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Angels, Actual Reality & AIDS in New Haven: a Case Study

by

Michele E Nichols
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Introduction

> "This disease will be the end of many of us, but not nearly all. And the dead will be commemorated, and we'll struggle on with the living, and we are not going away. We won't die secret deaths anymore. The world only spins forward. We will be citizens. The time has come."--- Prior Walter, *Angels in America*.[1]

This is how Prior Walter, a character who is HIV-positive in Tony Kushner's Pulitzer-prize winning play, *Angels in America*, which chronicles the lives and loves of those suffering from HIV and AIDS in New York City during the 1980's, describes AIDS. His declaration demands action from those infected and those who silently watched the disease destroy lives. New Haven, Connecticut dealt with HIV/AIDS early in the epidemic. Private citizens began the response and provided services the city government would not. Select individuals mobilized and unified to force the city government to address the health crisis. Private activists influenced the city government and, because of their expertise and experience in dealing with HIV/AIDS, helped develop the city's pioneering and non-partisan response.

New Haven's epidemic mimicked the demographics and features of what is seen in other urban centers, where the dynamics of poverty, race, intravenous drug use and governance overlap. Yet New Haven is atypical in the composition and design of their HIV/AIDS agencies and programs and their results are dramatically different. Why? This question is answered by a close evaluation of the place of race in the epidemic and New Haven's response in addition to a consideration of the role the city government played in addressing the matter. Lastly, there is a broader

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[1] Tony Kushner, *Angels in America* (New York: Theater Communications Group, 1995): 80.

discussion of the context in which AIDS emerged in the 1980s and whether the action of private and public actors addressing HIV/AIDS resulted in a small-scale social movement under the umbrella of a national social movement addressing AIDS.

Human immunodeficiency virus, or HIV, causes AIDS. The virus attacks the immune system, finding and destroying T cells or CD4 cells, a type of white blood cell that the immune system needs to fight disease. AIDS, or acquired immunodeficiency syndrome, is the final stage of HIV infection. Once a person develops full-blown AIDS, the virus has significantly weakened his or her immune system and it is extremely difficult to fight infection. AIDS is characterized by specific infections, particular cancers or an extremely low number of T cells.[2] When HIV/AIDS was first seen in America, scientists were unsure of what it was and how to treat or even screen for the disease.[3] Without medical treatment, those infected were dying at a rapid rate. This uncertainty bred fear and would influence the reaction to HIV/AIDS.

HIV/AIDS in America is more than a medical and public health issue. The matter is at the center of a complex web of racial, socioeconomic, political and moral debates. The disease prominently emerged among homosexual men, a group seen as morally deviant. Over two decades, the disease has become increasingly common in intravenous drug users, another population marginalized by society at large. The disease's predominance in these two groups made the issue particularly difficult for politicians to address without fearing significant political backlash. The disease's subsequent rise among the poor and minorities caused further complications.

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[2]Further information on HIV/AIDS, including information on transmission and testing, can be found on the Center for Disease Control's website, http://www.cdc.gov/hiv/topics/basic/index.htm

Private individuals who witnessed HIV/AIDS first-hand were the first to act in New Haven. These citizens saw specific grievances within their marginalized communities and sought to provide the services that the city government would not. White, homosexual professionals created AIDS Project New Haven to address the needs of the homosexual community. AIDS Interfaith Network was expressly created by the wife of an African American minister to assist African Americans who were dying and often separated from their families. Hispanos Unidos, the most recently formed of New Haven's AIDS service organizations, was designed by Latino paraprofessionals to meet the specific linguistic and cultural needs of the Hispanic community.

The city government became involved at the urging of the white professional activist who established AIDS Project New Haven. The Mayor established a non-partisan Mayor's Task Force on AIDS which would drive the city-sponsored response to AIDS. The Mayor's Task Force on AIDS was also a wholly voluntary organization, and the group's unique composition would allow diverse people to be heard and to come together to battle a common foe. The organization brought together representatives from private AIDS organizations, various departments within the city government and private citizens representing diverse interests. The group successfully campaigned for a pilot needle exchange program. The Mayor's Task Force on AIDS facilitated discussion and cooperation that led to the design and implementation of a needle exchange program that addressed the needs and concerns of the relevant parties. Although the Mayor's Task Force no longer needs to fight for

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[3]For an in-depth account of the early years of the AIDS epidemic in America, please see Randy Shilts' *And the Band Played On: Politics, People, and the AIDS Epidemic.*

innovative programs, they continue to educate the community and assist organizations and the city's AIDS Division in receiving critical funding. The private AIDS service organizations maintain service to a diverse clientele with unique challenges as AIDS evolves into a long-term chronic illness.

