For analyses which employ, theorize, and characterize this and similar formulations of citizenship, c.f.
and Gender Shaped American Citizenship and Labor. Cambridge, Mass.: Harvard University Press; Isin, Engin
Citizenship in the 'cultural' Society: A Cosmopolitan Approach." Citizenship Studies 7: 331-348; Rose,
Politics, and Ethics as Anthropological Problems, edited by Aihwa Ong and Stephen J. Collier. Malden, MA:

76 On the mass incarceration of black males see, Wacquant, Loic. 2001. "Deadly Symbiosis: When Ghetto
and Prison Meet and Mesh." Punishment & Society 3: 95-134. On the "color of welfare," see Quadagno,
Press.
in this dissertation, I will show how and with what consequences processes and practices of both the welfare state and neoliberal state are expressed, particularly through the HIV prevention field. Furthermore, especially in examining the contemporary HIV prevention field, I document and analyze black Americans’ practices of accommodation and resistance to these differential, but coexisting governmental tendencies (See Chapter 4).

Before moving forward, I want to emphasize that my goal in using the concept of governmentality, a concept so closely identified with Foucault and his followers, is not to enter in or contribute to seemingly esoteric theoretical debates. Nor am I signaling an impervious allegiance to the Foucaultian theoretical tradition. As George Lipsitz so succinctly stated in his study of labor in the 1940s: “My sympathies and commitments begin with people rather than with theories.” I use a governmentality approach, and indeed all of the theoretical concepts within this dissertation, chiefly because I find them fruitful tools to render visible and more understandable the conditions and experiences of black Americans in the field of HIV/AIDS. In the next section, I present and explain the methodological and analytical approaches I employed that also assisted me in this task.

Methodological Issues

**SOURCES**

Mirroring my commitment to grounding my analysis in diverse theoretical and substantive traditions of scholarship, I employed multiple qualitative approaches and

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methodological tools to collect data that captures the changing racial dynamics of HIV/AIDS within the HIV prevention field from 1981 until 2009. In particular, I use participant observation at public health and community based HIV/AIDS conferences; interviews with both public health administrators and black American community activists; and content and discursive analysis of documents and publications from black American HIV activists and BCBOs, governmental hearings, the mass media, the “national medical-scientific-public health establishment,” and social scientists. My fundamental analytical strategy has been to bring into critical juxtaposition discourses generated by these various social worlds that, in part, construct the field of HIV prevention. I treat the range of sources as primary data; I briefly discuss each in more detail below.

I attended three national conferences from 2008 and 2009. One, a two-day conference was convened in Oakland, California during the early winter of 2008 by the National AIDS Education & Services for Minorities, Inc. (NAESM), a BCBO headquartered in Atlanta, Georgia. The second conference, the National Minority AIDS Council’s (NMAC) HIV Prevention Leadership Summit (HPLS), was held in Detroit, Michigan from June 11-14, 2008. The 2009 National HIV Prevention Conference (NHPC) in Atlanta, Georgia from August 23-26 was the third, and final, conference at which I participated and observed. The CDC, in consultation with a number of federal and state public health institutions, and community organizations, convenes the NHPC.78 My attendance at these conferences provided me the opportunity to observe black American HIV/AIDS activists in a primary contemporary domain where HIV/AIDS

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78 The HPLS and NHPC are held in alternate years.
prevention programs, policies, and knowledge are discussed, debated, and disseminated. Additionally, at the conferences I collected publications and other materials produced by BBCOs, the CDC, and others, which I submitted to a discourse and/or content analysis. The conferences also served as an opportunity for me to identify or to make initial contact with potential interview subjects.

However, for both practical and theoretical reasons interview subjects for this analysis were limited to organizational actors located in Atlanta, Georgia. As I indicated earlier, an important goal of my dissertation is to intervene on narratives and histories of HIV/AIDS that render invisible black Americans' experiences. Yet another, obviously related, intervention is to combat a curious attribute of the scholarship that limit both our historical and contemporary understandings of HIV/AIDS in the U.S.: That cities on the North Atlantic East Coast and the West Coast have garnered most of scholars' analytical attention. To meet each of these goals, I chose the unofficial capital of the so-call “New South,” as my field-site. Atlanta, the capital and most populous city of the state of Georgia—as well as, to many, the unofficial capital of “black America”—draws many of its black residents from rural communities all over the South and the post-industrial urban North. Thus, Atlanta's demographic profile and geographic locale in the South closely follows the broader incidence trends of HIV/AIDS in the country. Moreover, as Atlanta is home to both a large black population and the CDC it was a practical, if not ideal, location to collect ethnographic data to assist in generating an analysis of black


From September 2008 until August 2009, I lived in Atlanta to conduct interviews with CDC administrators and black American community HIV/AIDS activists and to participate in local HIV/AIDS prevention events. The black American community activists I interviewed were employees of either NAESM or SisterLove—two BCBOs located in Atlanta. I interviewed a total of thirteen respondents, all whom identified as black or African Americans, for thirty-eight minutes to two hours on variety of topics, including but not limited to: their personal and work histories; how they came to be involved in HIV activism; how they came to work in BCBOs and/or in the CDC; perceptions of how the HIV/AIDS epidemic has changed over time; their understanding of the salience of race in their work; assessments of prevention technologies and interventions; and how they perceive and work with the various actors, organizations, and communities that are relevant to their work. The interviews provided me access, in addition to other pertinent information, to these actors' retrospective and present-day experiences within, and their understandings of, the HIV prevention field.

My final source of data was more archival, consisting of documents and publications produced by and within various “social worlds” that report and (often simultaneously) produce knowledge about HIV/AIDS. As the social geographer, Michael Brown, notes “...there is a strong and longstanding argument for researching media portrayals of HIV and AIDS because of their power in not just reflecting, but convincingly framing perspectives on the nature of the virus, the epidemic, and the
people living with, and dying from it.” I look to the mass media, relying mostly on *The New York Times* and *The Washington Post*, to document at what times and the ways in which black Americans and their communities were featured in nationally orientated press coverage of HIV/AIDS from 1981 to 1991. Likewise, I use other publications and sources from sites within the national medical-scientific-public health establishment, most notably the CDC produced *Morbidity and Mortality Weekly Report (MMWR)*, to further trace the trajectory of the salience of black Americans in the general HIV/AIDS discourse and, more specifically, the HIV prevention field.

**ARCELOGY, GENEALOGY AND CRITICAL DISCOURSE ANALYSIS**

The mode of my analysis is inspired by a diverse lineage of scholarship. In addition to the analytical and methodological insights provided by the literatures in which I situate this dissertation, I am also inspired by the historical method of Foucault. Like Epstein, I characterize my analysis as having affinities with Foucault's archaeological and genealogical methods. It is archaeological in that I trace the evolving experiences of black Americans in the HIV prevention field by focusing on events over the course of the epidemic that recover the “immanent rules of what is sayable and unsayable, thinkable and unthinkable.” I show how what now seems obvious and necessary (i.e. black

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subjectivity within the HIV prevention field) was not just a matter of course; but rather, its formation relied on “a multiplicity of processes,” or historical events.\textsuperscript{83} Such an account, “means rediscovering the connections, encounters, supports, blockages, plays of forces, strategies and so on which at a given moment establish what subsequently counts as being self-evident, universal and necessary.”\textsuperscript{84}

This analysis is genealogical in that it emphasizes the shifts and discontinuities in both the construction of the prevention field and the trajectory of HIV prevention knowledge. I present the shift in the racialization of HIV/ADS and black Americans' subjectivity within the HIV prevention field as the results of contingent turns in history. Additionally, the dissertation's narrative is generated by considering the “situated knowledges” of black Americans even-handedly with more so-called authoritative or official sources. Epstein, quoting Foucault,\textsuperscript{85} describes genealogical research as entertaining “the claims to attention of local, discontinuous, disqualified, illegitimate knowledges against the claims of a unitary body of theory which would filter, hierarchise and order them in the name of some true knowledge and some arbitrary idea of what constitutes a science and its objects.”\textsuperscript{86} Thus, my analysis is constructed through attending to—and juxtaposing—the positions and claims of both black American activists and CDC administrators, in addition to those positions and claims emanating from prevention conferences, and the (social) scientific literature.

\textsuperscript{83} Foucault, Michel. 1991. "Questions of Method." Pp. 73-86 in The Foucault Effect: Studies in Governmentality: With Two Lectures and an Interview with Michel Foucault, 77)

\textsuperscript{84} (Ibid., 76. Foucault termed this mode of analysis as “eventualization,” or “[a] breach of self-evidence, of those self-evidences on which our knowledges, acquiescences, and practices rest” (Ibid.).


\textsuperscript{86} Steven, Epstein. 1996. Impure Science: AIDS, Activism, and the Politics of Knowledge, 357.
Finally, in addition to an analysis informed by methods of archeology and genealogy, I also rely on critical discourse analysis (CDA). CDA, as developed by the linguist Norman Fairclough, conceives of discourse as social practice, implying “a dialectical relationship between a particular discursive event and the situation(s), institution(s) and social structure(s) which frame it.”

In adapting CDA as an informing analytic method, this dissertation assumes that the claims made about HIV/AIDS and race—as reported by the media, or within congressional document, or (social) scientific texts, or within my interview data—in some ways reflect and help constitute the institutionalized practices that structure understanding of HIV/AIDS and experiences within the HIV prevention field. CDA is also useful to me in that it “sees itself not as dispassionate and objective social science, but as engaged and committed.”

Thus, my analysis and particularly my conclusions are constructed in a way that contributes not only to scholarly debates, but also to public policy.

**Organization of the Analysis**

Chapter 2 delineates the regime of black American exclusion in the HIV prevention field by critically juxtaposing expert, popular, and lay discourses about the mysterious disease that became known in 1981. I describe the confluence of social,

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cultural and structural forces that effectively constituted a disease regime of exclusion for black Americans. Accordingly, I show how for the first decade or so the epidemic of the discourse on HIV/AIDS the disease was racialized as a white disease, and further constructed as a gay male disease. This chapter highlights some of the discourses and practices produced by institutions, such as the media, public health, and medicine that helped to structure and to predominantly promote HIV/AIDS as a disease of white, gay men. I illustrate that this racialization, along with the stigmatization of the disease as one resulting from purportedly ‘deviant’ sexuality practices, at best, undermined and, at worst, rendered invisible black Americans experiences with—and early activism against—HIV/AIDS. This chapter relies largely (but not entirely) on secondary social science and historical accounts of the HIV/AIDS epidemic in the U.S. I recast this literature and use an analysis of media (and other archival sources) to provide evidence for the regime of black American exclusion.

In chapter 3, I present and examine the evidence that demonstrates a shift in the racialization of HIV/AIDS and the emergence of a more visible and significant black American HIV/AIDS mobilization. My purpose in this chapter is to increase Verstehen(understanding) that the racializing discourses, and institutional practices and policies in the HIV/AIDS fields have changed. I show, through attending to what Foucault calls the “micro-physics of power,” how a new regime, which better enables and makes visible black American activism and advocacy, arose both from the contradictions and tensions of the first regime and broader transformations of public health and biomedical policy. I argue that this second regime—the regime of black American
inclusion—begins around 1992. I chart and analyze significant moments and events in the emergence and institutionalization of (BCBOs), as well as other relevant organizations. I highlight significant changes in the popular media’s and the national medical-scientific-public health establishment’s discourses, practices and policies that also signal the changing racialization of the disease. Together Chapter 2 and 3 describe the changing racialization of HIV/AIDS from white to black and establishes that black Americans moved from exclusion to inclusion in the HIV prevention field.

I then turn, in Chapter 4, to exploring more concretely the dynamics of the regime of black American inclusion. Using the HIV prevention field as constituted in Atlanta, Georgia, as a case study, I analyze the ways in which prevention efforts of BCBOs and domains of public health align with, or conflict with, each other. In particular, I show how the CDC’s reliance on “objective science” (the Diffusion of Effective Behavioral Interventions or “DEBI” program) to create prevention programs is in long-standing tension with BCBOs, who often advocate and prefer homegrown prevention programs (those that black activists denote as “For Us and By Us” or “FUBU”). Relying on data collected through participant-observation at HIV prevention conferences; interviews with CDC officials and black American HIV/AIDS activists; and archival sources, I argue the tension is productive in constructing a “knowledge-intervention terrain” that increasingly—but problematically—incorporates black Americans’ concerns and cultural products. The chapter demonstrates that this incorporation has the ironic potential to undermine BCBO’s progressive mission as it encourages a black American neo-liberal citizen-subject position.

However, I detail some events indicating the beginning of the inclusion regime as early as 1987.
The conclusion of the dissertation, which comprises Chapter 5, has multiple goals. First, I summarize my findings and highlight the ways in which my analysis of HIV prevention in two regimes contributes to our understandings of the biopolitics of race in the HIV/AIDS epidemic in the U.S. I review how missions, tactics, and knowledge production practices of BCBOs and institutions of public health (most notably, the CDC) are differentially informed and structured by, as well as constitutive of, formations of race, gender, sexuality, and citizenship. I also discuss how this analysis demonstrates the continuing importance of the state in addressing health social problems that plague racial minority communities, as well as indicating the significance of health activism to the post-1960s civil rights movement. Conversely, I advocate for bringing the question of citizenship to the fore in studies of HSMs. Finally, I evaluate the promises and attendant risks of inclusion to address the racial disparities in HIV/AIDS related outcomes and other racial health disparities.
Chapter 2

When AIDS ‘Began’ to the Early 1990s—The Regime of Black American Exclusion

Human problems do not spring up, full-blown and announced, into the consciousness of bystanders. Even to recognize a situation as painful requires a system for categorizing and defining events.

Joseph Gusfield

Even a cursory consideration of the popular press or academic discourse regarding first AIDS, and latter HIV/AIDS, reveal the centrality of white, gay men in our knowledge about and responses to the disease in the United States. Especially during the first decade or so of the epidemic the disease was largely depicted as chiefly impacting and mattering to white gay men. Notwithstanding the exceptions discussed below, black Americans were largely “missing” in the discourse and practices revolving around both the disease and the emergence of the HIV/AIDS prevention field. In this chapter, I

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91 The syndrome that became designated, as AIDS was first reported in 1981, with the acronym AIDS (Acquired immune deficiency syndrome) being coin in 1982; HIV (Human immunodeficiency virus) as the etiological agent of the syndrome was first discovered in 1983. Though it is technical a syndrome, I interchangeably refer to AIDS as a disease and syndrome throughout the dissertation.
92 I refer to “black Americans” instead of “African Americans” because both native U.S. born blacks and black immigrants from land of the African diaspora are actors in the HIV prevention field. Furthermore, the CDC does not contemporarily distinguish between the nationalities or ancestries of those designated in their surveillance data as “black Americans.” Hence, within this context, I believe “black Americans” is the more appropriate term.
93 As black bodies at certain times (in certain context and historical conjectures) were often highly salient and visible, particularly within the fields of public health and biomedicine, I argue black Americans were largely “missing” in the discourse. “For to be missing means that something or someone was once visible and is now lost,” as sociologists, Casper and Moore, explains (Casper, Monica J. and Lisa J. Moore. 2009. Missing Bodies: The Politics of Visibility. New York: New York University Press, 3.)
critically analyze expert, popular, and lay HIV/AIDS discourses generated from when AIDS began until the early 1990s. My goal is to apply an intersectional analysis that uncovers the ways that from its emergence the general discourse and, more specifically, practices constituting the inchoate prevention field intertwined representations and formations of race, gender, sexuality, and class. I argue that these formations—produced chiefly and in dynamic conjuncture by the federal government primarily via domains of public health, the media, and the early mainstream HIV/AIDS social movement—constructed a disease regime, which effectively rendered invisible black Americans’ experience with the disease. Thus, black Americans were excluded from consistent consideration within the initial configuration of the HIV prevention.

This chapter is organized to answer two critical questions: 1) How were black Americans excluded; or in fact, how do we know they were? And, 2) What conditions or mechanisms enabled or sustained their exclusion? The chapter concludes with a brief consideration (to be further developed in Chapter 3) of the social forces converging from within and without the HIV prevention field in the early 1990s to disrupt the regime of exclusion, bringing forth the regime of inclusion.

**How Do We Know there was a Regime of Exclusion?**

To begin to answer the question of how we know black Americans were effectively excluded from the overall discourse of HIV/AIDS and, more specifically, the practices of the prevention field, I will start by specifying in more detail what I mean by *exclusion*. The term is employed to bring attention to the ways in which dominant images,
practices and discourses constructed a representation of HIV/AIDS that discouraged and largely disenabled the development of a positive black subjectivity vis-à-vis the disease.

In this analysis, I emphasize how the practices and discourses—or the “thinking, actions, and programs”—emanating from public health, the media, and the early social movement were integral in this construction. That is, these three social worlds were influential in producing the social relations of HIV/AIDS in the U.S. that facilitated black Americans exclusion from 1981 to the early 1990s.

In this section (and throughout the rest of the chapter), I call attention to the “politics of knowledge” and the aligned “politics of representation” in the construction of the exclusion regime. I pay attention to ways in which an unknown medical syndrome was rendered known in part through the production and use of discourses and practices that enacted and reinforced preexisting racialist, heteronormative, and classist structures. Moreover, I show some of the ways in which the socio-political domains of public health, the media, and the social movement are all implicated in the production of knowledge about and representations of HIV/AIDS that relied on familiar socio-historical scenarios. I argue that the efforts of these three domains effectively reduced a mysterious array of symptoms and unknown disease causes to easily understood codes that the lay public could grasp, and thus provided a “social prescription” for responding to the disease. In short, they helped to inaugurate a “regime”—that is, a systematic discursive and

96 Of course, it is not my argument that that this was an intentional or conscious construction, but a result of the embeddedness of, for example, historical informed racial logic in institutions of public health, biomedicine and the media.
behavioral model for understanding and responding to the disease that effectively excluded black Americans.

PUBLIC HEALTH, BIOMEDICINE AND EARLY AIDS DISCOURSE

In the first decade or so from when a puzzling medical syndrome that we now know as HIV/AIDS was first reported, the practices, policies and general *modus operandi* of the institutions of the U.S. federal government—chiefly through domains of public health—and biomedicine constructed the disease as largely a disease of white gay men. A brief reconstruction of this history based on the relevant secondary literature, and my own analysis of pertinent CDC documents and biomedical publications will reveal the broad parameters of this earlier disease construction. The goal here is to emphasize how most earliest understandings, or framings, of the disease were consequential to black Americans.


The first report of HIV/AIDS inauspiciously appeared in the CDC’s *Morbidity and Mortality Weekly Report* (MMWR) on June 5, 1981, in reference to “5 young men, all active homosexuals, [who] were treated for biopsy-confirmed *Pneumocystis carinii* pneumonia [PCP] at 3 different hospitals in Los Angeles, California” over the previous eight months. The report noted that two of the five men had died; and, in the report’s editorial comment section, that the occurrence of this particular strain of pneumonia “in these 5
previously healthy individuals without a clinically apparent underlying immunodeficiency is unusual.” The unidentified editor(s) postulated: “[t]he fact that these patients were all homosexuals suggests an association between some aspect of a homosexual lifestyle or disease acquired through sexual contact….” Curiously—especially in light of the centrality of race in the epidemic to come—there is no mention of the race or ethnic background of the five patients in this first report, although there was a detailed, albeit abbreviated, case history presented for each.