The research process for writing this thesis focused on becoming familiar with the important individuals in the city's response, and their specific experiences, particularly those experiences which had not been thoroughly documented elsewhere. Interviews conducted in the fall of 2008 and the winter of 2009 provide the basis for this thesis. I conducted interviews with representatives from the city's AIDS service organizations and past and present members of relevant city agencies and organizations. These interviews were designed to gather in-depth information on the individual's personal experience, their perception of the history of AIDS activism in New Haven, and specific details related to their specific agency or program. These interviews provided an understanding of the relationship between multiple factors, particularly across private organizations and city departments, within the city's response to HIV/AIDS. In addition, I visited each of the city's main AIDS service organizations – AIDS Project New Haven, AIDS Interfaith Network and Hispanos Unidos. The founder of AIDS Interfaith Network also took me on a tour of the facility. After each visit I took notes on the facility, including its interior and location. My interviews were augmented by information gathered from previous interviews conducted by a Yale University graduate for a senior essay, which are also used with her permission.

In addition to first hand accounts, research for this thesis included an examination of articles from multiple sources, including the *Yale Journal of Public*

Health, *The Yale Herald*, *The Yale Daily News*, *Needle Exchange Law & Policy* and *The New York Times*. Doug McAdam's work on social movements is examined and applied to what occurred in New Haven. I have also analyzed public health statistics provided by the Connecticut Department of Public Health and Yale University to gain a better understanding of the disproportionate impact of HIV/AIDS on poor minorities in New Haven.

In New Haven, minority communities have been impacted most by this disease. In the absence of direct and strategic government response, African American and Hispanic communities had to respond directly to the disease. Chapter 1 examines the role of race in New Haven's AIDS crisis. The city's minorities are significantly more likely to be infected or be at risk for HIV/AIDS infection. These statistics are insufficient for a full understanding of race and HIV/AIDS in New Haven. A racial discrepancy also exists between AIDS clients and professionals. Most significant is the role of race in New Haven's three AIDS service organization. There is a racial division in the composition of the three organizations – AIDS Project New Haven, AIDS Interfaith Network and Hispanos Unidos. These three organizations are analyzed to better understand the short-term and long-term consequences of race in addressing AIDS. Each organization's founder had a unique racial and socioeconomic status. How did the complex relationship between socioeconomic status and race complicate the organizations' responses to HIV/AIDS? And how did this complex relationship influence the organization's trajectory? These factors are shown to have significantly influenced the organization, particularly their nuanced grievances and the services they provided. Yet why did the city need three AIDS service organizations? And what does that say about the role of

race in AIDS? The answers to these questions should provide a better understanding of the interplay between race, socioeconomic status and HIV/AIDS in a mid-sized city. This is a shift from similar analyses that have focused on understanding the epidemic in larger cities, such as New York City, where the epidemic often overwhelmed the homosexual community before spreading to minorities.

Race is an irrevocable component of AIDS in New Haven. However, the city would not have been successful in fighting AIDS if concerned activists had not convinced the city government to become involved. Chapter 2 considers the role of the city government in New Haven's response to AIDS. Private organizations had achieved all they could while working with an apathetic city government. Who and what convinced the city government to take action? What action did the city government take? How was this action successful and exceptional? And what relationship, if any, did the city government have with the major AIDS service organizations? The bulk of the chapter answers the abovementioned questions by examining the New Haven Mayor's Task Force on AIDS and the city's needle exchange program. The Mayor's Task Force on AIDS characterizes the city's atypical response to the epidemic. As a semi-independent organization, the group's nonpartisan approach led to the establishment of an innovative and politically dangerous needle exchange program. To better understand the city's unique response, a comparison to New York City government's response to HIV/AIDS is interwoven throughout the chapter.

The last chapter examines the social and political context of the 1980s. I consider whether the actions of national activists and local activists and organizations during that decade constitute a social movement. Once a movement is defined and I

explain why there was a national and local AIDS movement, I define a new social movement and discuss whether the categorization fits the events in New Haven. Historical examples are considered before the activism in New Haven is found to be a new social movement.

Ultimately, the analysis of what transpired in New Haven provides a better understanding of a successful response to HIV/AIDS. Since New Haven instituted America's first successful needle exchange program, and saw a dramatic decrease in HIV/AIDS infection as a result, this information could be used to help other cities replicate the results. This evaluation relies heavily on personal interviews. Participants were selected based upon their positions within the city government or the city's AIDS service organizations.

Chapter One: Race

New Haven, Connecticut is home to one of the most prestigious universities in the country yet, paradoxically, it is among the most impoverished cities in Connecticut - in 2002, it was the fourth poorest city in the nation - and it was the first city in the state to address the AIDS epidemic.[4] These two extremes are not uncommon in urban areas, and they carry with them the conflicting connotations of poverty and privilege and leave tension in their wake. Race intimately intertwines with socioeconomic status and social power, and the combined forces of race and socioeconomic status shaped the HIV/AIDS epidemic. The same two factors affected the response to the epidemic in New Haven and also influenced the trajectory of key AIDS service organizations in New Haven. Race, and all the social privileges that are implicit in racial categories, permeate the New Haven's AIDS epidemic and the resulting response. The city's AIDS service organizations centered on race and culture, and the social privileges and cultural expectations of race have influenced the structure of these organizations.

The chapter opens with a statistical overview of race and poverty in New Haven and within the city's AIDS community. A brief discussion of race and poverty in Connecticut and America at large follows. The racial disjunction between the predominantly minority HIV/AIDS clients and the white service providers is considered. From there, there is an in-depth discussion of the African American and Hispanic communities' responses to AIDS. There is also an examination of the role of stereotypes towards race and mode of transmission in the city's response to AIDS.

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[4] Ed Vulliamy, "U.S. in Denial as Poverty Rises." *Guardian*, November 2, 2002.

Lastly, there is a discussion of race and the city's AIDS service organizations, AIDS Project New Haven, AIDS Interfaith Network, and Hispanos Unidos.

The city's significant minority population often struggles financially, and this battle is worsened by an epidemic that disproportionately impacted these minorities. According to long-time Yale-New Haven Hospital social worker and member of the New Haven Mayor's Task Force on AIDS, June Holmes, "HIV in New Haven is really a socioeconomic issue for the most part…it's more people with lower incomes" and this link between poverty, race and HIV/AIDS is inescapable.[5] Statewide, 36.5% of AIDS cases reported between 1980 and the end of 2008 were African American[6] and 26.4% were Latino[7]; during the same time, 49.4% of HIV/AIDS cases in New Haven were African-American and 25.3% were Latino.[8] Nationally, in 2006, only 13% of the nation's population was African American while 49% of the newly-diagnosed cases of HIV/AIDS were among African Americans. Latinos composed 18% of the nation's new HIV/AIDS cases in 2006. Unlike in New Haven, 30% of people diagnosed with HIV/AIDS nationwide in 2006 were white.[9] Nationally, 11.3% of all Americans lived below the poverty level in 2000; during that same year, 22.5%

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[5] June Holmes, Interview, November 14, 2008
[6] The terms African American and black are used interchangeably throughout the thesis.
[7] The terms Latino and Hispanic are used interchangeably throughout the thesis.
[8] Connecticut Department of Public Health. "Connecticut AIDS Cases by Year of Report, Sex, Race and Risk/Mode of Transmission in Percent of Total for the Category (1980-December 31, 2008)," *Connecticut Department of Public Health HIV/AIDS Surveillance Program*, http://www.ct.gov/dph/lib/dph/aids_and_chronic/surveillance/stat (accessed February 9, 2009), Connecticut Department of Public Health. "People Living with HIV/AIDS by City of Residence at Diagnosis, Risk/Mode of Transmission, Race, and Sex in Percent of Total for the Category (1980-December 31, 2008)," *Connecticut Department of Public Health HIV/AIDS Surveillance Program*, http://www.ct.gov/dph/lib/dph/aids_and_chronic/surveillance/city_and_county/ct_plwhivaids_selected_cities_table.pdf (accessed February 9, 2009), Yale University, "Data Haven – The Information Hub of South Central Connecticut," http://research.yale.edu/datainitiative/ (accessed February 9, 2009).
[9] Centers for Disease Control and Prevention, "HIV/AIDS in the United States," *Centers for Disease Control Department of Health and Human Services HIV/AIDS in the United States Fact Sheets*, http://www.cdc.gov/hiv/resources/factsheets/us.htm (accessed April 5, 2009).