A few weeks later on July 4, the CDC announced the diagnosis of twenty-six homosexual men (twenty cases in New York City and six in California) with Kaposi’s sarcoma (KS), “an uncommonly reported malignancy in the United States.” This second report noted, seemingly in passing, that twenty-five of these patients were “white” and that one was “black,” marking the CDC’s first employment of a racial categorization scheme to classify homosexual men afflicted with an “highly unusual” disease. As the second MMWR report on what would soon become know as AIDS continued to highlight the question of sexuality in the etiology of the disease, it also offered the claim that “immunosuppression may result in the development of KS.” The concluding paragraph of the report stated there was no certainty that the cases of KS and PCP pneumonia were restricted to homosexual men. Yet, given that “the vast majority of recent cases have been reported for this group, it advised physicians to “be alert” for these two unusual diseases, “and other opportunistic infections associate with

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immunosuppression in homosexual men. 98

With these two CDC reports the initial social construction of HIV/AIDS as a sexually transmitted disease specifically associated with male homosexuality was well on its way of becoming established. The recommendation that health providers to be on the lookout for opportunistic infections affecting homosexual men resulted in doctors and public health departments in cities with large gay communities focusing on the health charts and death certificates of known and suspected homosexual men. This “top down” arrival of the epidemic structured the earliest surveillance efforts of cities, such as San Francisco, 99 and (to be discussed in some detail later in this chapter) prompted the characterization of the HIV/AIDS in the media and popular discourse as being a “gay disease.” It was sensational references to gay men’s sexuality that inaugurated “the single most consequential aspect of the social construction of the epidemic.” 100 For instance, doctors reporting the cases of PC pneumonia and KS featured in the CDC reports recounted that “…most cases had involved homosexual men who have had multiple and frequent sexual encounters with different partners, as many as 10 sexual encounters each night up to four times a week.” 101 This resulted in a pervasive “speculative focus on ‘the gay lifestyle’” that led medical doctors/researchers and epidemiologists in the CDC and elsewhere to assume a link between AIDS and homosexuality even as the cause and rate

of incidence of the syndrome was yet to be determined.\footnote{Epstein, Steven. 1996. \textit{Impure Science: AIDS, Activism, and the Politics of Knowledge}, 49.}

Therefore, in the face of evidence—appearing as early as in the beginning of 1982—that the “nationwide epidemic of immunodeficiency among male homosexual was in fact not restricted to gay men,” the focus of attention in the epidemiological\footnote{I distinguish epidemiology from other biomedical practices because the CDC depends heavily on case reports and epidemiological investigations to monitor morbidity and mortality trends and to respond to acute outbreaks of infectious disease. Medical historian Gerald M. Oppenheimer made this related observation: “Epidemiology, in comparison with most other medical disciplines, is particularly well-suited to explore, portray, and explain new medical phenomena. It seeks to measure and analyze the occurrence and distribution of diseases and other health-related conditions, acting both as a sentinel who warns of shifts in disease patterns and as a scout who seizes on such shifts to discover their etiology” (Oppenheimer, Gerald M. 1988. "In the Eye of the Storm: The Epidemiological Construction of AIDS" Pp. 267-300 in \textit{AIDS: The Burdens of History}, edited by Elizabeth Fee and Daniel M. Fox. Berkeley: University of California Press, 269).} and biomedical literature continued to be squarely on male homosexuals.\footnote{Epstein, Steven. 1996. \textit{Impure Science: AIDS, Activism, and the Politics of Knowledge}, 47.} Doctors had become aware of at least two cases of the syndrome in “exclusively heterosexual men” in early December of 1981—just some six months after the initial MMW report.\footnote{Gottlieb, Michael S., Robert Schroff, Howard M. Schanker, Joel D. Weisman, Peng T. Fan, Robert A. Wolf and Andrew Saxon. 1981. "Pneumocystis Carinii Pneumonia and Mucosal Candidiasis in Previously Healthy Homosexual Men." \textit{N Engl J Med} 305:1425-31.}

Moreover, there were also accounts specifying cases of unusual opportunistic infections, such as PCP, in injection drug users not identified as homosexuals.\footnote{Masur, Henry, Mary A. Michelis, Jeffrey B. Greene, Ida Onorato, Robert A. Vande Stouwe, Robert S. Holzman, Gary Wormser, Lee Brettman, Michael Lange, Henry W. Murray and Susanna Cunningham-Rundles. 1981. "An Outbreak of Community-Acquired Pneumocystis Carinii Pneumonia." \textit{N Engl J Med} 305:1431-8.} Despite these cases in non-homosexuals, homosexuality became the identity feature most aligned with the new disease; for as the sociologist Steven Epstein noted:

\begin{quote}
Epidemiologists immediately fastened upon the most sensational markers
\end{quote}
of homosexual difference, trumpeting the cases of men with histories of thousands of sexual partners, while ignoring the cases, also reported by clinicians from the very beginning, of gay men who were monogamous or who engaged in relatively modest amounts of sexual experimentation.\(^\text{107}\)

This central focus on male homosexuality in the biomedical literature during the first few years of the epidemic was due in large part to the prominent role that epidemiological science played in “defining and ordering this ‘medical mystery.’”\(^\text{108}\)

Significantly, as Gerald M. Oppenheimer pointed out, “[u]nlike the reductionist paradigm of the germ theory, the multicausal (sic) model [used in epidemiology] embraces a variety of environmental and social factors.”\(^\text{109}\) Although the multi-casual model of disease is a laudable feature of epidemiological science, it makes evident a distinguishing feature of the discipline that—particularly as it is a scientific practice—may be construed as a weakness: Possible explanatory variables “may be drawn in (or left out) as a function of the social values of the scientists, the working group, or the society.”\(^\text{110}\)

With the benefit of hindsight, it is clear that epidemiology’s disciplinary avowal of both environmental and social factors, as explanatory variables with possible casual

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\(^\text{109}\) Ibid, 269. Epidemiologists favor multifactorial disease models as they seek to discern the causes and/or antecedents of diseases and the distribution of any given disease in a community. As explained by Oppenheimer, the ultimate objective of epidemiological investigations “is to isolate the causal variables of the disease in question. An intermediate goal is to discover a point in the natural history of the disease where intervention might alter its course, even if its etiology remains unknown (ibid).” Importantly, as Epstein (1996) notes, in isolating out what distinguishes a group that is newly affected with a disease from others not affected, epidemiology “is inevitably a ‘normalizing’ science, employing—and reinforcing—unexamined notions of normality to measure and classify deviation from the norm (49).”

\(^\text{110}\) Of course, following insights from the science and technologies studies (STS), I maintain that social values are an integral part of all scientific knowledge production disciplines. However, epidemiology is distinguished from other scientific disciplines as it reliance on social values is far more easily discernible to those outside of their epistemic field (see note 21 above). For more on STS, see note 4 of Chapter 1.
connections, helps to explain the initial emphasis on “the gay lifestyle” in the medical literature. As Epstein noted, “all speculation about causes [of the syndrome] proceeded from the premise of the centrality of male homosexuality.” This premise proliferated even though, in retrospect, the “dimensions of the disease were known in the first year: it affected homosexual men, intravenous drug users, both whites and blacks, and it could be passed on by a mother to her unborn child.”

As epidemiologists affixed upon etiological importance of homosexuality in the face of a mysterious syndrome appearing in white gay men, left unacknowledged by epidemiologists (and clinicians) was that white gay men’s relative privilege undoubtedly played a significant role in gay men being overwhelming represented in the initial cases. Their privilege—demonstrated by the access they have to doctors and prominent medical centers (such as UCLA)—meant that gay men appearing in doctor’s offices and then the medical literature got better medical attention than other segments of the U.S. population.

Clinicians who reported cases of PCP and KS in New York and Los Angeles and epidemiologists who analyzed the distribution of cases erroneously proceeded with an assumption that these cases were representative of unreported cases. Thus, other relevant categories of risk and populations suffering from the syndrome were occluded.

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113 The prior medicalization of homosexuality and medical surveillance of gay men immediately preceding the advent of AIDS also contributed to the zeroing in on the “gay life style.” As Cochran (2004) points out, “by virtue of concurrent research on hepatitis B and the focus on sexually transmitted epidemics among gay men [such as, in addition to hepatitis B, “gay bowel disease,” and shigellosis], government health officials were theoretically predisposed, at the very moment the Los Angeles cases of pneumonia [PC] were discovered, to infer that male homosexuality per se was epidemiologically and epistemologically salient for understanding the cause of this syndrome...” (24). See also Altman, Dennis. 1986. *AIDS in the Mind of America*. Garden City, N.Y.: Anchor Press/Doubleday, esp. 41-47.
114 Cochran maintains “the social construction of AIDS as a sexually transmitted disease meant that drug
For example, black Americans received little, or no, attention during this juncture in the biomedical and epidemiological literature even though black Americans were actually among the few initially known, within months of the initial the first CDC report, to be suffering from immunosuppression. Indeed, a curious—and in retrospect, especially striking—fact is that race is largely unremarked upon in these first reports of a “gay disease.” That is, only in passing (and only starting with the second MMW report) were the patients suffering from AIDS identified by race.

The Social Categories of Risk and the Continuing Non-Salience of Race:

From the perspective of the earliest biomedical and public health reports, race then appeared to be an unremarkable social or biomedical factor as the public health and biomedical infrastructure went about defining the syndrome and tracking its spread. As documented in the above section, homosexuals were the first and most consistently identified social group in reports specifying the morbidity and mortality of the epidemic. Thus, it was homosexuals and their supposedly distinctive lifestyle that drew the particular attention of the epidemiologists and biomedical scientists. Nonetheless, in March of 1983, even as the “gay lifestyle” itself were still presumed within the public health and biomedical discourse to be etiologically relevant, the CDC identified four social groups that were in increased risk to contract the AIDS virus. The four defined social categories of “highest risk” were homosexuals and bisexuals with multiple partners, use (and all other HIV/AIDS risks) among gay male AIDS cases has always been, and continues to be, significantly underreported in official AIDS surveillance statistics” (Cochrane, Michelle. 2004. When AIDS Began: San Francisco and the Making of an Epidemic, 56).
intravenous drug users, recent Haitian immigrants, and hemophiliacs.\textsuperscript{115}

In designating these high-risk groups the CDC verified that AIDS was spreading into multiple segments of society and that HIV infection appeared to follow a transmission pattern similar to that of the hepatitis B virus. More noteworthy however—even as the CDC maintained that “each [high-risk] group contains many persons who probably have little risk of acquiring AIDS”\textsuperscript{116}—was the socio-political impact of the CDC’s naming these high-risk groups. That is, the CDC’s designation of four seemingly mutually exclusive population groups, as the social categories that were at increased (the highest) risk of not only acquiring the disease but also of infecting others, led these groups to be regarded by scientists, the news media and the general public as synonymous with virus carriers.\textsuperscript{117} But, how did the social categories of risk contribute to black American exclusion from the AIDS discourse? An explanation of the logic in play in constructing the risk categories and an analysis of how the risk categories were used indicate the continuing non-salience of race, which assist in rendering cases of AIDS among black Americans invisible.


\textsuperscript{116} Ibid. Oppenheimer reminds us that as “no calibration of degree of risk was introduced [by the CDC]…no distinction could be drawn” between those members of the social group at high-risk from those at little risk or none (Oppenheimer, Gerald M. 1992. “Causes, Cases, and Cohorts: The Role of Epidemiology in the Historical Construction of AIDS.” Pp. 61 in AIDS: The Making of a Chronic Disease, edited by Elizabeth Fee and Daniel M. Fox. Berkeley: University of California Press).

\textsuperscript{117} A range of scholars have documented and analyzed the increase stigmatization and acts of discriminations suffered by the social groups identified as (and, at) high-risk. Renata Kiefer, MD, MPH and Stephen Hulley, MD, MPH put it this way: “Although the risk group designation for the purpose of voluntary blood donor deferral made sense, given the urgent need to protect the blood supply, there were unfortunate social implications for members of these four groups…The association of a life threatening disease with populations groups often held in low esteem had the potential for increasing discrimination against these groups”(1990. “A Modern Epidemic Emerges: History and Context.” Pp. 3-19 in Ending the HIV Epidemic Community Strategies in Disease Prevention and Health Promotion, edited by Steven Petrow, Pat Franks and Timothy R. Wolfred. Santa Cruz, CA: Network Publications, 7).
The construction and then use of the social categories of high risk relied on an uncritical assumption: The social groups therein identified were unproblematically distinct, discernible, and mutually exclusive. The CDC’s inter-agency recommendations published on March 4, 1983, which propagated the use of the four social categories of risk within public health and biomedical practice followed, in fact, the lead of an earlier issue of the MMWR. Released September of 1982, the first MMWR publication to identify these groups on the basis of a hierarchy of risk factors was based on a review of the 593 AIDS cases reported to the CDC between June 1, 1981, and September 15, 1982. In this report’s conclusion, the CDC placed the AIDS cases to date in this classification system as follows:

Reported AIDS cases may be separated into groups based on these risk factors: homosexual or bisexual males—75%, intravenous drug abusers with no history of male homosexual activity—13%, Haitians with neither a history of homosexuality nor a history of intravenous drug abuse—6%, persons with hemophilia A who were not Haitians, homosexuals, or intravenous drug abusers—0.3%, and persons in none of the other groups—5%.

What is particularly noteworthy about this classificatory scheme is the inclusion of four categories that by in large are primarily identity based rather than based on behavior or practices. In total and especially with the benefit of hindsight the inclusion of the national identity category of “Haitians” elicits pause and requires particular explanation. According to the British sociologist Alex Preda, it was through the function of the “economy of [the] risk categories” that cases of AIDS in “Haitians”—whom the CDC reported did not have a history of homosexuality, intravenous drug use/abuse, or hemophilia—could be conceived as a new phenomenon within the public health and

biomedical discourse. The case of “Haitians” uniquely brings to relief an important point: the four AIDS risk categories constitute “a classificatory system in which mutually exclusive categories reinforce each other.”

Thus, the construction and the proliferation of the take-up of the AIDS risks categories had the effect of filtering and directing how cases of immune deficiency were diagnosed and catalogued by doctors. Moreover, it also structured the inclusion and exclusion of certain populations in the AIDS discourse in the early 1980s. For example, the reported cases of AIDS in black Americans—not to mention the documented cases among “Hispanics,” women, heterosexual men and children—did not prove noteworthy enough to affect the risk categories; the classification system helped to render these cases invisible and/or unremarkable. Even the inclusion of Haitian was more about racialist understandings of nationality and citizenship, rather than about race as a potentially biomedical relevant social category in and of itself. Thus, within the classification system of the AIDS risk categories, race was not a salient category.

The non-salience of race as meaningful in the construction and use of the AIDS risk categories is clearly demonstrated by a September 1983 MMWR. In this CDC report it is explicitly noted that cases of AIDS “have occurred in all primary racial/ethnic groups

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119 With the word “economy,” Preda calls attention to how the AIDS risk categories were produced as a classification system and examines the relationship and exchanges between the categories. He notes: “In the economy of risk classification, 'Haitians' made very good sense: they were integrated by exclusion from other categories, thus both helping to define and being defined by this exclusion” (Preda, Alex. 2005. AIDS, Rhetoric, and Medical Knowledge. Cambridge, UK; New York: Cambridge University Press, 75, and esp. Chapter 2).
120 Ibid, 72.  In Preda’s words: “With the Acquired Immunodeficiency Syndrome as characteristic for some categories, which in turn were the risk of a specific immune deficiency, the classification system produced both its criterion and its categories” (Preda, Alex. 2005. AIDS, Rhetoric, and Medical Knowledge. Cambridge, UK; New York: Cambridge University Press, 71).
in the United States: 57% of those reported have been white, 26% black, 14% Hispanic, and 3% other or unknown.” However, there was no further elucidation on this finding in this MMWR; nor any mention that 26% represented a disproportionate number of AIDS cases among black Americans. In conjunction with the hyper-salience of homosexuality within the public health and biomedical discourse that is discussed above, it is this “colorblind” feature of the CDC’s risk classification system that assisted in constructing AIDS as a disease with which seemingly, black Americans need not have to been concerned.

Of course, when AIDS began, presumably few Americans, white or black, were regular readers of the MMWR or of medical journals, such as the New England Journal of Medicine. The reports as they appeared within these scientific journals ostensibly had little direct impact on how lay men and women, or their communities understood the impact of homosexuality or race as the epidemic was emerging and grew. Indeed, the media also played an important role in constructing and contributing to an AIDS discourse that undermined and largely excluded black Americans’ experiences.

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123 This also helps to explain how the privileges of whiteness was an unremarkable feature of the gay men who were the first identified, or the original, high-risk group.

Scholars have long considered the media an important site where the social relations and perspectives of the HIV/AIDS epidemic were not only reflected, but also actively produced and constructed. These analyses document and critique how various domains of media, including print and television news, film and television, have portrayed and dispersed knowledge and understandings of the syndrome. In particular, the news media has played an important role in informing and misinforming, educating—and often mis-educating—the public on the “when, who and what” within the first decade of the disease.

Privy to the information from the second MMWR announcement of July 4, 1981, The New York Times medical reporter, Dr. Lawrence Altman, wrote one of the earliest mainstream newspaper accounts on AIDS. Appearing within the newspaper under the title, “Rare Cancer Seen in 41 Homosexuals,” the article acknowledged that the cause of

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124 Such scholarship is part of a broader cross-disciplinary research tradition, which reveals—in the words of Lisa Cartwright (2000)—“[i]t would be impossible to understand health cultures in the United states without acknowledging the crucial role of media in their formation. Television, print media, cinema, online discussion, and medical educational computer programs are important, if underconsidered, means through which health issues are taught, communicated and lived” (120). For examples of analysis of HIV/AIDS in various forms of media across different national contexts see (Patton 1985, Hammonds 1987, Crimp 1988, Patton 1990, Colby and Cook 1991, Lupton 1994, Cook 1997, Treichler 1999, Raimondo 2003, Brown 2006).

125 Notwithstanding the persistent theme in the literature on HIV/AIDS in the media that emphasizes the initial hesitance of the news media to take up the HIV/AIDS story. See note 28 above. (Kinsella 1989) offers a journalist’s critical account of why it took “six years and twelve thousand deaths before most of America’s mainstream media—general-audience newspapers, magazines, network, and local television—started aggressively covering the epidemic” (1-2).

the mysterious immunosuppression syndrome was presently elusive to medical investigators. It further reported, “doctors who have made the diagnoses [of KS], mostly in New York City and the San Francisco Bay area, are alerting other physicians who treat large numbers of homosexual men to the problem in an effort to help identify more cases.” Additionally, Altman reported that doctors claimed that the majority of the forty-one cases making up the MMW report were male homosexuals with “as many as ten sexual encounters each night up to four times a week.” With this sensationalist detail, the article helped bring into the public discourse the presumed casual centrality of white gay men’s supposed abnormal lifestyle to the then emergent health crisis; thereby, it “sounded what would become one the most common themes in mainstream media coverage of the epidemic.”

As the news media plays a unique and important role in identifying and defining public problems, such as health crises, their coverage of what became known as HIV/AIDS promote particular understandings of the disease in relation to particular individuals and communities. From their initial reports the news media proceeded to

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128 Epstein, Steven. 1996. Impure Science: AIDS, Activism, and the Politics of Knowledge, 46. (Altman 1986, esp. 40-47.) Altman did not identify the race of the 41 homosexuals, or speak of the issue of race or ethnicity. However, scholars have long established the assumed whiteness of “gayness,” see, for example (Bérubé, Allan. 2001. "How Gays Stay White and what Kind of White it Stays." Pp. 234-65 in The Making and Unmaking of Whiteness. edited by Birgit Brander Rasmussen, Eric Klinenberg, Irene J. Nexica and Matt Wray. Durham, N.C.: Duke University Press). My designation of gay as white here, and in other moments in this dissertation, is meant to reflect the dominant understanding of the time, it is not my intention to reify the invisibility of black gay men or lesbian women.
129 In a series of articles, the late political scientist Timothy Cook critiqued the important role that the news media has in influencing not only the public’s perception of the disease, but also the possible social and political responses to it. For example, Cook (1992) noted: "The media’s identification and definition of public problems work not only on mass audiences but also on policymakers, who are highly attentive to news coverage...They [policymakers] are most likely to respond to highly salient issues, even those that provoke considerable conflict, but largely in the context of the initial frame that the media have provided. The construction of AIDS as a social and political problem thus has influenced not merely..."
largely define AIDS as a disease of white gay men, thus facilitating a white gay men's AIDS subjectivity and not a black Americans'. A review of two influential mainstream newspapers', The New York Times and The Washington Post, HIV/AIDS publication record demonstrate to which degree the media attention was overwhelming directed toward gay men—and to a lesser extent the other communities interpellated by the economy of the AIDS risk categories. It also demonstrates the relative dearth of media coverage black Americans received in the mainstream HIV/AIDS media discourse during the first decade of the epidemic.

In both The New York Times and the Washington Post, as shown by Figures 2.1 and 2.2, gay men were subjects within the vast proportion of HIV/AIDS articles during the first decade of the epidemic. The other AIDS high-risk groups designated by the CDC were variably represented. In 1982—the first year that either newspaper published articles containing a discussion of AIDS—articles about gay men, Haitians, and hemophiliacs appeared across the two papers.

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130 The historian Evelynn Hammonds (1987), sociologists Earnest Quimby and Samuel Friedman (1989), and the political scientists Cathy Cohen (1999), among others, have made this point. Chapter 3 will provide interview data, which reveal that contemporary (but long-serving) black American HIV/AIDS activists’ experiences and understandings of the first decade of HIV/AIDS provides further evidence that, in the words of Quimby and Friedman: “In the epidemic's early days, media reports that AIDS was a disease of white gay men reduced the attention blacks paid to it” (1989: 405).

131 In this discussion, I do not include the black American press. Here I am specifically interested in how mainstream news media sources constructed understandings of HIV/AIDS. Black media enters into the discussion, in Chapter 3, of black agency.