of African Americans and 21.5% of Hispanics lived below the poverty level.[10] In 2000, 27.6% of African Americans living in New Haven lived in poverty, while 34.7% of New Haven's Latinos also lived in poverty.[11] As a worker at one of the city's AIDS service organizations (ASOs) noted, "there has always been, in America, racial and class differences across the board…" and this is echoed in the reality of HIV/AIDS in New Haven.[12]

I. Minority Clients and White Service Providers

Although HIV/AIDS is disproportionately a minority disease in New Haven, many professionals in the city government and community based organizations are white. The city's first ASO, AIDS Project New Haven, was founded in 1983 by the late Alvin Novick, a doctor at Yale-New Haven Hospital, and his partner William Sabella, a graduate of the Yale University School of Public Health, in response to concerns over the unknown disease affecting their gay circle of friends.[13] These white professionals did not live in the same New Haven as most of the city's infected residents, and though they never discriminated, their focus was on gay white men. After establishing the organization, Novick and Sabella invited Yale University intellectuals and professionals to govern the board. Years later, Novick commented, "'They just don't happen to be on the usual board members in New Haven. But that's why we picked them, because they would never be invited to be on a usual board.'"[14] Scholars contend that "individuals rarely experience the world through a single social

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[10] U.S. Census Bureau. "Historical Poverty Tables," *U.S. Census Bureau Poverty*, http://www.census.gov/hhes/www/poverty/histpov/hstpov2.html (accessed April 5, 2009).
[11] Connecticut Department of Public Health, "Connecticut AIDS Cases by Year," *Connecticut Department of Public Health*, "People Living with HIV/AIDS," Yale University, "Data Haven."
[12] Interview, October 23, 2008.
[13] Jennifer Chi. *Early Response: The Oral History of AIDS Activism in New Haven, Connecticut: The Origins of AIDS Agencies in One Community*. Yale University Senior Honors Essay (2004): 14-15.

identity (i.e. gender, race/ethnicity, class, sexuality) but instead experience a matrix of domination and privilege."[15] White male professionals, accustomed to experiencing the embedded privilege of this status, Sabella and Novick chose to face the inescapable and uncontrollable threat to themselves and their friends with white professionals who understood many of the same realities they did. This shared identity provided AIDS Project New Haven with a unified front; these professionals, however, did not experience first-hand the racial and socioeconomic realities of most HIV-positive New Haven residents. While the white community faced the same misinformation and fear at the beginning of the AIDS epidemic as did the minority community, the privileges inherent in race and class further created a different perception of HIV/AIDS than was shared by most of the city's residents. As a medical professional, Novick had access to the newest information as it was discovered. In addition, as white men, Novick and Sabella believed that their voices could be heard and they could influence the situation – a belief that would ultimately prove true. In contrast, the majority of HIV-positive New Haven residents had neither the access to current, reliable information nor the positive relationship to those in power. Thus it was easier for misinformation and stereotypes to quickly spread. Without access to those in power or the knowledge of how to maneuver effectively through bureaucracy, minorities often had little to rely upon other than distorted information. As is later discussed, Novick acknowledged that those most vulnerable in New Haven were also those most actively marginalized; this did not create a

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[14] Ibid., 15-16.
[15] Kimberly Dugan and Jo Reger, "Voice and Agency in Social Movement Outcomes," *Qualitative Sociology* 29 (2006):472.

situation where minorities had either the power or the information to react in the same way as Novick, Sabella, and their friends.