132 I created Figures 2.1 and 2.2 through a LexisNexis search of the New York Times and Washington Post using these search terms: ((HIV or AIDS) and ((gay) or (homosexual) or (bisexual) or (“intravenous drug abusers”) or “iv drug users”) or (“intravenous drug users”) or (“iv drug abusers”) or (Haitians) or (hemophilia) or (hemophiliacs)), with the following subject terms (match any): AIDS & HIV, AIDS & HIV REPORTING, AIDS & HIV TESTING, AIDS & HIV TREATMENT. I reviewed each returned item to ensure they were indeed articles containing references (of any length) to the appropriate social category.

133 1982 is the first year that articles published discussing AIDS appeared in these two newspapers. There were, of course, a limited number of articles in the national press about a mysterious
Figure 2.1: Proportion of HIV/AIDS Articles in the New York Times in Regard to Each of the Four AIDS Risk Categories, 1981-1991
By 1983, each of the four high-risk groups was well represented in the articles of both newspapers, though none more than gay men. Indeed, that both newspapers experienced a significant increase from 1982 to 1983 in the number of articles they published (see Tables 2.1 and 2.2) about AIDS— for *The New York Times* an increase of 38.8-fold, and a 100-fold increase for *The Washington Post*—indicates that from “1983 on AIDS had entered the popular consciousness and was widely discussed.”

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134 Altman, Dennis. 1986. *AIDS in the Mind of America*. Garden City, N.Y.: Anchor Press/Doubleday, 19. Altman attributes this apparent sudden interest in AIDS in 1983 by the mainstream press to the speculations that the epidemic was extending from “gay men and other disreputable groups [meaning chiefly intravenously (i.v.) drug users] and Haitian” into far more sympathetic or innocent populations such as hemophiliacs, and recipients of blood transfusions (ibid 20). For further discussion of the 1983 peak and other fluctuations of print and television news media’s coverage over the first decade of the

<table>
<thead>
<tr>
<th>Year</th>
<th>Total # of HIV/AIDS Articles</th>
<th>Total # of HIV/AIDS Articles re 4 Risk Groups</th>
<th>Total # of HIV/AIDS articles re Black Americans</th>
</tr>
</thead>
<tbody>
<tr>
<td>1981</td>
<td>0</td>
<td>0</td>
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</tr>
<tr>
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<td>1115</td>
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<table>
<thead>
<tr>
<th>Year</th>
<th>Total # of HIV/AIDS Articles</th>
<th>Total # of HIV/AIDS Articles re 4 Risk Groups</th>
<th>Total # of HIV/AIDS articles re Black Americans</th>
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<td>1990</td>
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</tr>
<tr>
<td>1991</td>
<td>707</td>
<td>164</td>
<td>53</td>
</tr>
</tbody>
</table>

Yet black Americans were markedly absent from this discussion until 1983; that year that The New York Times published a single article, and the Washington Post two, about HIV/AIDS that included their first mention of black Americans. Below, figures 2.3 and 2.4 show that after 1983, at both newspapers, the proportions of articles with reference to black Americans experience marginal increase and stagnated until 1987. The New York Times pieces concerning black Americans ranged from a low of one percent in 1983 to a high of four percent in 1986. Conversely, at the Washington Post the range was from zero to four percent during the same time period.

It is thus clear that the media representation of HIV/AIDS during the first decade of the epidemic, as evidenced by The New York Times and the Washington Post,

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135 I created Figures 2.3 and 2.4 through a LexisNexis search of the New York Times and Washington Post using these search terms: (HIV or AIDS) and (African American or Blacks) and not Africa, with the following subject terms (match any): AIDS & HIV, AIDS & HIV REPORTING, AIDS & HIV TESTING, AIDS & HIV TREATMENT. I reviewed each returned item to ensure they were indeed articles containing references (of any length) to black Americans and HIV/AIDS.

136 Chapter 3 will offer explanations for the startling increase of both the absolute number and proportion of HIV/AIDS articles in regard to black Americans, which occurred in 1987 at both newspapers.
primarily interpellated gay men. Of course, this is not meant as appraisal of the quality of the discussion of gay men in the newspapers; for it is clear that during these earliest years, at best being associated with AIDS was a mixed blessings, as much of this coverage reflected and promoted stigmatization of gay sexuality. Rather, my point is simply to emphasize that newspaper media—following the lead of the public health biomedical discourse—overwhelming published articles that reinforced a notion of AIDS as being a largely gay and presumably white male disease, even as the epidemiological picture of disease was becoming increasingly diverse and more complicated.

Figure 2.3: Proportion of HIV/AIDS Articles in The New York Times in regard to Black Americans vs. any of the 4 AIDS Risk Groups, 1981-1991
THE EARLY HIV/AIDS SOCIAL MOVEMENT AND THE EXCLUSION AND INVISIBILITY OF BLACK AMERICANS

In addition to both the public health and biomedical discourse, and the representations of the news in the mainstream print news media, black Americans’ exclusion from the field of HIV/AIDS prevention is also evidenced through the social movement that emerged as a central feature of it. As indicated by the opening sentence of this chapter, any analysis of race and HIV/AIDS—indeed, any analysis of the prevention field at all—in the U.S. must to some extent contend with the role of white, gay men. The centrality of members of this social group has been consistently demonstrated by social scientists studying various aspects of HIV/AIDS. Perhaps, the
most influential of this scholarship—particularly in the discipline of sociology—details and analyzes how the white gay identity movement “after an initial period of fear and confusion...launched an impressive and multifaceted response to the epidemic.”\textsuperscript{137}

The response of the gay movement to the HIV/AIDS crisis was enabled by and indeed grew from the field of gay identity movement organizations that crystalized in the 1970s. Thus, when AIDS began, gay men—for perhaps the first time in U.S. history—were in a position to respond to their subjection in the discourses and practices of public health and (bio)medicine with not just individual force, but with also the weight of institutions indigenous to the gay community. The success of the gay identity movement itself was an important factor in “imped[ing] the development of an accurate understanding of the nature of the [AIDS] disease.”\textsuperscript{138} When men in the early 1980s were diagnosed with PCP and KS these men could self identify and be identified by the public health and biomedical establishment as members of a gay community, recently visible and empowered. This in turn helped to enable the interpretation of AIDS through a gay lens and the focus on the particularities of the gay “life-style” as a cause of the afflicted illnesses. Thus, as discussed above in this chapter, “the presence of AIDS in people other than gays was, at first, treated as anomalous, slowing the realization the source of the illness was viral.”\textsuperscript{139}

Importantly, as the epidemic dawned, “gay communities were both contributors

\textsuperscript{138} Ibid., 157.
\textsuperscript{139} Ibid.
to the ‘gay disease’ framed and important critics of it.”

Faced with the fact that members of their communities were dying from an unknown cause in 1981, the gay press, through their frequent characterization of the mysterious disease as an epidemic of “gay cancer,” sounded a rallying cry that alerted gay men to the presence of a new danger. However, as public health and biomedical researchers increasingly championed the etiological relevance of a sensationaly conceived gay “life style,” gay activists and the gay press begin to be openly critical of medical researchers tendency to hypothesize gay promiscuity as the cause of the epidemic.141 Thus, it was through a complex critical social and personal negotiation between the ethics of sexual liberation, which was a constitutive part embedded within—even as it was also an outgrowth of—the gay liberation movement of the 1970s, and an urgent need to inform gay communities about suspected sexual risk behaviors to protect gay lives that gay and lesbian activists begin establishing organizations to confront the epidemic.

That there were two grassroots organizations, the Gay Men’s Health Crisis (GHMC) in New York City and the Kaposi’s Sarcoma Research and Education Foundation, now known as the San Francisco AIDS Foundation (SFAF), started by early 1982 was a tribute to the successful political and resource mobilization of the gay identity organizational movement of the 1970s. This viable pre-established gay organizational field assisted in producing an enduring dialectical relationship between gay communities and AIDS writ large in the U.S; or to put another way, it helped to enable the early

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140 Epstein 1996, 53.
141 The logic of the gay writers’ and activists’ critique is succinctly explained by Epstein: “Much as an earlier generation of feminists had conceived of medicine as a sexist institution, these writers and activists argued that medical science was a heterosexist and sex-phobic institution that reinforced norms of sexual conformity” (1996: 54).
dominant construction of AIDS as a gay white disease.\textsuperscript{142}

The fact that black Americans were largely actively excluded from—or, at best marginalized within—the gay organizational field played an important, role in and of itself in limiting the possibility of multi-cultural or other cross-difference coalitions developing within the HIV prevention field of the 1980s.\textsuperscript{143} This exclusion encouraged the development of a HIV/AIDS social movement that largely ignored black Americans’ perspectives and needs, thus, providing another potential explanation for the seemingly unremarkability of black Americans’ presence in the epidemic morbidity profile. These points are evident in the tendency of gay-community-based AIDS groups, such as GMHC and SFAF, to develop “AIDS prevention material steeped in the language and practice of gay liberation.” In 1984, citing his belief that many of his “brothers and sisters of color” believed that “AIDS is a white gay male disease stemming from unusual, bizarre, excessive, and permissive sexual behavior practices,” Billy S. Jones, a member of the East Bay Chapter of Black White Men Together (BWMT),\textsuperscript{144} sent a letter to SFAF noting the potentially limiting reach of the organization’s pro-sex and sexual explicit prevention material.\textsuperscript{145} Jones challenged SFAF to collaborate with community

\textsuperscript{142} As Epstein puts it, “AIDS became a ‘gay disease’ primarily because clinicians, epidemiologists, and reporters perceived it through that filter, but secondarily because gay communities were obliged to make it their own” (Epstein 1996: 55)

\textsuperscript{143} This is rarely acknowledge in the literature; it is, of course, black American culture and/or (the limits of) black politics that are much more commonly implicated in analyzes of black Americans’ absence in the HIV prevention field during this period (see for example…). As I indicated before, while this work has been generative and remains important, to only or primarily locate the barriers to black Americans’ HIV/AIDS mobilization within the contours of black American communities risks occluding other salient mechanisms that limit blacks mobilization that were and are embedded within and empowered through more broader socio-political structures and assemblages.

\textsuperscript{144} BWMT is an organization formed in 1980 with a goal to fight racism within gay communities.

\textsuperscript{145} Jones quoted in Brier, Jennifer 2009: 53-54. I read Jones as suggesting that SFAF’s prevention material potentially reinforced the sensational “gay lifestyle,” a prominent stereotypical trope both among public health and biomedical researchers and providers, and in communities of color—not to mention
organizations “not organized exclusively around sexual practice, including BWMT and the National Coalition of Black Gays, to create campaigns for communities of color in general and gay communities of color in particular that moved away from an exclusive focus on gay liberation.”

Jones’ criticisms and the demands of SFAF “called attention to a small but growing network of black gay male activists who interpreted the interconnections between race and sexuality as necessitating AIDS prevention that moved beyond sexual explicitness.” Yet, gay community based AIDS groups steeped in the legacy of white gay liberation were hegemonic; and thus, it was the world-views and concerns of white gay men (and to a much lesser extent white lesbian women) that achieved dominance in the HIV/AIDS social movement. Hence, the interconnections between race and sexuality were consistently unacknowledged by gay originations like SFAF. Of course, however, there were black Americans, and other people of color, who were involved in SFAF and the GMHC in 1982 and in ACT UP in 1987.

However, it was common for racial minorities to reach a point where they felt a need to break away or distance themselves from the white gay male approaches of these gay community based organizations. These racial minorities, for instance, sought out other people or color and/or women to caucus with and to form separate committees, internal to the parent organization; or, they started their own separate organizations.

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146 Brier, Jennifer 2009: 54.
147 Ibid.
148 In San Francisco, in 1985, the Third World AIDS Advisor Task Force (TWAATF) was formed “in
Distinct from the hegemonic gay organizations whose approaches were incumbent on gay liberation and white male privilege, black Americans and others racial minorities, and their allies “sought a more thoroughgoing engagement with the class-based inequities of the U.S. health care system and with the racist, sexist, and homophobic dimensions of [public health and] biomedicine and, indeed, of the U.S. society as a whole.”

Conclusion: Black American Exclusion and the Politics of Knowledge and Ignorance

The quote from the sociologist, Joseph Gusfield that begins this chapter provides an appropriate conceptual framework to summarize the argument of this chapter: AIDS was constructed as a U.S. public health and biomedical problem through “a system for categorizing and defining events” that privileged white gay men, and simultaneously functioned to relatively exclude black Americans. This chapter documents and analyzes how this exclusion is evidenced through the non-interpellation of black Americans in public health and biomedical reports and recommendations, the lack of black American representation in the print newspapers HIV/AIDS coverage throughout the 1980s, and the dominance of gay white men and their viewpoints in the social movement that arose in direct response the inability of organizations like SFAF to acknowledge how its work functioned as much to exclude as it did to include.” TWAATF designed their steering committee “so that it had an overwhelming majority of people color, representing a range of sexual orientations” (See Brier 2009:59). TWAATF assisted existing AIDS organization with providing HIV/AIDS educational material that was “relevant, culturally sensitive, and can be understood by our communities” and advocated for the SF growing AIDS bureaucracy to implement change that addressed the special needs of people of color in the AIDS crisis (“Minutes for TWAATF Meeting,” Aug. 27, 1985 quoted in Brier 2009: 60). Other examples of racial minorities advocating for a different approach than the hegemonic gay AIDS organizations are discussed in the following: Patton 1990: 10-11; Saalfield & Navarro 1991 (Diana Fuss, ed. Inside/Out: Lesbian Theories, Gay Theories, 341-372); Epstein 1996: 290-294; Gould 2009.

Epstein 1996: 291-292
See note 1.
to confront the emerging epidemic.

Of course, black American’s relative invisibility within the general and more scientific HIV/AIDS discourse and their virtual exclusion from the field of HIV prevention certainly does not mean that black American individuals were not contracting and dying from the disease, or that there were no black American HIV/AIDS activists and organizations confronting the disease. After all, black Americans, as discussed earlier in this chapter, have been listed in the morbidity surveillance data since the second MMWR report on “highly unusual” immunodeficiency diseases—now indicative to much of the world at large, as symptomatic of AIDS—among previously healthy young men. And as early as September of 1983 the fact, or information, that black Americans were well over-represented in the surveillance statistics, calculated as the proportion of black American with HIV/AIDS versus their proportion in the population was available in a CDC report. Yet, as the next chapter (Chapter 3) will explain and analyze, it was not until late 1986 that data describing black Americans disproportionate burden of HIV/AIDS infection was taken up in the discourse. In the face of the relative early availability of this information, it is especially noteworthy the extent to which black Americans were not interpellated or represented in the public health and biomedical discourse and the mainstream print news media throughout the first decade of the HIV/AIDS epidemic in the U.S.

Similarly, just as there was generally a non-transfer of the knowledge of black Americans suffering from the disease, there is much ignorance—and, at best, little scholarly or popularly appreciation—of the fact that there were black Americans, as well as other racial minorities, who were involved in community based HIV/AIDS activism.
Of course, white gay community-based HIV/AIDS organizations were indeed hegemonic and their dominant approaches to combating AIDS, as well as the broader dynamics of the gay institutional field itself, worked to largely marginalize and exclude black Americans.\footnote{Patton (1990) makes this related observation: “In addition to the gay-community-based ASO [AIDS Service Organizations] and the PLWA [People Living with AIDS] movements, there were other small, community-based groups addressing AIDS in the African-American, Latin, Haitian, and Asian communities and to some extent among American Indians in urban areas and on reservations. These groups developed both from existing multi-service agencies and from cultural affirmation projects...Because the dominant approach to AIDS was to consolidate many services in one AIDS-specific agency, government planners, the media, and funders often failed to recognize how communities of color organized against AIDS by extending existing church or community programs” (10-11). Patton also noted that AIDS-related efforts among communities of color treated the epidemic, in stark contrast to gay communities, “as a phenomenon already understandable through existing analysis of government neglect, of property and of lack of access to health care and education” (ibid, 11). For one rare account of such HIV/AIDS community based efforts in the 1980s among racial minorities, see Nicholas Freudenberg, Jacalyn Lee, and Diana Silver (1989), “How Black and Latino Community Organizations Respond to the AIDS Epidemic: A Case Study in One New York City Neighborhood.” AidS Education and Prevention 1:1:12-21.}

It is imperative to understand black American exclusion from the early HIV/AIDS discourse and the prevention field within the context of the social, economic, and political relations of power that hauntingly structure and conditions the production of knowledge and ignorance around HIV/AIDS and black Americans during the first decade of the epidemic in the United States.\footnote{Here I am building upon insights from the history of science concept “agnotology.” Coined by historian Robert Proctor, agnotology is an analytical and methodological tool that calls attention to need to study “what we don’t know and why not” in addition to studying “what/how we know” (epistemology), (Proctor, Robert.1995. Cancer Wars: How Politics Shape What we Know and Don’t Know about Cancer, New York: Basic Books). I am specifically indebted to Londa Schiebinger’s development of the concept; Schiebinger argues: “What we know or do not know at any one time or place is shaped by particular histories, local and global priorities, funding patterns, institutional and disciplinary hierarchies, personal and professional myopia, and much else as well,” (2005, “Agnotology and Exotic Abortifacients: The Cultural Production of Ignorance in the Eighteenth-Century Atlantic World” Proceedings of the American Philosophical Society, Vol. 149, No. 3, pp. 316-343). See also, Robert Proctor and Londa Schiebinger, ed. (2008), Agnotology: The Making and Unmaking of Ignorance. Stanford, Calif.: Stanford University Press, and Steven Epstein (2010), ”The Great Undiscussable: Anal Cancer, HPV, and Gay Men’s Health.” Pp. 61-90 in Three Shots at Prevention: The HPV Vaccine and the Politics of Medicine’s Simple Solutions, edited by Keith Wailoo, Julie Livingston, Steven Epstein and Robert Aronowitz. Baltimore, Md.: Johns Hopkins University Press.} The historical but still (certainly within the contemporary HIV prevention field) influential misperceptions of HIV/AIDS as a distinctly “gay white men disease of little concerned for black Americans” must be traced
partly to the privileging of certain knowledge and certain subjectivities over others within the particular historical context of the 1990s. Importantly, we must understand the failure to cultivate the knowledge of the specific relationship between the epidemic and black Amerians within the context of the broader economic and political structure of the 1980s, which themselves were imbued with—and, just as crucially, productive of—certain racial, class, and sexual politics.

The Emerging Regime of Inclusion:

Yet, as the production and politics of knowledge and ignorance are subject to critique and “recontextualization,”¹⁵³ the regime of HIV/AIDS that largely excluded black Americans would not be maintained. Contradictions, tensions and inconsistences within—along with resistances to—the regime of exclusion would by the early 1990s bring about a HIV/AIDS disease regime that, in time, would grow to privilege black Americans. In this regime of inclusion, networks to specifically address the disease in black American communities are made more visible and their more robust formation encouraged by broader transformations in U.S. public health and biomedical policy. An analysis of key events and moments in the transformation from the regime of black American exclusion to the regime of black American inclusion is the focus of the next chapter.

Chapter 3

Changing the Color of HIV Prevention—From the Regime of Black American Exclusion to the Regime of Inclusion

By the close of 1991, black Americans were no longer invisible or missing within the broader HIV/AIDS discourse; HIV/AIDS was increasingly represented by the media and the public health and biomedical establishment as a disease of color. The goal of this chapter is to document and analyze key events and moments in the transformation from the regime of black American exclusion to the regime of black American inclusion (See the chronology in Appendix 1). My approach is to show how a conjuncture of socio-political events precipitated and/or characterized meaningful change in the discourses and practices of public health, the media, and the social movement. Moreover, in this chapter, I use interview data from CDC officials to highlight their understandings of events that not only represented a transformation in the racialization of the disease from white to black, but also helped to reconfigure the HIV prevention field to meaningfully include black Americans. Table 3.1 summarizes the salient differences between the regimes of exclusion and inclusion that will be featured throughout this chapter.

With this chapter, I will demonstrate, in short, that the regime of black American inclusion emerges in the early 1990s along with a much larger transformation in the infrastructures and policies of U.S. public health and biomedicine. I argue that this biopolitical paradigm shift accompanied by the actions, lives and deaths of black Americans throughout the 1990s helped to promote increasing attention to social and bodily differences, such as race, within the field of HIV prevention. The chapter
concludes by zeroing in on some of the multiple and contradictory ways that black Americans were more active in the HIV prevention field and more interpellated within the broader HIV/AIDS discourse from the early 1990s to the close of the 20th century; this will set the stage for Chapter 4, where I explore more concretely some of the tensions that are constitutive of (and accompany) black Americans’ ongoing incorporation in the prevention field in the 2000s.

Table 3.1: HIV Prevention in Two Regimes in relation to Black Americans

<table>
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<th>Regime of Exclusion</th>
<th>Regime of Inclusion</th>
</tr>
</thead>
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<tr>
<td><strong>Organizations and actors</strong></td>
<td>Run by and for gay men, predominately white men</td>
<td>Increasing presence of black Americans and other racial minorities in the organizational field</td>
</tr>
<tr>
<td><strong>Categories of risk</strong></td>
<td>Homosexuals, drug abusers, hemophiliacs, and Haitians</td>
<td>HIV risk continuum based on practices and social groupings/populations</td>
</tr>
<tr>
<td><strong>Visual and cultural dimension</strong></td>
<td>Black Americans largely invisible, missing</td>
<td>Black Americans increasingly visible through public health images and media representation</td>
</tr>
<tr>
<td><strong>Discourses of intervention</strong></td>
<td>Focus on enacting behavioral change</td>
<td>Focus on behavioral and increasingly socio-economic factors of change</td>
</tr>
<tr>
<td><strong>Practices of intervention</strong></td>
<td>Focus on enacting behavioral change</td>
<td>Focus on enacting behavioral change</td>
</tr>
</tbody>
</table>

Setting the Stage for Change, mid-1980's to 1993

Preconditions for the disease regime shift began to emerge in inchoate fashion in
the mid-1980s. Events and moments important in bringing about a HIV/AIDS disease regime of black American inclusion can be charted through a critical analysis of changes in policies, ideologies, and practices interdependently deriving from the domains of public health and biomedicine, the media, and the HIV/AIDS social movement.

**THE OCTOBER 24, 1986 CDC REPORT**

The first event that marked the incipient arrival of black Americans in the official HIV/AIDS discourse was the publication of a report in the *MMWR* in late October of 1986. This report, appearing under the title, “Epidemiologic Notes and Reports: Acquired Immunodeficiency Syndrome (AIDS) among Blacks and Hispanics – United States,” was the inauguration of the CDC’s ethno-racial categorizing scheme to classify the distribution of reported AIDS cases. Recall, however, as recounted in Chapter 2, in September 1983 the CDC reported that cases of AIDS “have occurred in all primary racial/ethnic groups in the United States: 57% of those reported have been white, 26% black, 14% Hispanic, and 3% other or unknown.” However, there was no further elucidation on this finding in the 1983 report—nor any mention that 26% represented a disproportionate number of AIDS cases among black Americans. The October 1986 report is thus the first time the disproportionate claim was made.

In this publication, the CDC announced that although “blacks” and “Hispanics” were only 12 and six percent, respectively, of the U.S. population, they were 25 and 14

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percent of the “24,576 patients meeting the AIDS case definition for national reporting” from June 1, 1981 to September 8, 1986. These numbers meant that the cumulative incidences of AIDS cases among both blacks and Hispanics were over 3 times the rate for whites. The report went on to briefly detail that the disproportionate rate of AIDS cases in these two racial minority groups (in relation to their proportions of the overall U.S. population) held across subgroups of patients, such as adults and children, and males and females. Among the 22,468 male AIDS patients reported to the CDC during the first 6 years and 3 months of the epidemic, 23 percent were black Americans and 14 percent were Hispanic. The proportion of black and Hispanic women among the (much smaller number of) 1,634 female patients was even more striking, accounting for 51 percent and 21 percent, respectively; this represented cumulative incidences that were 13.3 and 11.1 times the incidence for white women.

This MMWR publication appeared to signal that the CDC categories of risks were being revised and perhaps becoming more nuanced as the epidemiological and surveillance data was statistically manipulated. Moreover, in light of the CDC’s 1983 designation of the social groups at highest risk for contracting AIDS (which were defined as homosexuals, intravenous drug users, recent Haitian immigrants, and hemophiliacs), it is important to note that subsumed within the designated “black AIDS cases” in the October 1986 report were Haitian immigrants. Thus, no longer was being of Haitian

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155 Adult AIDS patients were defined as those patients 15 years of age or older.
156 The black and Hispanic adults and children with AIDS were more likely than their white American counterparts to live in the three states of New York, New Jersey, or Florida.
158 See Chapter 2, under section heading “The Social Categories of Risk and the Continuing Non-Salience of Race.”
national origin highlighted as a risk category; commonly used U.S. categories naming and constituting racialized social groups were emphasized instead. In focusing on the distribution of the AIDS cases by race and ethnicity, the quality of mutual exclusivity imbued within the original formulation of the four categories of risk was also undermined in the 1986 report. Accentuated instead were the “recognized transmission categories”—simply the previously defined four social categories of risk transformed from a subject position to a practice or behavior, plus the addition of a fifth risk designation—that is, heterosexual contact.

Another noteworthy feature of this late 1986 CDC report, appearing in the “Editorial Note” section, was its discussion of “factors” that may contribute to the elevated incidence of AIDS among blacks and Hispanics. One suggestion was that “[t]he racial/ethnic distribution of AIDS cases may reflect, to some degree, the racial/ethnic distribution of the populations at risk in the high-prevalence areas.” It was also noted in an unequivocal sentence that blacks and Hispanics’ increased risk was “a result of underlying risk factors, not because of their race/ethnicity,” before drug abuse was

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159 A publication authored by three CDC researchers in 1983 offers a contrast to the 1986 report. This review of the first 1,000 AIDS cases concluded that “all but 61 of the 1,000 cases could be classified into one or more of the following risk groups: homosexual or bisexual men, iv drug abusers, Haitians living in the United States, or patients with hemophilia.” After providing evidence that “these risk groups were not mutually exclusive,” the authors declared, “to simplify [the] data analysis, the 1,000 cases were reclassified into a hierarchy of mutually exclusive [four] risk groups” (Jaffe, Harold W., Dennis J. Bregman and Richard M. Selik. 1983. "Acquired Immune Deficiency Syndrome in the United States: The First 1,000 Cases." *The Journal of Infectious Diseases* 148: pp. 339-345).

160 The report detailed, “Homosexual or bisexual men who had AIDS and patients who acquired AIDS from blood or blood products were predominately white, whereas patients with a history of IV drug abuse or heterosexual contact with persons at increased risk for acquiring AIDS, and persons with no identified mode of transmission were predominantly black or Hispanic. The proportion of blacks or Hispanics with AIDS was relatively high (in terms of their proportions in the overall U.S. population) in all transmission categories with the exception of hemophilia” (“Epidemiologic Notes and Reports: Acquired Immunodeficiency Syndrome (AIDS) among Blacks and Hispanics – United States,” 1986, October 24. *MMWR: Morbidity and Mortality Weekly Report* 35(42): 655-8, 663-6).
zeroed in on as the most probable risk factor. The assumed greater propensity of blacks and Hispanics to abuse drugs was also employed to provide clarity to a potentially salient claim: “Economic and cultural factors may also be associated with the observed differences in incidence for racial/ethnic groups.”

The “Editorial Note” concluded with two paragraphs that announced the need for “targeted” education and prevention programs specifically designed for blacks and Hispanics. Education and behavioral modification of persons at increased risk was heralded as the most effective prevention technology in the absence of effective pharmaceutical therapy or a vaccine, as were the need for “additional health-education/risk-reduction projects” that “actively involve minority communities in the accomplishment of overall community AIDS risk-reduction activities.”

Despite being the first to highlight the distribution of AIDS case by race and ethnicity, this CDC report seemed to produce limited initial change—at least in regard to the CDC developing collaborative relationships with minority communities or funding allocations targeted for treatment or prevention efforts among racial minorities. It was two years after the report, in 1988, that the CDC’s “collaboration with national and regional minority organizations and the faith based community began.”

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161 The example demonstrating how economic and cultural factors might be a factor in higher AIDS incidence was that “education and economics may play a role in the observed difference in needle-sharing practices.”

162 The last paragraph also contain an unsubstantiated claim (meaning no references or support were provided in otherwise well documented report) that the U.S. Public Health Service, “has assisted and encourages involvement or minority professional and community organization in providing education about AIDS and its prevention in black and Hispanic communities.”

the first time, the CDC earmarked funds, nearly $11 million, for “specific African American initiatives.” In 1989, the CDC began to directly provide funding to minority community-based prevention organizations with the specific goal to reach “underserved African American communities.”

**NEWS EVENTS: THE ‘COMING OUT’ OF BLACK AMERICANS WITH HIV/AIDS**

The CDC report of the disproportionate rates of AIDS among blacks and Hispanics was also relatively slow to make much of an impact in the news media. For example, as evidenced by the *New York Times* and *The Washington Post* direct coverage, the knowledge that the cumulative incidences of AIDS cases among both black Americans and Hispanic Americans were over 3 times the rate for white Americans made an uneven impact in the two mainstream newspapers. In the closing months of the year following the October 24, 1986 *MMWR*, no article discussing, or containing an explicit reference to, the disproportionate burden of AIDS among blacks or Hispanics was published in the *New York Times*. Faring better was *The Washington Post*, which published two articles on the topic. The first article covered the CDC report and appeared in the first section of

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165 Ibid. I have attempted to obtain records from the CDC of their allocations of funding to or for communities of color during these years and until the 2000s. However, I have learned that to obtain such information, which is located in the Library of Congress, I must first complete the Freedom of Information Action process. As I believe it would be generative to track the allocation of funds to minority communities, I will pursue this research search during my postdoctoral tenure.
the Post’s newspaper on the very same day as the MMWR publication. A second Post article published in December of 1986 focused on a presentation by Dr. Denise M. Buntin, medical director of the Delgado Venereal Disease Clinic in New Orleans, to the National Black Caucus of State Legislators Health Committee. It referenced—nearly word for word—the findings of the CDC report, though without any explicit attribution to that report.

However, the New York Times and The Washington Post experienced a 4.7 and 7.8 times increase, respectively, in the number of HIV/AIDS articles they published in 1987 with a discussion or reference (of any length) to black Americans compared to the previous year. This fact suggests that the CDC’s new practice of presenting and at times emphasizing the distribution of AIDS cases by ethnoracial classification was ultimately influential in the news media. Moreover, from 1981 until the end of 1986 across both national newspapers there were only a total of 32 published articles about HIV/AIDS and black Americans in these papers, versus 86 articles in 1987 alone. Yet, one test of the probable direct influence of the CDC 1986 report in the new media is to determine if the increase from 1986 to 1987 in the number of newspaper articles covering a discussion of HIV/AIDS and black Americans also contained an increase in articles directly

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167 The Washington Post article, written by Courtland Milloy, in proposing “a need for self-constraint [among black men and women in particular]… to reduce the appetite for sex” so to halt the “current epidemic of sexually transmitted diseases,” mentions a number of number of diseases (e.g. genital warts, chlamydia, gonorrhea, herpes viruses, and syphilis) along with AIDS. Milloy, thus includes, without directly attributing the source, this strategic summary of the CDC report: “Indeed, as of October, there had been nearly 27,000 reported AIDS cases in the United States, including almost 15,000 deaths. Twenty-five percent of the American acquired immune deficiency syndrome victims have been black, and 80 percent of the children with AIDS are black or Hispanic” (Milloy, Courtland. 4 December, 1986. "A Need for Self-Restraint." The Washington Post DC: 1).

168 See Tables 2.1 and 2.2 (Chapter 2).
referencing a claim that blacks and Hispanics make up a disproportionate number of AIDS cases. There was indeed an increase in the number of articles in 1987 containing such a claim in both the *New York Times* and *The Washington Post*, as is demonstrated by Table 3.2.

**Table 3.2: Distribution of Articles Regarding Black Americans and ‘Blacks and Hispanics’ Proportion Claim**

<table>
<thead>
<tr>
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<tr>
<td>Total regarding Black Americans</td>
<td>10</td>
<td>47</td>
</tr>
<tr>
<td>Total containing proportion claim</td>
<td>2</td>
<td>14</td>
</tr>
</tbody>
</table>

Another noteworthy feature of the newspaper articles published regarding black Americans from the period of 1981 through 1987 was that the vast majority of the articles focused on the probable role of drug abuse as the casual explanatory factor for higher proportional incidence of AIDS cases among blacks and Hispanics. In doing so they followed the lead of public health and biomedical discourse, in addition to the discourse and practices of the justice department in the 1980s, which specifically equated racial minorities with a unique propensity to abuse drugs. While, as in the 1986 CDC report the lack of income and education among blacks and Hispanics was often references in the newspaper articles as an intermediary factor in their “drug abuse,” the consistent reliance on the phrase “drug abuse,” rather than “drug use,” seemed to raise the specter, if somewhat clandestinely or unconsciously, that something essentially or innately specific to the culture of blacks and Hispanics was also culpable. Thus, left
conspicuously under-considered in this specific discourse as well as in the larger discourse about AIDS and HIV prevention were other possible social, political-economic, or legal processes that, in complicated ways, rendered blacks and Hispanics more susceptible to contract the disease. This feature—of the articles covering the issue of black Americans and HIV/AIDS to overwhelmingly feature stigmatizing stories of drug abuse—indicate an important feature of inclusion. In multiple and complicated ways, inclusion may be built upon and at variable times reinforce problematic constructions of race and sexuality.  

The “Magic Johnson Effect:”

On November 7, 1991, Earvin “Magic” Johnson, Jr., the black American “superstar” basketball player for the National Basketball Association’s (NBA) Los Angeles Lakers, publicly announced that he was HIV positive and would therefore be retiring from the NBA. Although in the early 1990s there were numerous public disclosures or “outings” of noteworthy individuals’ HIV/AIDS statuses in the media, Johnson’s disclosure was major news and at the time, and perhaps since, the most influential in prompting change in the HIV/AIDS discourse. To that end, Magic Johnson’s announcement represents a turning point in the construction of general public perceptions and opinions on HIV/AIDS. Moreover, one important effect of Magic Johnson’s and other black Americans “coming out” as HIV positive or as a person living

169 I believe, if not only for the fact that they can become a source of mobilization and action, that even problematic forms of racialization or of stigmatizing gay sexuality are (at times) a basis of being included, particularly in a discourse.
with AIDS (PLWA) is that it is also assisted in bringing black Americans more centrally into the overall HIV/AIDS discourse and prevention field.

The “Magic Johnson Effect” is evident in its impact in the news media. Johnson's announcement brought greater attention to the impact of HIV/AIDS on the black community. For example, the year following Magic Johnson's announcement (that is, until November 7, 1992) the New York Times published a total of 61 articles containing a discussion of HIV/AIDS and black Americans. Magic Johnson was featured in nearly 30 (29.5) percent of these articles. Likewise, at the Washington Post there were a total of 63 articles published, with 40 percent containing some discussion of Magic Johnson within the context of HIV/AIDS in black American communities more generally.170 Magic Johnson’s celebrity and sport’s hero status within the U.S. in general, and specifically his regard and influence among blacks Americans and other minority communities, encouraged journalist, as they covered the Magic story, to direct more explicit attention to the disproportionate impact of the disease particularly in black and brown communities.171

Take for example an article written by Michael Specter of the New York Times, which appeared the day after the press conference announcement, under the following

170 These percentages were calculated through a LexisNexis search. Excluded from these numbers are articles that discussed Magic Johnson and HIV/AIDS with no explicit mention of black communities or the broader black American community. Though I did not do a search to isolate such articles from November 7, 1991 until November 7, 1992, a small number of them appeared in my initial search given my search terms (see note 130 of Chapter 2); these were disregarded during my review of the retrieved articles.

171 For a critical analysis of such media coverage see, Cole, Cheryl L. and Harry Denny. 1994. "Visualizing Deviance in Post-Reagan America: Magic Johnson, AIDS, and the Promiscuous World of Professional Sport." Critical Sociology 20: 123-47. Cole and Denny III argue that mainstream media coverage of Magic Johnson’s announcement helped to maintain “the duplicitous discourse of heterosexual AIDS,” particularly through the way it codified his HIV status “through the pro-family agenda, the war on drugs, and anti-welfare strategies established under Reagan so as to render deviance visible and contain AIDS in the national imaginary” (123).
headline: “Magic’s Loud Message For Young Black Men.” Provocatively, Specter declared that Magic Johnson’s public disclosure of his diagnosis “will help provide grim proof to a skeptical nation that [HIV/AIDS] is not an aberrant disease that most of society can readily ignore.” Specter, supported by his citation of CDC reports and other sources predicted that, “what public health officials have stressed for years will now reverberate viscerally across the nation. And the message will be loudest for those who need to hear it most: the millions of black and Hispanic children for whom Johnson has been a special hero and an invulnerable symbol of hope.” Social scientists, historians and public health scholars have shown that Magic Johnson’s disclosure did indeed have considerable impact on how the disease was understood, as it helped to change attitudes regarding which social groups were appropriately associated with the disease.

Moreover, the fact that Magic Johnson embraced, practically from the day he publicly announced his HIV positive status, a highly visible and important role in the

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172 Specter, Michael. 8 November 1991. "Magic’s Loud Message for Young Black Men." New York Times: B12. That Specter’s sources also included interviews with representatives of the AIDS Action Council, a Washington, DC based lobbying group, and New York’s Minority Task Force on AIDS also suggests that Magic Johnson announcement may have brought more visibility to HIV/AIDS activism occurring in minority communities prior to 1991. A later section of this chapter will document and analyze the role of black American community based HIV/AIDS activists in encouraging the emergence, maintenance and further development of the HIV/AIDS regime of black American inclusion (see also Chapter 4).

173 An example: Within the 20 working days following Magic Johnson’s announcement, in Denver, Colorado, the city’s public health department experienced “an immediate increase in persons seeking HIV counseling and testing,” particularly among heterosexuals with no identified risk for HIV infection—individuals who neither were homosexual men nor had a history of injecting drug use.” The Denver HIV counseling and testing site experienced a “203% [in clients] over the same period in 1990, and 151% over the 20 days preceding the announcement (Cohn, David L., Lisa A. Miller, Keith J. Yamaguchi and John M. Douglas. 1992. "Denver’s Increase in HIV Counseling After Magic Johnson’s HIV Disclosure." American Journal of Public Health 82: 1692.). For an analysis of how Magic Johnson’s announcement precipitated a “durable shift in the type of values people use when deciding where they stand on policies dealing with the disease see, Pollock III, Phillip H. 1994. "Issues, Values, and Critical Moments: Did “Magic” Johnson Transform Public Opinion on AIDS?" American Journal of Political Science 38: 426-46, 430. Pollock III showed that the disclosure led to a change in general public opinion through shifting the value laden association of AIDS with homosexuality to attitudes of heterosexuality.
world of HIV/AIDS prevention—not to mention that he currently has been living with HIV for more than 20 years—confirmed his import in the HIV/AIDS discourse and social world of public health. More specifically, his fame and stature as a black male sport star—and his activism that was and is enabled by his celebrity—has rendered him a spokesperson at large for the disease, and particularly in regard to addressing the disease impact in black American communities. Thus, Magic Johnson was a prominent featured guest at the opening session of the 2009 National HIV Prevention Conference (NHPC), which was held in Atlanta, Georgia from August 23-26.

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174 Johnson founded the Magic Johnson Foundation in 1991, an organization that to this day provide charitable programs and services and develop businesses ventures within and for urban communities. In the Foundation’s own words: “Since its inception in 1991, the Magic Johnson Foundation has had a significant, impact towards positively changing the face of urban, minority communities. Our programs and services are dedicated to harvesting an affirmative affect on community revitalization by eliminating negative cultural barriers; advancing economic and social equality by engaging minorities in every aspect of their communities; increasing academic and innovative achievement; raising AIDS/HIV awareness, treatment and prevention; the creation of positive emerging leaders; and promoting collaboration and alliance among all sectors of the community (businesses, educational institutions, legislative, community and faith-based organizations, and policymakers)” (“Magic Johnson Foundation,” http://magicjohnson.com/foundation/about.php Retrieved 7/10/2012.

175 Magic Johnson is contemporarily considered among black American HIV/AIDS activists as the most prominent black celebrity “who has invested in the [black] community by bringing back jobs, being out there in the forefront of HIV/AIDS prevention advocacy” and who “comes back to the community to bring awareness [of the disease] to it” (Interview by author, Atlanta, GA, March 2009). A 1991 survey of 97 black American males (47 who were homeless and 50 that were enrolled in college) in Los Angeles County, California assessed Johnson’s “credibility and his qualifications for being an HIV spokesperson for the African-American community.” The researchers found that both group of men considered Johnson as a good spokesperson for the African-American community. Furthermore, they rated highly on a 7-point Likert-type scale measuring degree of support for the Johnson’s attributes—presented in the survey as the following variable: connection, with the African-American community, being an African American, trustworthiness, and heterosexual status—that contribute to his credibility (See Mays, Vickie M., June A. Flora, Caroline Schooler and Susan D. Cochran. 1992. “Magic Johnson’s Credibility among African-American Men.” American Journal of Public Health 82: 1692).