That New Haven's first AIDS service organization was begun by and focused on the homosexual community is not exceptional in light of the larger HIV/AIDS epidemic in America. The nation's earliest cases were among men who had sex with men, particularly in urban areas, such as New York City. Consequently, many of the first organizations' addressing the epidemic were founded by white homosexual men living in urban centers. For example, AIDS Coalition to Unleash Power, or ACT UP, was founded by homosexual men in New York City in the 1980s. ACT UP focused on political activism, something rarely seen in New Haven. One of the organization's members' comments may shed light on the relatively quick response within the homosexual community: "'We [homosexual men] were liberated, and the world was ours. Suddenly, we were dying, and nobody gave a shit. And those are conditions for revolution.'"[16] However, ACT UP, which was run by and focused on white homosexual men, could not properly address the minority community. *Village Voice* reporter Frank Browning observed that "ACT UP might give lip service to the AIDS-related needs of women, poor people, and people of color…but it should not and could not speak on behalf of those groups."[17] Since an organization founded by and focusing on homosexuals in a large city where the epidemic originated within the homosexual community could not sufficiently address the needs of minorities, it is unsurprising that AIDS Project New Haven failed to properly reach minorities in a community where the epidemic was disproportionately minority from the beginning.

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[16] Peter F. Cohen, *Love and Anger: Essays on AIDS, Activism and Politics* (Binghamton, NY: The Haworth Press, Inc., 1998), 22.
[17] Ibid., 130-131.

This discord between professionals and clients extended into the diverse city's government; although the city's only African American mayor, John Daniels, served between 1989 and 1993, key professionals within the city government were white. Elaine O'Keefe, former employee of the city's Health Department and founder of the New Haven Department of Health's AIDS Division, is among such professionals.

Although they no doubt enjoyed the social privileges that come with being white, these professionals were aware of the discrepancy between themselves and the bulk of their clients and target population. Faced with a difference of immutable characteristics, these professionals actively attempted to compensate in an effort to reach their clients. The significant shift in the epidemic's demographics was brought to Novick's attention in 1986 when a nurse in charge of Yale-New Haven Hospital's AIDS Ward told him that "'since January, we've admitted 8 patients with AIDS, and 7 of them were black'" and many of these patients were intravenous drug users.[18] The implications were evident to Novick – "'That [demographic shift] increases the burden of providing necessary services by a million fold. This is a population of people that we don't serve. Except to hate them. And now to stigmatize and ostracize them.'"[19] Novick's comment indicates both minorities discomfort with homosexuality and AIDS *and* white discomfort with minorities and drug use that made it difficult for one group to reach out to the other. There is no evidence that Novick was racist; his statement, however, supports some scholars assertions that "race and black identification in particular still have significant negative meaning for many white Americans."[20] Specifically, as whites have become more publicly accepting of

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[18] Chi, *Early Response*, 20.
[19] Ibid., 20.
[20] Cathy J. Cohen, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics* (Chicago:

African Americans, privately they continue to believe stereotypes of blacks "that contradict the dominant norms of hard work, intelligence, and self-sufficiency."[21] Novick also acknowledged that AIDS Project New Haven, although it sought to educate the entire community, was ill-prepared to serve and unable to connect with the African American community.[22] Eventually, this awareness would lead Novick to support the establishment of AIDS Interfaith Network, an organization focused on serving the city's African American community.

The white professionals within the city government, however, were able to compensate for the racial and socioeconomic discrepancy quicker than their private organization counterparts. The Health Department's original three outreach workers "had either personal or professional experience with drug addiction and native ties to the community" – one of the original outreach workers even spent time in a state prison on drug-related charges - because the department "sought to achieve cultural and ethnic diversity" particularly because of the African American and Hispanic populations that dominate the outreach's targeted neighborhoods.[23] Specifically, early outreach workers were from the city's Dixwell neighborhood "who saw what was happening and didn't want it to happen to their friends."[24] Even as the City of New Haven Health Department's AIDS Division prepares to enter the second decade of the twenty-first century, the outreach workers are predominantly black and include one Latino, and of the two Division staff members paid by the state, one is Hispanic

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The University of Chicago Press, 1999), 68.
[21] Ibid., 68.
[22] Ibid., 20.
[23] Paula M. Jones, "Needle Exchange in New Haven," *AIDS Information Exchange* 9, no. 1 (1992):3, Andi Rierden, "New Haven Sends Needles Into Battle Against AIDS," *The New York Times*, December 9, 1990, Jones, "Needle Exchange in New Haven," 3.
[24] Janeen Hayat, "Needle Program Defies its Critics," *Yale Daily News*, November 6, 2001.

and the other white and, while the city government recognizes there are still unique needs in specific minority populations, "it's hard to get bi-lingual and b-cultural people."[25] These difficulties were far more severe in the 1980s, and by 1986 the predominantly white members of the Mayor's Task Force on AIDS acknowledged that "one of the greatest needs was to establish AIDS organizations similar to AIDS Project New Haven, which could reach out and educate Latino and Black communities"[26] yet the resistance within these minority communities would make this a significant challenge.