176 Johnson received the warmest and loudest welcome of the opening session speakers who represented a “dynamic and distinguished group of advocates and leaders living with HIV (Conference Program: 2009 National HIV Prevention Conference: Promoting Synergy between Science and Program Innovation and Action to End the Epidemic, 42).” Unlike the other speakers, Johnson stepped down from the imposing stage and delivered his talk while pacing among the conference audience of public health experts and community based advocates and activists from various backgrounds and communities nationwide. He was interrupted throughout his talk, entitled “Celebrating Life and Advancing HIV Prevention,” by conference attendees (perceived by me as males and females of various ages, and races) seeking handshakes and pictures (fieldnotes, 8/23/2009). See Chapter 1: p. 32 and note 78 for more
Of course, Magic Johnson’s was not the only public disclosure of HIV or AIDS status by a black American to garner noteworthy media coverage in the early 1990s. The other most notable public figure to “come out,” as HIV positive or a person living with AIDS, was the legendary black American tennis player and civil rights activists, Arthur Ashe. Ashe, to date the only black American male to win the singles title at the Tennis Championships of the Australian Open, Wimbledon, and the U.S. Open, announced on August 8, 1992 that he was living with AIDS (a consequence of a blood transfusion, likely during heart-bypass surgery in 1983). After his disclosure, Ashe “spent the rest of his days campaigning for public awareness, including a speech on the floor of the United Nations on World AIDS Day on Dec. 1 [December 1, 1992, a couple of months before his death on February 6, 1993].” The mainstream media coverage of both Magic Johnson and Arthur Ashe, two black American male heroes, brought more visibility to the social problem of HIV/AIDS more generally, and—particularly in the case of the Johnson coverage—to the specific problem of the disease among black Americans. Yet it must be noted that Essence, a popular black-own magazine marketed to black American women, was the first national publication to publish a cover story about black women and HIV/AIDS—written by Rae Lewis-Thornton, a black American woman living with

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177 Ashe’s public disclosure occurred four years after his initial diagnosis in 1988—the time when he told his family and friends—and was forced due to his being informed by a USA Today reporter that the newspaper intended to publish an article about his illness (See, “1992: Arthur Ashe Announces He has AIDS,” available as of 7/01/2012 at http://cnn.com/video/?/video/us/2011/04/08/new.vault.ashe.hiv.1992.speech.cnn).

AIDS.\textsuperscript{179}

The Biopolitical Context of Inclusion

In addition to the 1986 CDC report that introduce the knowledge of the disproportionate incidence of AIDS cases among blacks and Hispanics and media events that often featured the impact of HIV/AIDS on prominent black Americans in the earlier 1990s, there were broader biopolitical forces at play, which increasingly promoted the inclusion of black Americans in the HIV/AIDS discourse and the HIV prevention field. Specifically, there was the far-reaching reform “codified in a series of federal laws, polices, and guidelines issued between 1986 and the present that require or encourage research inclusiveness and the measurement of difference” across human differences such as, gender and sex, race and ethnicity, and age.\textsuperscript{180} This mandate of inclusion resulted in an important and far-reaching reorganization of the U.S. public health and biomedical infrastructure. For instance, new offices within the federal health bureaucracy have been established to focus on specific populations, such as women and minorities; in order to secure funding from the federal government, researchers are required to conduct their studies on diverse populations, or explain the absence of diversity in their study samples; just as, pharmaceutical companies are now obliged to include women, racial and ethnic

\textsuperscript{179} Lewis-Thornton, Rae. 1994, December. "Facing AIDS." \textit{Essence} 8: 62. A photo of Lewis-Thornton is centered on the magazine cover with the magazine title, \textit{Essence}, above her head, and her article’s title “Facing AIDS,” with this quote below: “I’m young, I’m educated, I’m drug-free, and I’m dying of AIDS,” is imprinted to the left of her head on the cover.

minorities, children and the elderly as research subjects in their clinical trials in order to obtain approval of their product from the Food and Drug Administration (FDA).\textsuperscript{181}

With this set of changes in research policies and practices, and the accompanying creation of bureaucratic offices and procedures, what Steven Epstein has termed the “inclusion-and-difference paradigm” was, since the mid-1980s, instituted in biomedical research.\textsuperscript{182} The potential to redress “health disparities” was a primary frame, which helped to legitimate the institutionalization of this new paradigm.\textsuperscript{183} However, it was the 1985 report from a committee commissioned by DHHS Secretary Margaret Heckler—the Secretary’s Task Force on Black and Minority Health—that brought the issue of health disparities (specifically across racial groups) to the national health agenda.\textsuperscript{184} In her foreword to the report, Secretary Heckler lamented “a sad and significant fact:” Although

\textsuperscript{181}As demonstrated by Steven Epstein (2007) in his history and analysis of the development and meanings of these reforms, and their consequences, both intended and unintended, the state was the chief target of an eclectic assortment of reformers who advocated for attending to biomedical differences across group identity and group difference. Thus, the National Institute of Health and the Federal Drug Administration, two agencies)—just as the Centers for Disease Control and Prevention is—within the U.S. cabinet level Department of Health and Human Services (DHHS have been and are primary sites where this new common sense about human differences been instituted (Ibid.).

\textsuperscript{182}This paradigm, as defined by Epstein, “reflects two substantive goals: the inclusion of members of various groups generally considered to have been underrepresented previously as subjects in clinical studies; and the measurement, within those studies, of differences across groups with regard to treatment effects, disease progression, or biological processes” (Ibid., 6).

\textsuperscript{183}The concept of “health disparities” generally refers to the uneven distribution of health and illness by social groups in a society.

a previous annual DHHS produced report card (Health, United States, 1983) on the nation’s health had documented that “the overall American health picture showed almost uniform improvement….there was a continuing disparity in the burden of death and illness experienced by Blacks and other minority Americans as compared with our nation’s population as a whole.”

The Task Force put forward eight recommendations that they and Secretary Heckler hoped, along with the overall report itself, would “mark the beginning of the end of the health disparity that has, for so long, cast a shadow on the otherwise splendid American track record of every improving health.” Curiously, especially in the benefit of hindsight, the report contained no thorough discussion of HIV or AIDS. In fact, AIDS is mentioned only once in the entire 200-plus page report, which suggests that the impact of AIDS on black Americans (not to mention other minority communities) remained largely unknown before the CDC report appeared a year later. Actually, given that much of Task Force’s 1985 report focused on the need for the DHHS agencies to produce and collect better and more data on the scope and depth of racial health disparities, it is more than likely that the CDC decision to analyze the distribution of AIDS cases by racial groups was directly prompted by it.

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186 Ibid.
187 The one mention of AIDS in the report occurs within a conjectural discussion about how “[t]he health consequences of drug abuse may be greater for minorities than for nonminorities (iii) as a result of the route used to administer the drugs.” The report states: “To the extent that minorities are more involved in the intravenous use of drugs, they are at increased risk of potentially fatal infections from hepatitis B virus, bacterial endocarditis, and acquired immune-deficiency syndrome (AIDS)” (Ibid., 135).
188 The Task Force define its recommendations as emphasizing the following principles: “incorporate minority health initiatives into existing DHHS program areas in order to address health conditions amenable to immediate improvement, press for greater public and private involvement in a common effort to eliminate the health disparity, resolve unanswered questions through a concerted program of
Secretary’s Task Force on Black and Minority Health helped to define the biopolitical and institutional preconditions that set the stage for the HIV/AIDS regime of black American inclusion to emerge. This HIV/AIDS regime arose alongside and as a part of the broader mandate of inclusion that resulted in a new consensus on how social and bodily difference (such as, race, gender, and age) should matter in biomedical research and within the public health infrastructure.

1993 As a Transition Year:

For both the more general biopolitical paradigm of inclusion and the HIV/AIDS regime of black American inclusion, the year of 1993 was a key year of transition. In that year the U.S. Congress passed the NIH Revitalization Act, which mandated that by 1995 women and racial and ethnic minorities must be included as research subjects in studies funded by the NIH. Likewise in 1993, the FDA created new guidelines to encourage drug manufacturers to study the effects of their products on women and racial and ethnic minorities.\textsuperscript{189}

1993 is also a year marked by banner events and critical moments that would ultimately assist in changing the color of HIV/AIDS. One primary example is the CDC’s revised classification system for HIV infection and the expansion of the AIDS surveillance case definition, which became effective on the first of January. On the face of it, this revision replaced the earlier classification system of HIV infection and case research and data collection, and seek new strategies to ameliorate health inequities between minorities and nonminorities (ibid.)\textsuperscript{8} (Ibid., 8).


With these changes, just “at the very moment that the epidemic appeared to be in decline, overnight,” the cases of AIDS in the U.S. doubled.\footnote{Cochrane, Michelle. 2004. \textit{When AIDS Began: San Francisco and the Making of an Epidemic}. New York: Routledge, 157. Cochrane shows that the AIDS caseload would have, if the 1987 definition survived through 1993, dropped (by 2 percent) rather than increase nationally by 111 percent.} This increase in the country’s overall caseload was a result of the addition of the three diseases to the definition of AIDS. An anticipated result was that the inclusion of opportunistic infections specific to women would increase the proportion of reported (heterosexual) female AIDS patients.\footnote{While the mainstream news media 1993 attributed the revision to the increase in biomedical, clinical, or scientific knowledge (“better science”), as it was represented as such in CDC publications, the revision was in fact compelled largely by women’s—including black women—health advocacy. As the journalist Elinor Burkett (1994) recounted, “a small band of female activists and a group of physicians with large numbers of female AIDS patients inundated the CDC with data on women specific manifestations of AIDS, but were met with resistance from CDC officials (Burkett, Elinor. 1995. \textit{The Gravest show on Earth: America in the Age of AIDS}. Boston: Houghton Mifflin Co., 194-196). The role of women activism around HIV/AIDS and other health issues was also particularly influential in forging the biopolitical paradigm of inclusion, as is indicated by their roles in compelling the standards held within the 1993 NIH Revitalization Act and the revision of the FDA guidelines.} Yet, the inclusion of pulmonary tuberculosis—a disease that in 1982 was explicitly excluded from the diagnostic definition—played a greater role in increasing the AIDS caseload.\footnote{Cochrane, Michelle. 2004. \textit{When AIDS Began: San Francisco and the Making of an Epidemic}. New York: Routledge, 159.} Specifically, the addition of pulmonary tuberculosis, along with invasive cervical cancer, in 1993 had the effect of increasing the reported cases
of AIDS among minorities, the urban poor, and injecting drug users. The CDC noted that “[f]ollowing the 1993 expansion of the AIDS surveillance case definition, the number of AIDS cases reported among racial/ethnic minorities in 1993 increased 135% over that in 1992, while the number among whites increased 114%.” Black American men and women had the highest rate of cases among racial/ethnic minorities in 1993.

In the words of the September 9, 1994 MMWR, “blacks” were “disproportionately affected by the HIV epidemic: the AIDS rate for black females (73) was approximately 15 times greater than that for white females (5), and the rate for black males (266) was nearly five times greater than that for white males (57).”

Thus, 1993 marks an important year in the transition from the disease regime of black American exclusion to inclusion. With the expansion of the of the AIDS surveillance case definition the disproportion burden of HIV/AIDS suffering of black Americans was more firmly established. Also more secure, particularly within U.S. public health, was the belief that “preventive interventions should be developed at the local level to ensure that they reflect the language, culture, and behavioral norms of the targeted community.” However, the transition from the regime of exclusion to inclusion did not occur, nor was its maintenance and development secured, because of benevolent changes in policy. Indeed, black American activism and advocacy played an important role.

194 "AIDS among Racial/Ethnic Minorities — United States, 1993." 9 September 1994. MMWR: Morbidity and Mortality Weekly Report 43(35): 644-55, 653. According to this report, racial and ethnic minority males (aged 13 or more) accounted for 45,039 (51%) of 89,165 of report AIDS cases, and racial and ethnic minority women were 75% of the 16,824 cases among adult and adolescents females.

195 According to the CDC, the rate among “Hispanics” was second highest, and American Indians/Alaskan Natives and Asians/Pacific Islanders had the lowest rate among the 1993 AIDS cases. Ibid.

196 Ibid., 644.

197 Ibid., 654.

198 The role of social movements in the development of U.S. HIV/AIDS policy and the inclusion-and-
Black American's HIV/AIDS Activism and Advocacy and the Inclusion Regime

An additional and consequential factor, especially (but not only) since the late 1990s, in bringing about the regime of inclusion is black Americans' activism and advocacy. Black Americans’ mobilization has been particularly successful in helping to define the ongoing dynamic parameters of inclusion, particularly within the field of HIV prevention. Indeed, though consistently largely rendered invisible in and by social, cultural, and historical scholarship, black Americans have been active participants in HIV/AIDS social movements since the emergence of the disease.  

BLACK AMERICANS’ AGENCY

Specifically, black American gay men and lesbians were among the earliest HIV/AIDS activists. Black American lesbians and men achieved a level of visibility and difference paradigm should make this clear.

199 The overwhelming and persistent focus of academic scholarship, as well as the popular press, is on identifying and analyzing the socio-cultural and political factors that inhibited mobilization within black American communities. For example, the sociologists Ernest Quimby and Samuel R. Friedman identified the task of their research as “specifying the obstacles to minority mobilization around AIDS” and thus say little about the mobilization that was occurring in spite of the obstacles (1989. "Dynamics of Black Mobilization Against AIDS in New York City." Social Problems 36: 403-415, 403). Other scholars have documented and analyzed the central role of gay white men in mobilizations against HIV/AIDS as they have explored various theoretical concerns—e.g., the politics of knowledge and lay expertise (Epstein, Steven. 1996. Impure Science: AIDS, Activism, and the Politics of Knowledge. Berkeley: University of California Press); new social movements (Gamson, Josh. 1989. "Silence, Death, and the Invisible Enemy: AIDS Activism and Social Movement ‘Newness’." Social Problems 36: 351-367); and emotions (Gould, Deborah B. 2009. Moving Politics Emotion and Act Up’s Fight Against AIDS. Chicago: University of Chicago Press) and give little sustained attention to the agency of black or other racial minorities in the movement. To date, the political scientist Cathy Cohen provided the only book-length scholarly analysis focused on black American HIV/AIDS mobilization. Cohen devoted a chapter (Chapter 3) to “those black organizations, leaders, and activists that did attempt to address the needs of those with AIDS in their communities” (Cohen, Cathy J. 1999. The Boundaries of Blackness: AIDS and the Breakdown of Black Politics. Chicago: University of Chicago Press.) However, the central focus of Cohen’s book was an analysis of how the political, social, and economic marginalization of black Americans—and the further stigmatization of being gay or an intravenous drug user in black communities—encouraged the African-American leaders reserve in addressing HIV/AIDS as a vital community issue.
awareness that was theretofore unprecedented—though built upon and partly constitutive
of the liberation and social movements of minorities and women since the 1950s—just at
the moment of the emergence of AIDS.200 These black Americans produced cultural
works and founded political and social organizations that celebrated being black and gay.201 Thus, when AIDS began, there was a small but noteworthy black gay
organizational field on which black American HIV/AIDS activism was launched.202 That
is, “the work of black gay men and lesbians largely defined the formal organizing—
conferences, community education, and service provision—during” the 1980s when the
traditional black organizations and leaders were slow to respond to AIDS in black
American communities.203

Yet, another indicator of the activism and advocacy of black Americans—gay and straight, female and male—in the 1980s is their creation of HIV/AIDS black

200 As Cathy Cohen recounted, “we find not only the emergence of AIDS [in the late 1970s and early 1980],
but also the emergence of an outspoken and brave black lesbian and gay leadership—a new ‘vanguard’
who openly claimed and wrote about their race and sexual identities. Individuals like Audre Lorde,
Cheryl Clarke, Barbara Smith, Pat Parker, Michelle Parker, Joseph Beam, Essex Hemphill, and
Marlon Riggs were intent on creating not only new cultural voices, but also a political analysis which
made central the connections between homophobia and other forms of oppression” (1999. The
Boundaries of Blackness: AIDS and the Breakdown of Black Politics. Chicago: University of Chicago Press, 93-
94).

201 See also note 43. Organizations founded in the late 1970s and early 1980s included, Salsa Soul Sisters,
Third World Wimmin, Inc. (1974, New York City, NY); the Bay Area Black Lesbians and Gays (year?,
Bay Area, CA); DC Coalition of Black Lesbian, Gay, Bisexual and Transgender Men and Women (1978,
Washington, DC); and The National Coalition of Black Lesbians and Gays (1978, Washington, DC).

202 As Cohen noted, “the developing infrastructure in black gay communities did not approach in numbers
or resources that found in many white gay communities” (1999. The Boundaries of Blackness: AIDS and the
Breakdown of Black Politics. Chicago: University of Chicago Press, 94). See Chapter 2 for a discussion of
the white gay organizational field that birthed white gay HIV/AIDS activism; see also Armstrong,
University of Chicago Press.

University of Chicago Press, 97. Cohen also rightly advised, “it is important to remember that prior to,
and often in conjunction with, the formal response of black gay activists during the very early years of
the epidemic, families—most often mothers, lovers, and friends—took on the task of caring for their
loved ones” (98).
community based organizations (BCBOs). Table 3.3 below presents a list of select HIV/AIDS BCBOs that are operating to date in the United States with their year of establishment. From the table, it is clear that BCBOs with a direct mission to confront HIV/AIDS, either independent of or alongside other black American health concerns, have existed since the mid 1980s.

Three of eight of the organizations listed were founded in 1985, a year before the CDC officially acknowledged black Americans’ disproportionate burden of suffering from HIV/AIDS. The missions of each of these organizations were to serve black Americans in their respective communities when overall in the country there was little to no HIV/AIDS educational programs or services targeting black Americans or other communities of color. The list of BCBOs in Table 3.3 gives testament to this grossly under-appreciated fact: Black Americans have been part of the struggle to fight HIV/AIDS—albeit in the face of a regime of practices that largely rendered them and their work invisible within the greater HIV/AIDS discourse—from the beginning of the epidemic.

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204 As discussed in Chapter 1, black community organizations, or (BCBOs) are those organizations that are founded by black Americans and that are predominately administered by and for black Americans. Unfortunately there exist no comprehensive list of present day BCBOs, or those lost to history. The organizations in Table 3.3 were identified through my participant observation at HIV/AIDS prevention conferences in Oakland, CA, Detroit, MI and Atlanta, GA from 2007-2009. I conducted an Internet search to confirm their histories and their active status as of June 20, 2012.
Table 3.3: Select HIV/AIDS Black Community Based Organization and their Year of Establishment

<table>
<thead>
<tr>
<th>Name of BCBO</th>
<th>Date of Establishment</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minority AIDS Project (MAP)</td>
<td>1985</td>
<td>Los Angeles, CA</td>
</tr>
<tr>
<td>Us Helping Us, People Into Living, Inc., (UHU)</td>
<td>1985</td>
<td>Washington, DC</td>
</tr>
<tr>
<td>BEBASHI</td>
<td>1985</td>
<td>Philadelphia, PA</td>
</tr>
<tr>
<td>The Black Coalition on AIDS (BCA)</td>
<td>1986</td>
<td>San Francisco, CA</td>
</tr>
<tr>
<td>The National Black Leadership Commission on AIDS (NBLCA)</td>
<td>1987</td>
<td>New York City, NY</td>
</tr>
<tr>
<td>The National Minority AIDS Council (NMAC)</td>
<td>1987</td>
<td>Washington, DC</td>
</tr>
<tr>
<td>The Balm In Gilead, Inc.</td>
<td>1989</td>
<td>Richmond, VA</td>
</tr>
<tr>
<td>SisterLove, Inc.</td>
<td>1989</td>
<td>Atlanta, GA</td>
</tr>
</tbody>
</table>

The Late 1990s as a Period of Maintenance and Growth:

The agency of Black Americans became more pronounced in the late 1990s, when they began to exert significant influence within the HIV prevention field in which they were increasingly included. One prominent example of this influence occurred in 1998. In March of that year, the CDC assembled a meeting in Atlanta, GA with black American HIV/AIDS activists and community leaders “to brief them on the agency's African American Initiative.” After a CDC presentation at the meeting on newest surveillance data detailing alarming HIV infection rates in black American communities, the activists and advocates in attendance stormed out in protest. Soon after, calling for the

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implementation of a more concerted federal effort to address this disease disparity, the activists declared HIV/AIDS a “state of emergency” in black American communities. Moreover, the black American activists called on President Clinton and David Satcher, the first black American male appointed Surgeon General, to make a statement on behalf of the federal government confirming their declaration of a “state of emergency.”

The black community activists’ lobbying throughout the spring months led to the White House’s Presidential Advisory Council on HIV/AIDS and the Congressional Black Caucus (CBC) asserting their support for the state of emergency declaration. Though the President stopped short of declaring HIV/AIDS as a state of emergency in black America as the black activists and their allies demanded, in October 1998, President Clinton announced the creation of the Minority AIDS Initiative (the MAI). The MAI—often referred to as the “CBC Initiative” during its first year of implementation due to the CBC’s leadership in designing the initiative and securing funding—was a notable achievement. During its first year of operation, 1999, $166 million was allocated by congress and the DHHS to the initiative “to improve HIV-related health outcomes and reduce HIV-related disparities for racial and ethnic minority groups.”