This racial disconnect among those affected and those who serve the AIDS community in New Haven is further emphasized by the animosity and misconceptions within minority communities regarding HIV & AIDS. There were misunderstandings from the beginning of the epidemic. One longtime AIDS activist and founder of the National Black Lesbian and Gay Leadership Forum and the National Task Force on AIDS remembers his first reaction to AIDS – "'My first reaction to AIDS was 'Thank God this is happening to them and not to us,' because I believed as everybody else did that this was about white gay men.'"[27] This initial belief was not quelled by the black press coverage of AIDS. For example, Amsterdam News, a Harlem-based weekly newspaper that has the largest circulation of any black paper in New York City, did not run any AIDS-related stories until December 1983.[28] While Amsterdam News did a great disservice to their community, the Centers for Disease Control was equally negligent to alerting the African American community to the risk they faced. The CDC did not report the "racial breakdown of AIDS cases

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[25] Interview, December 19, 2008.
[26] Chi, *Early Response*, 27.
[27] Cohen, *Boundaries*, 196.

in any recognizable fashion" until 1983." [29] However, even with the relevant data, few of the AIDS-related stories in the black press discussed who was becoming infected within black communities, "especially those segments most at risk – black gay men, black men who have sex with men, and black injection drug users."[30] These misunderstandings continued into the 1990s. A 1992 study of adolescent attitudes and understanding of HIV/AIDS found that minority adolescents in at-risk social environments are less informed on HIV/AIDS than white adolescents. Specifically, "a survey of 1,869 students from a community college located in the South Bronx, which is considered an epicenter for HIV infection, reported only 69% knew sexual intercourse without a condom increased their risk for HIV infection."[31] Another study, done during the same time frame, of students at eight public schools in Dade County, Florida found white students were "significantly more knowledgeable [regarding AIDS] than blacks or Hispanics."[32] The risk of acquiring the virus due to ignorance was compounded by Hispanic students who showed "significantly less positive" attitudes towards condom use than either their white or black counterparts.[33] While no specific studies or surveys have been conducted within New Haven, anecdotal evidence shows that activists and organizers faced similar challenges within the city's minority communities.

The original perception of the disease, along with the stereotypes that accompanied early misunderstanding and confusion over the realities of HIV/AIDS,

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[28] Ibid., 196.
[29] Ibid., 197.
[30] Ibid., 197.
[31] Lilly M. Langer, Rick S. Zimmerman and Ralph McNeal, "Explaining the Association of Race and Ethnicity with HIV/AIDS-related Attitudes, Behaviors and Skills of High School Students," *Population Research and Policy Review* 11, no. 3 (1992): 234-235
[32] Ibid., 240.

made the minority community particularly difficult to reach. As Chi notes, "[m]isconceptions about transmission and cultural prejudices against AIDS risk groups made it hard to educate the New Haven community about the facts of HIV and AIDS." [34] Much of the early media attention to HIV/AIDS focused on its devastating effect on gay men – the disease that came to be known as AIDS entered public consciousness and discourse in a July 3rd, 1981 headline in *The New York Times* which read "Rare Cancer Seen in 41 Homosexuals"; those who were diagnosed with this "cancer", believed then to be Kaposi's Sarcoma, were diagnosed with "serious malfunctions" of "T and B cell lymphocytes,"[35] critical markers of HIV/AIDS. The article claimed there was "no apparent danger to heterosexuals"[36] and the following year the disease, which had come to be known as GRID or "gay cancer," was changed by the Center for Disease Control to Acquired Immunodeficiency Syndrome, or AIDS.[37] Although this framing reached the target audience, the specific tailoring of information on HIV/AIDS to gay men left all other at-risk groups oblivious to the danger, as "[w]hat [data and events] is centrally attended to by one kind of interest or audience may not be attended to at all by another."[38]

This attention to the disease's affect on the otherwise privileged group of white men inextricably attached the stigma of homosexuality to HIV/AIDS. This impacted the ability of New Haven organizations and professionals to reach out to

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[33] Ibid., 240.
[34] Chi, *Early Response*, 11.
[35] Lawrence K. Altman, "Rare Cancer Seen in 41 Homosexuals," *New York Times*, July 3, 1981.
[36] Ibid.
[37] Gay Men's Health Crisis. *GMHC: Gay Men's Health Crisis*. http://www.gmhc.org (accessed April 18, 2006)
[38] Joseph R. Gusfield, "The Reflexivity of Social Movements: Collective Behavior and Mass Society Theory Revisited," in *New Social Movements*, ed. Hank Johnston, Enrique Larana and Joseph R. Gusfield (Philadelphia: Temple University Press, 1994): 69.

minorities at risk and affect how Black and Hispanic communities addressed AIDS.[39] For years, the dominant white stereotype of African Americans involved deviant sexual behavior, behaviors that contradicted the moral lessons taught by the black churches that grounded these communities.[40] The African American community as a whole was hostile towards black lesbians and gay men. Cohen documents how many of these black gays and lesbians willingly hid their sexuality from their family and friends, as it prevented verbal and physical assaults and it allowed them to "receive the support, care, and protection of African American communities and, more important, the love of immediate family members."[41] Keith Boykin, a former director of the National Black Lesbian and Gay Leadership Forum, proposes that much of the community's attitude towards AIDS is related to the negative white perception of African Americans.

> We don't want to deal with HIV and AIDS issues because the two principle groups of people affected by it in our country are IV drug users and homosexuals. And, of course, we don't want to talk about the fact that we have homosexuals in the black community. We don't want to talk about IV drug use problems in the community because we expect it to reinforce the perception that all black people are drug addicts and not productive working people.[42]

New Haven's earliest AIDS service professionals encountered the same challenges. An original employee of the Health Department's AIDS Division remembers "there was a lot of blaming people for getting the disease, there's a lot of stigma. For that

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[39] Derek Adam-Smith and Fiona Goss. "Opportunity Lost: HIV/AIDS, Disability and Legislation," in *AIDS Activism and Alliances*, ed. Peter Aggleton, Peter Davies and Graham Hart (Bristol, PA: Taylor & Francis, Inc., 1997): 30., Chi, *Early Response*, 12.
[40] C. Cohen, *Boundaries*.
[41] Ibid., 92.
[42] Ibid., 73-74.

reason it made it all the harder to reach the people who were at risk or already impacted."[43] By the late 1980s, the Latino and Black communities in New Haven had already experienced significant numbers of AIDS cases, but there remained the perception of the disease "'as a white gay problem'"[44] although resistance and misconceptions differed within each minority community. A culturally appropriate response was required as minorities, already the victims of social injustices due to their race and socioeconomic status, were left to consider how the stigmatization attached to their race may be overshadowed by their identity as an HIV-positive person.[45]

II. The African American Community, Culture & AIDS

The African American community, overwhelmed by misinformation and prejudices, was slow to respond to the crisis and equally slow sharing information on HIV/AIDS, leaving their population more at risk. Unlike many within the white community, the African American community did not enjoy many of the same social and economic privileges. Strategically placed members of the white community could exploit their access and power to obtain and disseminate accurate information and force a quicker response to HIV/AIDS; this was not an option readily available to the African American community. As previously mentioned, the CDC could not provide African Americans with data on the racial breakdown of AIDS cases until 1983.[46] African Americans, particularly those most vulnerable to AIDS, also tend to be more medically marginalized than whites. They lacked health insurance or consistent

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[43] Interview, October 30, 2008.
[44] Chi, *Early Response*, 29.
[45] Neil Small, "Suffering in Silence? Public Visibility, Private Secrets and Social Construction of AIDS," in *AIDS Activism and Alliances*, ed. Peter Aggleton, Peter Davies and Graham Hart (Bristol, PA: Taylor and Francis, Inc., 1997): 18.

medical care, without which it was difficult to obtain accurate information on AIDS.[47] In addition, African American intravenous drug users, who are at great risk of infection, often intentionally avoided medical settings for fear of their drug use being discovered and subsequent incarceration.[48]