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206 Aragón & Kates (2004) recounted: “The statement of emergency also included a call for: various federal agencies to develop new strategies targeting African Americans within 90 days; the provision of federal demonstration funding to test new community planning and program models; and an analysis of the correlation between the allocation of federal AIDS funding to communities and epidemiological trends” (Ibid).

207 In his announcement of the MAI—then called the “Initiative to Address HIV/AIDS in Racial and Ethnic Minority Communities”—President Clinton declared HIV/AIDS to be a “severe and ongoing health care crisis” in racial and ethnic minority communities (Ibid).

208 Ibid., 2. According the CDC, their agency “received $18 million in new prevention funding for African Americans and $21 million in emergency funding to address prevention needs of communities of color. In addition, CDC received $10 million in funding to support efforts to reduce mother-to-child HIV transmission, which disproportionately affects African Americans. Of these combined funds [from the MAI], a total of nearly $41 million is specifically targeted to African Americans” (1999. “On the Front Lines: Fighting HIV/AIDS in African-American Communities,” Available online, July 14, 2012:
review of the CDC’s response to the HIV/AIDS crisis among black Americans, the MAI, which was initially compelled by black American activism, was described as “groundbreaking.”

Thus, black Americans in concert with other activists and activists groups were a force in bringing about and further maintaining the disease regime of inclusion. Dr. Kevin Fenton, who is the first black American to be appointed the director of the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) at the CDC, confirms this fact. Dr. Fenton summarily acknowledges black activists’ role in pressuring the CDC to increase their efforts toward black Americans:

There are a number of factors, which cause change within in a public health agency, or within in a government agency [such at the CDC]. On the one hand, yes we would like to think as a science based agency it was the attention to the surveillance research data that helped us [the CDC] to change our prevention programming and the distribution of resources. But the reality is that many of the influences that drove the change was clearly advocacy by the community, demanding more, asking for more, asking for greater accountability in the use of federal resources [that] really helped to drive us in this direction.

Black Americans in the CDC

It is important to note that black Americans who work (or have worked over the years) at the CDC, such as Dr. Fenton, represents another important factor and feature of

http://www.thebody.com/content/art17105.html).


210 Interview by the author, digital recording, Atlanta, August 4, 2009.
black American’s agency in the bringing about the inclusion regime. Especially, if my interviews at the CDC and participant-observation at HIV prevention conferences are any indication, it is safe to assume that many of the black Americans who came to work at the CDC in the 1990s and the 2000s, particularly in the CDC Division of HIV/AIDS Prevention, were first involved in gay and/or black community HIV/AIDS, and other health advocacy, efforts. Moreover, Dr. Fenton and other current black CDC administrators and workers were upfront about describing their entrée into HIV prevention through these minority communities, and seeing their work as, in the words of one CDC administrator, an opportunity “to be a voice for people that didn’t have much of a voice [in the HIV/AIDS discourse or prevention field].”

According to this same administrator, during the time, in the early 1990s, when she came to work at the CDC,

> There was not this huge number of African Americans and people of color who were within the agency—but people [of color] did exist here. Certainly, there have been people of color working for CDC for years and years; but in terms of an institution, [in the 1980s] it was an institution…[Whose level of racial diversity] was representative of what most institutions were like during that time… I come from [the black American] community, and I’m always really clear about that. Yes, I represent the federal government, and I do so proudly. But also, as a black American, I have a responsibility in being here [at the CDC] to say what is needed to be said, as far as I know and can communicate, about what is important to our community. What issues our community faces; and how those issues impact our ability to make a difference in terms of the epidemic.

Such a sentiment clearly suggests that the inclusion of black Americans in the HIV/AIDS discourse and prevention field is not a simple product of an “us vs. them” dynamic,

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211 This is especially true today; my participant-observations at HIV/AIDS prevention conferences revealed a vibrant and visible black American CDC workforce.
212 CDC administrator, interview by author, digital recording, Atlanta, 4 August 2009.
213 Ibid.
relative to the CDC and the black American HIV/AIDS health social movement. As Dr. Fenton affirmed, “clearly having a minority leader [such as himself]…can make a difference in [public health] organizations.” The next chapter, Chapter 4, will confirm ways that the demarcations between the state and social movement are indeed permeable in the field of HIV prevention under the regime of black American inclusion.

**Conclusion: The Effects of Disease Regimes**

This chapter demonstrates how changing the color of HIV prevention and discourses and practice around AIDS was a distinctive socio-political process. Together with Chapter 2, it reveals ways in which transformations in biomedical and public health discourses and practices eventually brought more visibility to the burden of AIDS in black American communities. The concept of disease regimes is useful to characterize the practices and polices that emerged in 1981, which first constituted what would become the social fact of HIV/AIDS as a white, gay, men’s disease, and, until the early 1990s, largely rendered invisible and excluded black Americans. Particularly from 1993, biomedical and public health policy and practices and the HIV/AIDS discourse grew and developed to more include black Americans and make more visible their HIV/AIDS burden.

As we recall from Chapter 1, disease regimes consists of the “institutionalized practices, authoritative discourses, social relations, collective identities, emotional

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214 Prior studies of professionals, scientists, and/or governmental workers and their roles in social movements and advocacy in highly social and political valiant issues indicate that these actors too may, at different times and spaces, occupy the role of a social movement actor. For examples, see

215 Interview by the author.
vocabularies, visual images, public policies and regulatory actions through which diseases are socially constituted and [subjectively] experienced.”216 Tracking and critically analyzing key moments and events in relation to the HIV/AIDS epidemic within the social worlds of biomedicine, public health, the media, and the social movement from 1981 until 2000, this chapter—in conjunction with the previous one—particularly demonstrates some of the institutionalized practices, authoritative discourses, public policies and regulatory actions that constructed and structured HIV/AIDS regimes of black American exclusion (1981-1992), and later black American inclusion (1993-present day). In short, we have seen how two regimes of HIV/AIDS differentially produce subjects along racial and/or sexuality-based lines.

Additionally, and importantly, Chapter 3 illuminate how changing social relations of HIV/AIDS and the racial formations they produced from the late 1980s enabled black Americans HIV/AIDS-based identities and collective action. The discursive and bureaucratic shift that is represented by the regime of black American exclusion and inclusion came about from multiple sources and, as represented by Table 3.1, the transformation has been far-reaching and has broad effects within the HIV/AIDS discourse and prevention field. The next chapter, Chapter 4, will more concretely explore the dynamics of the regime of inclusion by looking at interactions between two Atlanta BCBOs and the CDC. In the exploration some of the ways in which black Americans’ agency is shaped and bounded by discourses and practice of the inclusion regime will be documented and critically analyzed.

Chapter 4

On the Dynamics of Inclusion: Two Atlanta BCBOs, the CDC and the HIV Prevention Field

Together Chapters 2 and 3 document and analyze, through a range of primary and secondary data sources, the socio-political transformation of a regime of HIV/AIDS from one that largely excluded black Americans in the 1980s, to a regime that increasingly included black Americans in the 1990s. What this shift means “on the ground” for black American HIV/AIDS activists/advocates and those actors more embedded in the organizational structure of federal public health remains to be explored. Such an exploration requires a critical consideration of questions such as the following: How have prevention discourses, programs and practice changed in the advent of the inclusion regime? How do black Americans and public health workers themselves understand the changing salience of race across the two regimes? In what ways have the relationships and interactions between institutions of U.S. public health and the black community changed? What are the concrete benefits and/or drawbacks for black Americans being included specifically within the field of HIV prevention?

This chapter begins to explore these questions through analyzing the experiences of two BCBOs in Atlanta, Georgia; it pays particular attention to the changing relationship—and understandings of that relationship—between the community organizations’ and the CDC’s prevention discourse and practice. More specifically, I rely on life history interview data with members of the BCBOs and key CDC informants, alongside documents and publications produced by their organizations, to analyze the
ways in which their prevention efforts align with, or conflict with, each other.

Three specific characteristics of Atlanta make it a practical, if not ideal, location to anchor an analysis of the on-the-ground dynamics of black Americans’ exclusion and inclusion within the field of HIV prevention. First, Atlanta has long been considered a Mecca of ‘black America,’ and its black American majority population is the inheritor to a long history of black institution building and civil rights activism. Second, HIV/AIDS infection rates in Atlanta are among the highest of metro areas in the country. That the CDC, the premier federal public health agency, is headquartered in Atlanta is the third characteristic that makes the city an appropriate location for the analysis of the HIV prevention field. Taken all together, these three features suggest that Atlanta would (or, at the very least, should) have an active HIV prevention field, one where the institutional agency of BCBOs and the CDC—and the interactional processes and practices between

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218 The annual rate of AIDS cases (per 100,000 population) in 2007 in the metropolitan statistical area (MSA) of Atlanta–Sandy Springs–Marietta, GA was the 10th highest among all MSA (population ≥ 500,000). Also as of 2007, the state of Georgia as a whole had the 8th highest cumulative cases of HIV infection of the 47 states, the District of Columbia, and 5 U.S. dependent areas with confidential name-based HIV infection reporting (Centers for Disease Control and Prevention. 2009. *HIV/AIDS Surveillance Report, 2007*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention Vol. 19. http://www.cdc.gov/hiv/topics/surveillance/resources/reports/). The surveillance data indicate that Atlanta’s black residents are over-represented in the number of HIV/AIDS cases in Georgia as, according to the Georgia Division of Public Health (GDPH), “African Americans have represented the largest proportion of [HIV/AIDS] cases [in the state] each year since 1990” (Georgia Department of Human Resources. 2002. *Epidemiology Profile for HIV Prevention Community Planning in Georgia*, 46.
these institutions and the individuals embedded within them—can be documented, analyzed, and theorized.

Therefore, it is in Atlanta that I explore the local repercussions of the HIV/AIDS regimes of exclusion and inclusion in relation to black Americans. I show how the CDC’s reliance on “objective science” (as exemplified by the Diffusion of Effective Behavioral Interventions, or “DEBI” program) to create prevention programs is in long-standing tension with BCBOs, who advocate and prefer homegrown prevention programs (those black activists denote as “For Us and By Us” or “FUBU”). I argue, however, that—contrary to the conventional wisdom that portrays DEBI and FUBU as oppositional and incommensurate—this tension, which is emblematic within the contemporary HIV prevention field, helps to enable black Americans’ ongoing inclusion. That is, the tension, or the contentious friction that is exemplified by DEBI vs. FUBU dynamic, is constitutive of a “knowledge-intervention terrain,” my term meant to designate both a process and, at the same time, a conceptual space through which black Americans’ concerns and cultural products are or are not incorporated into the prevention field. Moreover, I argue that the regime of black Americans’ inclusion, even as it is increasingly institutionalized, presently comes with both benefits and costs to BCBOs and ultimately to the effort to prevent HIV/AIDS among black Americans.

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219 It was through a conversation with Andrew Lakoff that the name of this concept came about.
Black American HIV/AIDS Activism in Atlanta

Atlanta is a unique city; in addition to being a historical hotbed of black American activism, it is also distinguished by being the one city in U.S. where black Americans have held governmental power and political control since before the advent of HIV/AIDS in 1981. Despite—or, perhaps, if political scientist Cathy Cohen is right, because of—black Americans’ prominent mainstream position, a black organizational response to HIV/AIDS was slow to occur, relative to other cities with a significant black American population. That, of course, does not mean that some black Americans in Atlanta were not involved in some aspect of HIV/AIDS prevention and treatment activism. As Dázon Dixon Diallo, an original member of the National Black Women's Health Project and a community based HIV/AIDS activist in Atlanta since the mid-1980s, recalled:

“There were very small pockets of efforts happening [in the black American community in Atlanta]; yes, by 1985 there were individuals who were doing things.”


221 See Table 3.3 in Chapter 3. See also Chapter 3 for more on Cohen’s argument that HIV/AIDS is an issue that revealed the limits of mainstream black American institutions and politics to address and include the diversity of black American lives (1999. The Boundaries of Blackness: AIDS and the Breakdown of Black Politics. Chicago: University of Chicago Press).

222 Dázon Dixon Diallo, interview by author, digital recording, Atlanta, 17 July 2009. The National Black Women's Health Project (NBWHP) got its' start in 1983 at the first National Conference on Black Women's Health Issues held at Spelman College in Atlanta. Diallo, who was an undergraduate student
One such effort was started “by some local gay and bisexual black men to create support networks so that they could provide support to men who were dying of AIDS.” These black gay and bisexual men received some organizational support from AIDAtlanta, the first HIV/AIDS organization in the city, which formed in 1982 from the gay identity movement organizations of the 1970s and “grassroots” efforts of largely white, gay men responding to the emerging epidemic. Yet, it was not “until the late 1980s that a more concerted effort [by black Americans] in the black American community started to rise.” Two BCBOs that had their start near the close of the first decade of HIV/AIDS and still continue to date to serve black American communities of Atlanta are SisterLove, Inc. and the National AIDS Education & Services for Minorities, Inc. (NAESM).

Two Atlanta BCBOs: SisterLove, INC and NAESM, INC

Diallo started SisterLove, Inc., a BCBO whose current mission is “to eradicate the adverse impact of HIV/AIDS and other reproductive health challenges upon women and their families through education, prevention, support and human rights advocacy in the

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223 Ibid.
225 Diallo, interview.
United States and around the world,” in July of 1989. Diallo’s HIV/AIDS advocacy and activism was built upon her participation in the reproductive rights movement that was a part of her work for the National Black Women’s Health Project. Yet, according to Diallo, this is the “cute story” she likes to tell when asked how she, as “a straight black woman,” got more directly involved with HIV/AIDS activism; the story begins with this line: “Rock Hudson is the reason I’m involved in HIV.” She then offers clarification:

You see, what happened was that I was working in women’s health…[when] Rock Hudson made his announcement [of his AIDS diagnosis in] the summer of ’85. And for some reason, women just started calling into our [Atlanta’s] local AIDS service organization [i.e. AIDAtlanta]—which was primarily being run by and for gay men, predominantly white men. And they just didn’t know what to do… They called us [women involved in the women’s health movement] in to help them figure out how to respond to these women in the community [calling]…

Thus, Diallo’s formal entrée into HIV/AIDS activism was as a volunteer for AIDAtlanta. Within two years of responding to AIDAtlanta’s call for help, the volunteer group of black and white women, of which Diallo was part, created a women’s educational workshop that was deliberately sex-positive as it sought to empower women to negotiate around safer sex practices with their sexual partners. In 1987, Diallo “initiated a collaboration with a local women’s organization to improve access for all women and

226 http://sisterlove.org/about-us/ accessed 20, July 2012. Even though SisterLove, Inc. is an Atlanta based organization, its’ contemporary mission extends beyond the local sphere of the city. Thus, in June 2002, SisterLove opened a “Program Office” in Witbank, Mpumalanga Province, South Africa. Yet, in my interviews with Diallo and other women of the organization, they readily identified their work in Atlanta as being primarily for black American women and rooted in experiences of being a black American woman. However, all willing women (an even men—unless a program or intervention was designed for a women-only audience) are welcomed to participate and take advantage of the prevention programs and services offered by SisterLove.

227 During my interview with Diallo, undoubtedly noticing my look of puzzlement when she stated the Rock Hudson line, laughing she said: “And you know, I always get the Scooby Doo response, you know: How does that work?”

228 Diallo, interview.
especially those of color” to HIV/AIDS education and treatment, which resulted in the Women’s AIDS Prevention Project (WAPP).\^229 However, by 1989, the lack of support for WAPP lead Diallo to start SisterLove Women’s AIDS Project “with an unemployment check in hand, [in her] dining room” and along with the assistance of the WAPP’s women of color advisory board.\^230 In 1992, SisterLove Women’s AIDS Project name was officially changed to SisterLove, Inc. Today, SisterLove bills itself as the “oldest nonprofit in the state of Georgia dedicated specifically to women living with, and at risk for, HIV/AIDS.”\^231

A year following Diallo’s establishment of SisterLove, three black American Atlanta residents of Atlanta—Rudolph H. Carn, Ms. Mae Reed, and Madam Edna Brown—founded National AIDS Education & Services for Minorities, Inc. (NAESM).\^232 Born from conversations, between the three founding members in December 1990, regarding the lack of prevention and educational services for black gay men in Atlanta, NAESM originated as an outreach program with the goal “to help African Americans learn about the disease and how to protect themselves from infection.”\^233 The BCBOs

\^230 Diallo, interview. See also, Ibid.
\^231 SisterLove, Inc. 2009. Agency Overview. SisterLove, Inc. Atlanta, GA. In this overview of the agency, SisterLove defines the focus of its’ core programs and services as being “decidedly” on: “1) increasing awareness of HIV/AIDS and other sexually transmitted infections (STI); 2) increasing knowledge of behaviors, conditions and systems that increase women’s risk for HIV and other STIs; 3) increasing knowledge of HIV prevention methods and risk reduction strategies; 4) challenging and supporting individuals and communities as they address, re-evaluate and adjust attitudes/thinking, behaviors, conditions and systems that contribute to the spread of HIV and other STIs; and 5) advocating, coordinating and organizing on behalf of those most affected by the AIDS pandemic in the interest of altering policies, systems and conditions that impede the rights of women and communities negatively affected by HIV and other reproductive health and rights issues.”
\^232 Mr. Carn is the only surviving founding member and currently serves as CEO of NAESM, Inc. Though, workers and volunteers for SisterLove and NAESM today are socially and professionally well aware of each other, their founding independently occurred.
\^233 NAESM. NAESM’s Agency Brochure: Facing Tomorrow’s Challenges. Atlanta: NAESM, INC.
initial base of operations was Mr. Carn’s living room. And, its earliest prevention programs in the black community was to “go out in the streets of Atlanta, passing out condoms, [and] talking to people about…protecting themselves.”

Today, NAESM is a leader among African American advocacy/service groups, which operates on both a local and national stage, "promoting self-empowerment, providing service for healthier living, and raising the [black] community’s awareness about the HIV epidemic and its adverse impact on communities of color."
changing relationships with the CDC—will meet two important goals: First, it will provide more concrete evidence of the contextual dynamics of both exclusion and inclusion, and, secondly, it will further elucidate the opportunities and costs for black Americans of preventing HIV/AIDS in black American communities within the contemporary prevention field.

A robust U.S. HIV/AIDS prevention field did not fully yet exists within the emergent regime of inclusion when SisterLove and NAESM started, respectively in 1989 and 1990. The post-1985 focus of the federal government domestic prevention strategy in large part rested upon an HIV/AIDS education initiative tainted with a New Right social and moral conservatism that promoted abstinence and heterosexual marriage as effective forms of prevention. Yet, discord among the social conservatives of the Reagan administration led also to a different, if not contradictory, approach to prevention based on a commitment to rational science and Christian compassion. That, by the late 1980s, the CDC had begun prevention programs that “increased basic knowledge about

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238 As detailed by historian Jennifer Brier, at the heart of this discord was, on one side, education and religion advisors to President Reagan, such as, Gary Bauer, William Bennett, and Carl Anderson; and, on the other side Surgeon General C. Everett Koop and Admiral James Watkins, the head of the Presidential Commission on the Human Immunodeficiency Virus Epidemic (Presidential Commission on HIV) (2009. "Infectious Ideas: U.S. Political Responses to the AIDS Crisis." Chapel Hill: University of North Carolina Press, Chapter 3).
HIV transmission and prevention, reduced risk behavior within populations at high risk for infection, and decreased negative attitudes toward persons living with HIV/AIDS” is a testament to the success, though limited, of rationality and compassion during the Reagan (and Bush) years.239

Nonetheless, Ms. Diallo still found that the HIV prevention work she was doing with black American women “didn’t pass muster at the CDC” in the late 1980s and early 1990s. A centerpiece of SisterLove, Inc.’s prevention efforts in 1989 was a prevention intervention, called the Healthy Love Party that took a sex-positive approach of teaching women “how to negotiate safer sex” practices in a group conversation and demonstration facilitated through the use of “erotic” and “real language.” Ms. Diallo’s organization as a whole reflected a reproductive rights and feminist centered agenda that was “not acceptable to the CDC,” or the DHHS in general. In Ms. Diallo’s words, “they were flying under the Reagan [and Bush] radar during those time;” their prevention efforts “did not fit within the CDC notion of just distributing condoms and counting them.”240

Indeed, it was not until the mid-1990s, under the presidency of Bill Clinton, that a direct relationship began to develop between both SisterLove and NAESM and the CDC.241 Signaling the start of a more innovative national HIV prevention strategy—


240 Diallo, interview. Interestingly, Diallo also explained that federal funds “had not been an option” during the days at Women’s AIDS Prevention Project because it was a part of an abortion clinic, and thus the Hyde Amendment precluded federal funding.

241 However, prior to that, in the early-1990s the BCBOs received funds from the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act that assisted their efforts to treat and care for individuals living with HIV or AIDS in the community, and HIV testing. The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was sign in to law on August 18, 1990 and authorized funding of outpatient and ambulatory medical and support services for people with AIDS or are infected with HIV. Under Title 1 of the act services in those urban areas with the highest number of reported AIDS cases, such as Atlanta, Fulton County, GA, where funded as of 1991 (See, Bowen, G.
along with solidifying the emergent field of HIV prevention—the CDC initiated HIV Prevention Community Planning at the start of 1994. With community planning the CDC and the federal government distanced itself from conservative prevention poli ces of the prior decade. In the words of one CDC administrator, the agency “had [come to] understand that government could no longer go and tell people what they needed to do about their own health,” and to appreciate that including voices from the populations suffering from AIDS or at risk of becoming HIV infected was “essential in terms of planning for HIV” prevention efforts.

From its inception, a stated goal of community planning was to develop “priority individual group-, and community-level strategies and interventions” that were “culturally and linguistically appropriate for defined target populations,” including racial and ethnic minorities. The community planning process provided an avenue for black Americans to be included as the CDC developed a more systematic HIV prevention program strategy. Thus, as members of both SisterLove and NAESM, since 1994, have

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Community Planning was developed in consultation with governmental and nongovernmental organizations, such as the National Alliance of State and Territorial AIDS Directors (NASTAD), the Association of State and Territorial Health Officials (ASTHO) and the National Minority AIDS Council, site visits and public hearings in seven geographic and ethnically diverse communities across the U.S. (See, Valdiserri, Ronald, Terry Aultman and James Curran. 1995. "Community Planning: A National Strategy to Improve HIV Prevention Programs." Journal of Community Health 20: 87-10). It is officially defined as “an ongoing process whereby” state and territorial health departments and seven city-local health departments “share responsibilities for developing a comprehensive plan with other state and local agencies, nongovernmental organizations, and representative of communities and groups at risk for HIV infection or already infected” (quoted in Ibid, 89). The seven city-local health departments are Chicago, Houston, Los Angeles, New York, Philadelphia, San Francisco, and Washington.

Valdiserri, Ronald, Terry Aultman and James Curran. 1995. "Community Planning: A National Strategy to Improve HIV Prevention Programs." Journal of Community Health, 90. According to these authors, a National Minority AIDS Council report on the impact of AIDS on communities of color was influential factor in planning the community planning process.
consistently served on the Georgia Community Planning Prevention Group, they have
established a more direct and mediating relationship with the CDC. For example, as
Reginald Graham, a NAESM staff member explained, his organization has “a very good
rapport with the CDC” based in part on the fact that “NAESM has always been a part of the community planning group.”

\[\text{DEBI vs. FUBU AND PREVENTION}\]

In addition to the development of community planning, the CDC’s HIV Prevention Research Synthesis Project (HPRSP) marks one of the most important moments in the build-up of a national systematic prevention strategy. Started in 1996, the HPRSP conducts meta-analyses of data from intervention trials to determine the scientific rigor and evidence-based efficacy of interventions. In short, the knowledge produced by this on-going research project defines which interventions are the best effective tools for prevention in ‘high-risk’ populations. As of 2006, more than 50

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245 Reginald Graham, interview. Moreover, both NAESM and SisterLove report that given their well-known position in the Atlanta black community, they were often called on by the CDC as community representatives. Similarly, as one employee of SisterLove (since the mid-1990s) recalled, “we were always someone that they [the CDC] called upon when they needed to reach the community for their studies” (Interview by author, digital recording, Atlanta, 9 July 2009).

246 The CDC defines scientific rigor of prevention interventions with the following criteria: “Behavioral and social intervention studies are classified as methodologically rigorous if they used random assignment to intervention and control groups (experimental designs) and reported at least post-intervention data. Behavioral and social studies are also considered rigorous if they used non-biased assignment (e.g., systematic assignment) to intervention and comparison groups (quasi-experimental designs) with equivalence of groups or used statistical adjustment for any nonequivalence, and reported pre- and post-intervention data (Centers for Disease Control and Prevention, HIV/AIDS Prevention Research Synthesis Project. Compendium of HIV Prevention Interventions with Evidence of Effectiveness. Atlanta, GA: Centers for Disease Control and Prevention; November 1999, Revised, 4-3).

247 According to the CDC, these analyzes have demonstrated the legitimacy of behavioral interventions, specifically, in their ability to “substantially reduce sexual risk among young adults, men who have sex
Interventions have been scientifically identified as effective by the HRSP; and since 2002, a number of these “evidence-based interventions” have been packaged and distributed to HIV prevention providers, including BCBOs such as SisterLove and NAESM, through the CDC’s Diffusion of Effective Behavioral Interventions (DEBI) project. The complex dynamics of the inclusion regime, including the mixed effects that it has on the experiences, rights and opportunities for black Americans are discernible through the conflicts and tensions that arise through the DEBI project. For instance, the missions of BCBOs in the 21st century may be betrayed through the CDC’s reliance on the logic of DEBIs (as the interventions distributed through the program are colloquially referred to by both the CDC and black American community activists/advocates). That is, as further discussed below, the CDC’s reliance on the scientific method—e.g. the methodological rigor of randomized intervention and control groups in experimental designs to demonstrate the efficacy of interventions—encourages the increasing professionalization of black Americans activism (along with the aligned process of the increasing credentialization of black American activists) and pulls precious resources away from BCBOs that might go toward their more progressive social change goals.

Yet, as conceptualized and implemented by the CDC, the DEBIs also provide another avenue of inclusion for black Americans in the HIV prevention field. As Kevin Fenton, the director of the National Center for HIV/AIDS, Viral Hepatitis, STD, and

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TB Prevention (NCHHSTP) at the CDC, noted in regard to DEBIs: “it is really important that as we think about our prevention programming that we [the CDC] not only have effective and evidence based strategies, but that we are working with communities to find culturally component approaches for delivering and implementing, and evaluating these prevention programs.” However, despite this sentiment a common refrain from black Americans working in HIV prevention is that the DEBIs are largely inappropriate for black Americans. As Paul Williams, a NAESM worker who has been active in prevention and treatment advocacy since 1981 attests, the DEBIs “are not really for black folks, they're [for] white folks.”

For Mr. Williams, the DEBI project is based on faulty logic: a belief “in the rational power of science” to objectively define what tools or methods would be effective for prevention—irrespective of the local particularities of communities. Explaining the difficulty of implementing DEBIs, Mr. Williams rhetorically asks, how can one implement standardize “core elements” of a DEBI (as required) and still be expected to also “tailor the DEBI to your audience?” Instead, Mr. Williams and other black Americans working in the prevention field advocate for an understanding that prevention interventions must be tailored to “our [i.e. black] communities.” Such interventions would come from the local community and be produced by black Americans, for black

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249 Kevin Fenton, Interview.
250 Paul Williams (pseudonym for a NAESM staff member), interview by author, digital recording, Atlanta, 26 March 2009. In addition to my interviews, I heard this refrain about the inappropriateness of DEBIs for black Americans repeated in conversations doing my participate-observation at the National Minority AIDS Council’s (NMAC) HIV Prevention Leadership Summit (HPLS), was held in Detroit in 2008 and the 2009 National HIV Prevention Conference (NHPC) held in Atlanta, Georgia.
Mr. Williams insists that the “CDC should go back to the drawing board,” rethink the DEBI project, and in the meanwhile “put more money into building infrastructures and programs of African Americans.”

Similarly, Ms. Diallo, of SisterLove, appeals to the adage that "Africa problems will be resolved with African solutions," and argues that “black people, have some of our answers; we can be innovative.” Thus, black American prevention activists/advocates put more faith in the development of prevention tools that are based more on indigenous practices (or logics of interventions) internal to black Americans’ experiences and their communities. For them, preventing HIV/AIDS among black Americans is about black Americans and their BCBOs’ “having the capacity, and being creative enough, to acquire the resources we need...And to be recognized, respected, and resourced [e.g. by the CDC] for that lived experience and indigenous technology—that indigenous expertise that only we [black Americans] can deliver in our own communities.” Instead of DEBIs, black Americans appeal for prevention tools that are “For Us, and By Us;” or FUBU interventions that are locally produced from the ground-up by black Americans.

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252 Mr. Williams expresses his frustration with the top-down approach of DEBIs and his commitment to locally community-based produced knowledge by sarcastically noting, “people have went to these diversity course, and the culture sensitivity classes, and now that makes them an expert on how to deal with black folks, or blacks folks think we can deal with Latinos and this and that” (Paul Williams, interview).

253 Ibid.

254 For a critique of the top-down approach of DEBIs, see Dworkin, Shari, Rogério Pinto, Joyce Hunter, Bruce Rapkin and Robert Remien. 2008. "Keeping the Spirit of Community Partnerships Alive in the Scale Up of HIV/AIDS Prevention: Critical Reflections on the Roll Out of DEBI (Diffusion of Effective Behavioral Interventions)." *American Journal of Community Psychology* 42:51-9.) Dworkin et al. note: “Despite the record of proven success in [D]EBIs, it is indeed possible to harm relationship building with community partners and garner negative intervention effects when selecting top-down approaches for dissemination efforts. This is because inequitable distributions of power and control among funding agencies, health departments, service organizations, and prevention providers can be viewed as a disrespectful or paternalistic imposition on communities and organizations. This can affect organizational buy-in, perceived relevance, or the desire for organizations to translate the need for a change in their current prevention practices to community members that are being served” (54).
themselves.\textsuperscript{255}

It is a testament to black Americans inclusion—and the extent of their inclusion in the contemporary HIV prevention field—that the CDC has begun to recognize black Americans’ critiques of DEBIs and their community based indigenous expertise. Indeed, according to a CDC official, black American community workers “have brought up very valid concerns around the DEBIs.” There is the acknowledgement of the uncertainty involved in “taking interventions that have been proven to be effective and efficacious in a research setting” and expecting those interventions to be successful out “in the field where you have all type of external factors that could affect their implementation.”\textsuperscript{256} However, this does not lead to a repudiation of DEBIs; from the CDC’s perspective, the DEBI project is an ongoing scientific endeavor that in time will mature to better address the concerns of black Americans and other communities of color.

One noteworthy development in the CDC’s policy regarding the production of effective interventions, specifically for racial and ethnic minorities, was the establishment of the CDC’s “Innovative Interventions project” in 2004.\textsuperscript{257} Designed “to support CBO [community based organization] efforts to conduct rigorous evaluations of HIV prevention interventions [that] they [the CBOs] had developed for high-risk minority populations in their [own] communities,” the CDC initiative provided a distinct

\textsuperscript{255} Unfortunately, during my fieldwork in Atlanta, I was not able to participate in and/or able to witness members of SisterLove or NAESM conducting a DEBI or FUBU intervention program. Therefore, I am unable to provide a more concrete analytical contract of DEBI vs. FUBU techniques in action on the ground.

\textsuperscript{256} CDC administrator, interview by author, digital recording, Atlanta, 4 August 2009.

mechanism of inclusion for local minority produce interventions.\textsuperscript{258} In short, the Innovative Interventions Project provided a means to test the efficacy of FUBU interventions; and, if the FUBU intervention was deemed efficacious, to add it “to the body of evidence based interventions that are available for use by CBOs and health departments.”\textsuperscript{259} With this initiative, the CDC gave official credence to the notion expressed in the quote above by Director Fenton that it is necessary for the agency to create not only effective evidence based interventions but also to work with local communities to find culturally appropriate interventions.

SisterLove’s Inc.’s “Healthy Love Party” and the CDC’s Innovative Interventions Project:

SisterLove, Inc., of Atlanta, was one of three CBOs in the nation funded by the Innovative Interventions project.\textsuperscript{260} With this funding from the CDC, SisterLove embarked on the process of evaluating the efficacy of their FUBU intervention known as the “Healthy Love Party.” Since 1989, the Healthy Love Party has been offered by SisterLove as a sex-positive women’s educational three-to-four-hour party that is “not only focused on women at risk to and from men, but…[also focused] on women taking

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\textsuperscript{258} Painter, Thomas M., Paulyne M. Ngalame, Basil Lucas, Jennifer L. Lauby and Jeffrey H. Herbst. 2010. "Strategies used by Community-Based Organizations to Evaluate their Locally Developed HIV Prevention Interventions: Lessons Learned from the CDC’s Innovative Interventions Project." \textit{AIDS Education and Prevention} 22:387-401, 388-89. The CDC sought to support interventions “that had been developed with substantial input from served communities, which the CBOs were currently delivering and believed to be innovative and effective in reducing HIV-related risk behaviors but which had never undergone a rigorous outcome evaluation” (ibid., 389).
\textsuperscript{259} Ibid.
\textsuperscript{260} The other two CBOs funded to evaluate their “home-grown” interventions were People of Color in Crisis, Inc. (POCC), located in Brooklyn, New York, and the Philadelphia Health Management Corporation (PHMC), of Philadelphia, Pennsylvania.
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care of themselves and being responsible as well." As conducted by SisterLove for more than two decades, the Healthy Love Party is a single session intervention “delivered to intact, pre-existing groups of women from, for example, sororities, churches, and friendship circles.” Created from and inspired by “the stories that were coming from women,” SisterLove’s signature intervention “incorporates principles of social behavioral theories, delivers HIV prevention information and teaches condom-use skills in a highly interactive, festive, and non-judgmental manner.”

SisterLove, Inc. seized the opportunity to apply for funding from the CDC’s Innovative Interventions project in order to evaluate the efficacy of Healthy Love Party’s as an HIV prevention intervention. For Ms. Diallo it represented a chance “to prove” that SisterLove, Inc.’s very own intervention “was evidence based [and] was just as good, if not better [than those interventions created at the university level], because it had be created for us, by us, and with us.” After all, Ms. Diallo, who in the 1990s—a decade after completing her BA at Spelman College—commuted from Atlanta to the University of Alabama, in Birmingham to complete a Masters of Public Health, just “knew” that what SisterLove “had created just by talking with each other…[and] from our own stories” was, in fact, also imbued with theories of public health—they “just needed to prove it.”

However, despite their eagerness to prove the evidence-based validity of

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261 Diallo, interview.
263 Diallo, interview.
265 In Ms. Diallo’s own words, “it had the health belief model, [and] social cognitive theory in it, [and it also]
their FUBU intervention, SisterLove were also well aware and weary of the challenges that conducting a CDC funded evaluation study would pose to the organization.

Indeed, even as SisterLove, Inc.’s funding through the Innovative Interventions project represents how within the HIV/AIDS regime of black American inclusion there are official opportunities for black Americans’ concerns and locally produced innovations to be incorporated within the field of HIV prevention, it also demonstrates how contention and mixed-blessings are part and parcel of inclusion. This is clearly seen in the contestation that occurred between SisterLove and CDC project staff over the very name of the innovative intervention under evaluation. As SisterLove staff member Alisha Winters recalled: “We couldn’t call it a party anymore. So, we were funded by the CDC to evaluate our Healthy Love Party and the first thing they changed was the title, because they said the government—and I guess they meant Bush, at the time—would not allow them to do a party.”

Thus, in a move “to facilitate CDC approval of the evaluation protocol,” the Healthy Love Party became “the Healthy Love Workshop for purposes of the evaluation.” This name adjustment occurred even though SisterLove staff members feared that changing the party to a workshop would “remove the organic-ness” of the intervention. SisterLove staff members generally expressed their concern that applying controls and standardizing the delivery of the intervention for the evaluation protocol itself would undermine its’ efficacy; as Ms. Winter explained: “The

had the trans-theoretical model of behavior in it…we just needed to prove it.”

266 Alisha Winters (pseudonym for a SisterLove, Inc. staff member); interview by author, digital recording, Atlanta, 9 July 2009).


268 Alisha Winters, interview.
success of it [the Healthy Love Party] was [in] tailoring it to the audiences, to the women that we served, to their particular needs.”

However, the end result of the four-year evaluative study was that SisterLove’s newly christened “Healthy Love Workshop” was scientifically deemed effective as an HIV prevention tool. With the publication of the findings in 2010, the intervention created by SisterLove, Inc. became eligible to be included in the national compendium of HIV prevention programs, which have been scientifically demonstrated as effective. Though this was undoubtedly a success for SisterLove and for the idea that the efficacy of FUBU interventions can be shown, even with the funds from the CDC project, SisterLove expended considerable time and resources to build-up their organization’s capacity to successfully implement the rigorous evaluation. For example, SisterLove had to hire an evaluation coordinator, and contract with university based research and evaluation consultants, efforts and relationships that required persistent care and negotiation. The sacrifices made to the local integrity of SisterLove’s FUBU intervention in the name of being evaluated, along with the opportunity costs imbued in the time and resources the evaluation project elicited from other organizational projects and goals, exemplifies some of the contemporary costs of BCBOs’ active inclusion in the HIV prevention field.

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269 Ibid.
Conclusion: The “Knowledge-Intervention Terrain” and the Opportunities and Constraints of Black Americans’ Inclusion

SisterLove, Inc.’s particular experience with the CDC’s Innovative Interventions project, along with the tension exemplified between DEBI and FUBU interventions more broadly, demonstrates that the HIV/AIDS regime of black American inclusion comes with challenges, constraints, and opportunities for black Americans and their BCBOs in the prevention field. To analyze the alignments, intersections and struggles that are, at once, constitutive and a product of black Americans inclusion in the contemporary field of HIV prevention, I offer the concept of the “knowledge-intervention terrain.”

Generally speaking, the concept is meant to highlight the fact that the production and scientific verification of knowledge is an increasingly paramount task of actors embedded within organizational fields, perhaps particularly so within those fields that blur and transverse the boundaries of the social movement (or civil society) and state divide. These knowledge production practices, while “symptomatic of the depoliticizing and managerialist dynamics of neoliberal governance,” also help to create assemblages and socio-technical arrangements and mechanisms that enable and structure a terrain whereby the knowledge produced (potentially) becomes useful, and/or is used, as, a tool of intervening into populations. More specifically within the field of HIV prevention and in regard to black Americans, the “knowledge-intervention terrain” is a process and conceptual space through which black Americans’ concerns, understandings, and cultural products are or are not incorporated within the HIV prevention field. More generally, the

knowledge-intervention terrain is the means by which evidence-based HIV policy making is increasingly conducted.\footnote{272 In this sense then, HIV/AIDS prevention policy in the U.S. is aligned with more global developments in neoliberal states—or the rational of advanced liberal governmentality—which increasingly relies on the procurement of credible knowledge and expertise in the name of a heightened reflexive state. For example, John Grundy and Miriam Smith maintained: “…over the past decade, evidence-based policy making has been explicitly formulated as a dominant rationale informing policy-making across an expanded array of policy fields and within non-governmental organizations. Policy discussion is increasingly informed by what is seen as a more rational appraisal of evidence generated from selected academic and policy research, statistics evaluations and pilot projects” (Ibid., 297). On advanced liberal governmentality see Rose 1993 and Dean 1999, and my discussion of governmentality studies in Chapter 1.}

Thus, it is through the knowledge-intervention terrain that SisterLove, Inc.’s FUBU intervention was scientifically demonstrated as efficacious and added to the national compendium of evidence-based interventions available for use within the broader prevention field. This experience of SisterLove reveals one increasingly important parameter of black Americans’ ongoing inclusion: the need to formalize their knowledge. Hence, the credible knowledge of the Health Love Workshop efficacy was produced only through a rigorous CDC defined evaluation based on methods of scientific practice—such as, a randomized experimental research design with intervention (i.e. treatment) and control groups.

As a process by which the regime of black American inclusion is increasingly constituted, the knowledge-intervention terrain has mixed political implications for black Americans’ HIV/AIDS activism and advocacy. On the one hand, as shown by developments such as the CDC’s Innovative Interventions project, the fact that black Americans are actively and centrally included and interpellated in the prevention field means that the knowledge-intervention terrain provides increasing opportunities for black Americans’ indigenous knowledges or cultural products to enter into the official
intervention policy and practice. That is, in simpler terms, black Americans are now increasingly “at the HIV prevention policy/program table,” and BCBOs, such as Atlanta’s SisterLove and NAESM, are becoming increasingly well embedded within the state-nonprofit system of relations that constitute the HIV prevention field. Yet, on the other hand, within the contemporarily biopolitical context of increasing and firm reliance on evidence-based interventions, there are inherent risks to inclusion as participation in the knowledge-intervention terrain may come at considerable costs—particularly as it imposes substantial constraints—to BCBOs and black Americans’ HIV/AIDS prevention activism.

For instance, as indicated by the experience of SisterLove, BCBOs are compelled to further professionalize their activist organizations, as gay (and largely white) HIV/AIDS non-governmental organizations in the 1980s were before them.273 As BCBOs largely came to be included within the HIV prevention field only in the 1990s, and thus were later to enter into direct relationship with the CDC—and other professionalized (private and federal) institutions—the process of professionalization of BCBOs is still a vibrant ongoing process.274 The costs of such professionalization come in various forms: There are opportunities lost and potential FUBU interventions not

273 The professionalization of HIV/AIDS activism has garnered scholarly attention since as early as, Patton, who noted in 1990, “it was largely groups based in gay community traditions which formed the basis of what was to become an AIDS service industry which now stands in an institutionalized relationship to the medical industry and government (Inventing AIDS, 12, italics in the original). Following Patton, a key feature of this scholarship is indeed its emphasis on how professionalization occurred as HIV/AIDS activism came further embedded in direct relationships to U.S. public health (the government) and the biomedical and pharmaceutical industry. In addition to Patton, see also (Lune, Howard and Hillary Oberstein. 2001. “Embedded Systems: The Case of HIV/AIDS Nonprofit Organizations in New York City.” Voluntas: International Journal of Voluntary and Nonprofit Organizations 12:17-33; Gillett, James. 2003. "The Challenges of Institutionalization for AIDS Media Activism." Media, Culture & Society 25:607-24.

274 Indeed as professionalization standards change over time, I believe it is best to think of professionalization, more generally, as an on-going process.
developed or instituted in and for the community as BCBOs garner their limited resources to develop their research capacity and engage in “years of studies and this and that” to demonstrate the “scientific based” efficacy of just one FUBU intervention. At the same time, with mandates from funding streams that obliges BCBOs’ development of their research capacity, comes also the perpetuation of “the need to have the alphabet soup [of educational credentials] behind people's name” that may dictate BCBO hiring decisions and reorient indigenous program goals. Moreover, increasing professionalization, at worse, entails and, at best, encourages BCBOs abandonment of non-hegemonic modes of black American HIV/AIDS activism and knowledge production, as it makes more tenuous BCBOs links to the black American communities most vulnerable to HIV/AIDS infection. In short, with black Americans’ inclusion in the prevention field comes potential loses to the autonomy of BCBOs.

Therefore, in general, following the political scientists John Grundy and Miriam Smith, I understand the professionalization of activist work “may be interpreted as reproducing dominant forms of knowledge production, neoliberalizing social movement activism and reducing the sphere for advocacy and democratic politics.” Yet, I also give credence to the ways that in addition to the financial resources that accompany BCBOs’ increase direct engagement with professionalizing institutions, there are also technoscientific expertizes and methodologies that accompany or are produced by the professionalization process that may bring great opportunity to BCBOs.
within the HIV prevention field, professionalization enables black Americans’ participation and assists their agency in the interacting with domains of federal public health. Consequently, I understand the knowledge-intervention terrain as enabling or limiting black Americans’ claims to social and political rights of citizenship. That is to say, the knowledge-intervention terrain is a process and conceptual space through which black Americans ongoing citizenship struggles are staged.

Of course, the question of citizenship is pertinent across the HIV/AIDS regimes of black American inclusion and exclusion. Particularly within the first few years and largely throughout the first decade or so of the HIV/AIDS epidemic, black Americans’ exclusions from both the biomedical and public health HIV/AIDS discourse and the emerging HIV prevention field signals black Americans’ ongoing marginality within the political life of the U.S. Conversely, under the inclusion regime we see a way in which the question of black Americans’ “life itself” is increasingly taken up within the greater discourse of the epidemic and the prevention field by both black Americans and federal government (via primarily domains of public health). And through the logic of DEBI with the HIV prevention, we see how the inclusion regime requires for black Americans an “evidence-based citizenship practice,” where citizenship struggles “are seen to require the production of ‘evidence’” or credible knowledge. Moreover, as the contemporary political life of black Americans is defined by the neoliberal virtues of autonomy, responsibility and calculated prudence, the regime of inclusion does not guarantee progressive outcomes, but instead produce variable and problematic consequences for

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producing and enacting citizenship for marginalized groups” (Ibid.).

279 Ibid., 295.
the status and quality of black Americans’ lives and citizenship.
Chapter 5

Conclusion: HIV Prevention and the Biopolitics of Black Americans’ Health and Citizenship

HIV/AIDS in Two Regimes

RECAP

As the first decade of HIV/AIDS came to a close in the United States, a conjuncture of socio-political events assisted in bringing more visibility to black Americans’ burden in the epidemic. Over the now 30-year plus course of the epidemic, black Americans became increasingly primary objects and active, but limited agents in the construction and implementation of prevention discourses, policies, and practices. The growing inclusion of black Americans in the broader HIV/AIDS discourse is particularly evidenced through and within the burgeoning field of HIV prevention that arose in the 1990s and grew even more robust in the 2000s. This greater black American visibility or inclusion, which is also manifest in the growing interpellation of black Americans in the discourses and practices emanating from domains of public health and biomedicine, the media, and the HIV/AIDS social movement, stands in stark contrast to the general invisibility of black Americans in the first decade of HIV/AIDS.

A rationale faithful to the notion that inherent in the production of technoscientific or biomedical knowledge is ongoing progress may be conveniently marshaled to explain these developments. Aligned with this hegemonic, or largely
dominant, faith is not only, the belief that through an unencumbered science we find the advancement of knowledge and technological resources, but also, social and political progress that produces greater inclusion, visibility, and participation for former disinherited and marginal populations. Specifically, in the context of HIV/AIDS, the aforementioned reasonings would posit that as scientific knowledge of the socio-biological content, character and impact of HIV/AIDS grew over time; the practices, policies and discourses of the disease would mature to better address those very populations most vulnerable to contract and/or presently be burdened by it. Yet, in spite of the power of teleological scientific explanations for, more generally in the U.S., a broad range of socio-political developments, and, particularly in, accounts of advances in medicine and public health practices, policies, and outcomes, transformations in HIV/AIDS discourse and HIV prevention policies and practices cannot be fully accounted by such logic.

The fact that scientifically produced knowledge of the disproportionate burden of HIV/AIDS among black Americans was available as early as 1983, but not taken up—or, meaningfully headed during a period when HIV/AIDS was for the most part a death sentence—until, at the very least, five years later markedly complicates any explanation based solely on the progressive power of science. Thus, in this dissertation, I have provided a sociological explanation for this meaningful transformation that I have called “the changing color of HIV/AIDS and HIV prevention.” With the concept of disease regimes, as originally developed by Maren Klawiter, I have brought analytical attention to the systems of discursive and material practices and events that undergird the public administration, of HIV/AIDS, and that historically and contemporarily constructs our
variable subjective understandings and experiences with the disease along racially formatted lines.

This dissertation, following—yet also critical of—a robust and diverse scholarship in the social and cultural studies of HIV/AIDS, race, and science, technology, and biomedicine, demonstrates that a multiplicity of socio-political and cultural events and moments helped to transform the HIV/AIDS disease regime of black American exclusion to one of black American inclusion. At the core of both the construction of each regime and the transformation of regimes were discourses and practices emanating from actors embedded within public health, biomedicine and community based institutions and organizations. Thus, as these distinct—yet importantly also interdependent—social worlds represent a diverse set of interests and experiences, the dynamic social relations of HIV/AIDS in the U.S., particularly as they revolve around and involve race and racial and sexual minorities, are inevitably intertwined with socio-political, biomedical, cultural, and technoscientific processes.\(^280\)

Implications, Complications and Limitations

_DISEASE REGIMES AND CRITICAL RACE THEORY_

Bringing the literatures of racial formation and intersectionality (defined here under the rubric of critical race studies) together with the analytical insights of the

\(^{280}\) To be sure this is not a quality solely unique to the production of HIV/AIDS knowledge and policy, indeed—though more or less discernable—it is characteristic of all biomedical and scientific knowledge production.
concept of disease regime allows me to zero in on the differentiated processes of HIV/AIDS responses and HIV/AIDS subjectivities and social solidarities as they relate to both sexuality and race. That is, as I have shown in this dissertation, the dominant color of HIV/AIDS changed as the salience of gay white bodies and sexuality in understanding of HIV/AIDS risk waned and as the understanding of risk as dependent on distinct practices became hegemonic. Additionally, socio-political factors both internal and external to the HIV/AIDS disease regime, along with black American agency and activism, encouraged the interpellation of people of color more broadly, and black (and brown) bodies more specifically in the HIV/AIDS discourse and prevention field (See the chronology in Appendix I).

In centering the role of authoritative discourses and institutional practices on producing subjects and social relations of HIV/AIDS, I have relied on the concept of disease regimes, as developed by Maren Klawiter. Through my analysis of the HIV/AIDS discourse and the changing color of HIV prevention over the course of the U.S. epidemic, I have also foregrounded the role of the media and social movements in the racialization of disease formations. These two foci allow us to assess how disease regimes, as they are both constructed and instituted, differentially enable and constrict the formation and agency of subjects and disease subjectivities. It is clear that over the course of the U.S. epidemic this differentiation has occurred along racial lines. Thus, with this dissertation, I demonstrate the importance of centering race within studies of disease regimes by principally focusing on how meanings attributed to diseases and diseased

281 Klawiter, Maren. 2008. *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism*. Yet, as I indicated in the previous paragraph, my use of disease regimes differs from Klawiter, as she does not consistently analyze breast cancer activism through a critical race lens.
populations by biomedical and public health domains, and practices emanating from other relevant institutions, contribute to processes of racialization or racial formation. The foregrounding of the politics of race in both disease construction and biomedical and public health responses to disease is especially pertinent in an age when the cataloging of human biological difference by race is deemed important to determine the putative genetic basis for disparities in health outcomes and health responses among social groups.  

BLACK AMERICANS AND STUDIES OF GOVERNEMENTALITY CITIZENSHIP, AND HEALTH SOCIAL MOVEMENTS

Furthermore, there is an urgent need for literature on race and neoliberal modes of governance that examines the experiences of black Americans, a group whose perspectives and experiences have yet to be adequately explored in studies of governmentality and citizenship. As discussed briefly in the introduction to this dissertation, black Americans are virtually absent from both of these recently developed literatures. This paucity exists even though black Americans have had, and continue to have, a contentious relationship to the rights and “belongingness” that symbolically and practically constitute U.S. citizenship. That is, for both the more classically political and more recent (and progressive) socio-cultural understandings of citizenship, claims of black Americans to citizenship remain partial and uneven.

This dissertation underlines both the analytical and substantive leverage of

282 See references in footnote 10.
centering black Americans in studies of governmentality and cultural or biopolitical citizenship in the specific context of health. As a result, and breaking with the trend in the literatures of governmentality and citizenship (and, not incidentally, studies of health social movements), the continuing relevance of the state comes into view. Expressly, as the case of black Americans as both objects and agents within the contemporary configuration of the field of HIV prevention reveals, health is contentiously and increasingly conceptualized as a right of the citizen-subject. Good health is a right that arms of state, such as the CDC, must protect and work discursively and materially to uphold among the various social groups in the population.

However, as the U.S. is an epicenter of the historical shifts towards neoliberalization and the privatization of government and governance, a neo-liberal citizen-subject position is also encouraged that serve to moderate the responsibilities of the state. The HIV/AIDS regime of black American inclusion arose and matured as these larger historical shifts took hold. Therefore, the HIV prevention field is a site that reveals the continuities, discontinuities, and tensions between the dynamic dwindling welfare and increasingly robust neoliberal modern state. Thus, the broader historical context, in concert with trends within the HIV prevention field itself, indicates that black American inclusion may ultimately prove to be a pyrrhic victory in the fight to prevent the spread of HIV/AIDS in ‘black America.’ After all, what is the role of structural interventions to combat HIV/AIDS and other racial health disparities under a neoliberal government? Further study of the HIV prevention field, and other critical studies of public health and biomedical attempts to combat other disease that disproportionately affect marginalized communities in the U.S., are needed to adequately assess the intended
and unintended consequences of prevention and treatment campaigns under the specter of neoliberalism and privatization. To meet this goal, analysts of health social movements and biomedicine must begin to consistently take seriously and begin to critically question the entanglement disease construction and disease response with the politics of citizenship.

**ENGAME?**

*A WELCOME REVOLUTIONARY HISTORICAL ACCOUNT OF AIDS IN AMERICA*

On July 10 of 2012, as I was in the midst of completing the writing of this dissertation, PBS aired a “Frontline” documentary, billed as “a groundbreaking two-hour exploration of the country’s most urgent, preventable health crisis,” entitled *Endgame: AIDS in Black America*. Within the first few minutes of the program, *Endgame*’s narrative presents the story of the history of HIV/AIDS from a perspective, to my knowledge, not expressed in mainstream HIV/AIDS documentaries before, but that supports a central argument of this dissertation. Marshaling and interspersing interview statements from Drs. Michael Gottlieb and David Ho, the unidentified and unseen female narrator begins the history at a familiar start: the first case of the then mysterious affliction, discovered in the summer 1981 by Dr. Gottlieb at UCLA. However, seconds thereafter, the narrator’s voiceover states, “When every patient with the new disease died [in the months after June...
1981], alarmed officials sent out an international alert, but from the start something was missing.” Dr. Gottlieb suddenly appears on the screen and recounts:

In medicine when we describe a patient we say ‘this is a 31-year old, white, single gay male.’ But in our reports [of the first AIDS cases], we said nothing what so ever about race. It really is an omission on our part. The first five patients were white, the next two were black; the sixth patient was a Haitian man; the seventh patient was a gay African American man here in Los Angeles. Most of those first patients died within months.

Dr. Gottlieb concludes his recount by indicating that for the biomedical and public health social world of 1981 the fact of a disease afflicting gay men, “some who were white and a couple who were black,” was “no big deal.” “But it [presumably referring to both the disease and its early occurrence among black Americans] was a big deal;” and, “the media ran headlines of a killer plague among gay men, but the stories and images were white,” the narrator reminds viewers.

Such statements from Endgame confirm my arguments of the unremarkablity and non-salience of whiteness as a race, the faultiness and negligence of both a “color-blind” biomedical and public health approach to HIV/AIDS, and the media’s coverage of the disease, which firmly and quickly fasten upon gay sexuality. The exclusion of black Americans from consideration by these institutions during an urgent medical/health problem in the U.S. during

284 Ibid.
285 Ibid.
286 Ibid
the 1980s—when the knowledge of the disproportionate rates of HIV/AIDS among black Americans was available as early as 1983—should be read as, at best, a grave omission (as seemingly indicated by Dr. Gottlieb), or at worse, unconscionable.

**BLACK AMERICAN ACTIVISM AS AGENTIC AND THE ONGOING STRUGGLE TO COMBAT HIV/AIDS**

Despite the welcomed revisionist account of the history of HIV/AIDS that centers race, much of *Endgame*’s 120 minutes running time is spent on detailing, through personal stories, the ways in which homophobia and stigma prevented black Americans’ ownership of the disease. Black Americans themselves thus are predominately featured as, perhaps, most culpable in the HIV/AIDS crisis striking black American communities throughout the U.S.\(^\text{287}\)

While it is not my intention to wholly discount the historical, or present day, role of homophobia and stigma, this dissertation centers the role of mainstream sources, including the state, in constructing a HIV/AIDS disease regime of black American exclusion. Moreover, in contrast to scholarly account that focuses on the absence of HIV/AIDS activism among black Americans, it documents black Americans’ activism and advocacy as an essential component to transforming the

\(^{287}\) To be completely fair, and as is suggested by its’ depiction of the history of AIDS discussed above, the PBS documentary *Endgame* does acknowledge that forces beyond homophobia and gay stigma in black American communities contribute to the black American AIDS crisis. As a press release announcing *Endgame* states, “Racism and homophobia have played roles in the spread of the disease, but so have religion, poverty and politics” (Childress, Sarah. "Race and America’s HIV Epidemic." FRONTLINE:PBS, Retrieved 7/13/2012, 2012 (http://www.pbs.org/wgbh/pages/frontline/social-issues/endgame-aids-in-black-america/race-and-americas-hiv-epidemic/)).
exclusion regime into a regime of black American inclusion.

To be clear, this transformation is not represented by a hard historical break or shift: changing the color of HIV/AIDS is an ongoing process that can be usefully construed as a stage where struggles for the rights and privileges of citizenship is constructed and contested. Black Americans’ history and contemporary existence in this country attests to a contingent citizenship status that historically originates from the limits of “bare life,” i.e. the banning of African born slaves and their descendants from the political body and the protection of law; and, to this day, black Americans continue to inhabit a precarious citizen-subject position. Thus, black Americans’ HIV/AIDS activism is a part of the long tradition of black activism (including disease based activism) that has historically and contemporarily challenged black Americans’ regulation to socio-political positions that render their lives and opportunities unstable or marginal.

Black Americans have consistently fought for the health of black Americans as an indispensible right. However, as inclusion within the HIV prevention field indicates, black Americans’ activism is persistently confronted by the perils of cooptation and professionalization. No one (progressive) outcome is secured, even as the ‘knowledge-intervention terrain’ provides opportunity for black Americans within the contemporary HIV/AIDS regimes of inclusion. Therefore, it is clear that inclusion in the HIV prevention field, as it is contemporarily configured, is not a panacea to solve the social problem, or injustice, of black Americans’ disproportionate burden in the U.S. HIV/AIDS epidemic.

**APPENDIX 1**

**Timeline of Important Events across the HIV/AIDS Regimes in Relation to Black Americans, 1981-2004**

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1981</td>
<td>CDC reports first cases of a mysterious disease among male homosexuals</td>
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<tr>
<td>1982</td>
<td>AIDS is named</td>
</tr>
<tr>
<td>1983</td>
<td>CDC reports that AIDS cases have occurred among all primary racial/ethnic groups, 26% of cases to date among black Americans</td>
</tr>
<tr>
<td>1984</td>
<td>Discovery of HIV, the virus that causes AIDS</td>
</tr>
<tr>
<td>1985</td>
<td>the DHHS Secretary’s Task Force on Black and Minority Health published</td>
</tr>
<tr>
<td>1986</td>
<td>CDC publishes first report employing the claim of the over-proportion of AIDS among black Americans &amp; Latinos in September; the National Coalition of Black Lesbians and Gays sponsors the National Conference on AIDS in the Black Community in Washington D.C. in July</td>
</tr>
<tr>
<td>1988</td>
<td>CDC provides funds to “Minority Community Based Organizations, such as the NAACP; CDC Office of the Associate Director for Minority Health created</td>
</tr>
<tr>
<td>1989</td>
<td>CDC begins providing funds to “minority HIV prevention community organizations”</td>
</tr>
<tr>
<td>1991</td>
<td>Magic Johnson announces he is HIV positive</td>
</tr>
<tr>
<td>1992</td>
<td>Tennis legend, Arthur Ashe announces he has AIDS</td>
</tr>
<tr>
<td>1993</td>
<td>Tennis legend, Arthur Ashe, dies from AIDS; CDC’s revised classification system for HIV infection and the expansion of the AIDS surveillance case definition is implemented, doubling the total number of HIV/AIDS cases in the U.S., an increase attributed mostly to the rise in the reported cases of AIDS among racial minorities, women, the urban poor, and injecting drug users; the NIH Revitalization Act mandates that by 1995 women and racial and ethnic minorities must be included as research subjects in studies funded by the NIH; the FDA creates new guidelines to encourage drug manufacturers to study the effects of their products on women and racial and ethnic minorities.</td>
</tr>
<tr>
<td>1994</td>
<td><em>Essence</em> Magazine’s “Facing AIDS” cover story; a black American woman, Dr. Helene Gayle, is named the director of the newly created CDC National Center for HIV,</td>
</tr>
</tbody>
</table>
Timeline of Important Events across the HIV/AIDS Regimes in Relation to Black Americans, 1981-2004 (Continued):

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>Famed African American rapper Eazy-E dies of AIDS</td>
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<tr>
<td>1998</td>
<td>CDC announces new surveillance data at meeting in March in Atlanta, leading black American HIV activists and advocates in attendance to storm out in protest and to declare AIDS a “State of Emergency” among black Americas. The Congressional Black Caucus later endorses the activists’ declaration. President Clinton declares HIV/AIDS a “severe and ongoing health care crisis” in racial and ethnic minority communities, and announces the creation of the Minority AIDS Initiative</td>
</tr>
<tr>
<td>1999</td>
<td>The Minority AIDS Initiative receives $166 million in funding</td>
</tr>
<tr>
<td>2000</td>
<td>The National Center on Minority Health and Health Disparities created</td>
</tr>
<tr>
<td>2004</td>
<td>CDC launches “Innovative Interventions project” with aim to identify an evaluate HIV preventions interventions developed by and within minority communities in the U.S.</td>
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