By the late 1980s, the epidemic had been in New Haven over five years and over one-third of the city's victims were African American. Yet no services targeted this minority community, and often their own community ostracized those who were infected. In the African American community, the problem was clear – there was "not much known about it [HIV/AIDS], [it was] very mystique and mysterious. What is the disease? What is the virus?...There were so many myths and things that were construed out of proportion,"[49] explained one case manager at AIDS Interfaith Network New Haven. Black Churches are the heart of the African American community in New Haven. Cohen notes the historical significance of the black church; it was "a rare center of economic, social, and political independence in black communities, operating with the autonomy to tackle the most sensitive of issues."[50] A 1990 national study of black churches from seven historically black denominations showed approximately 67.9% of black ministers who were questioned reported that their church "'cooperated with social agencies or other nonchurch programs in dealing with community problems.'"[51] Black churches also historically address health needs in their communities.[52] Yet in 1987 most New Haven ministers refused to visit

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[46] C. Cohen, *Boundaries*, 210-212.
[47] Ibid., 129.
[48] Ibid., 130.
[49] Interview, October 24, 2008.
[50] C. Cohen, *Boundaries*, 276.
[51] Ibid., 276-277.
[52] Ibid., 277.

parishioners afflicted with AIDS, or allow them to be buried out of their parishes.[53] The fear and misunderstanding ran so deep in the very center of the African American community that "even Ministers would refuse to shake the hands of people known to have AIDS."[54] Hollie I. West contends that the introduction of AIDS into the African American community triggered two traditions within the black church, "one centered around provision of services and care to those in need, the other based in teaching Christian scripture."[55] There were some within the African American community who did not believe there was a contradiction. For example, Dr. Marjorie Hill, former director of New York City's Office of Lesbian and Gay Concerns under Mayor David Dinkins and a board member for Gay Men's Health Crisis believes "the reluctance of the church to respond to AIDS means they are not following the mission of Christ. I was taught in the Baptist church that Christ took care of the sick. Because the Black church has not taken care of gays, lesbians, and IV drug users, who are definitely in need, they are not fulfilling the mission of Christ."[56] This opinion is shared by Elsie Cofield, wife of the late Reverend Curtis Cofield, longtime leader of a large New Haven black church, and her opinions would help shape the African American community's response. Yet the fear associated with AIDS in New Haven's African American community ran beyond the churches and often black families could not overcome their fears, even for a loved one. Long-time Yale-New Haven Hospital social worker June Holmes remembers "one patient, who was a gay African American male, and his family refused to come identify his body."[57]

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[53] Chi, *Early Response*, 12.
[54] Ibid., 34.
[55] C. Cohen, *Boundaries*, 279.
[56] Ibid., 280.
[57] Chi, *Early Response*, 9.

Although AIDS Interfaith Network, established in the late 1980s to fill the gap in the African American community, continues to work to care for and raise awareness among the community in New Haven, a lack of knowledge and awareness remains. An African American employee at AIDS Project New Haven recalled when the disease and the significant shift in the demographic of those infected from men having sex with men to African Americans. She became "concerned about that shift and the lack of information because here it is, as an African American person, this was happening in my community, right in my back yard, and I didn't know it, I really didn't know. The word wasn't out; there was nothing in the media that indicated this."[58] For all of the differences between the demographics and the responses to the epidemic in the African American and gay communities, this lack of accessible and shared information echoes Freire's culture of silence and Elbaz argues that it is to this "'cultural silence' that activists impugned the deaths of many of their friends and lovers. When this culture addressed sexuality, it was only in negative terms…"[59] Even though the epidemic has been in New Haven for over twenty five years, traces of this cultural silence persist within the African American community, even among those already afflicted with the disease. A long-time African American survivor lamented that part of the cause for the "lousy medical attention" that HIV/AIDS patients receive is "not only do they not get to [the] doctors; some of them are unwilling to go because they're nervous. Afro-Americans, especially men, don't want to go to the doctor unless they're at the end. That's their story."[60]

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[58] Interview, October 23, 2008.
[59] Gilbert Elbaz, "Adolescent Activism for Postmodern HIV/AIDS Education: a New Social Movement," *The Urban Review* 29, no. 3 (1997):153.
[60] Comments, Town Hall Meeting, October 29, 2008.

The difficulty in reaching the African American community is not solely attributed to the black community's resistance. As mentioned earlier, there remained negative perceptions of African Americans within the white community, particularly regarding those most at risk. In addition, the very problems that African Americans hoped to avoid by ignoring AIDS were also the realities that the white community would rather not address. It was, at least in part, concern over "'political failure'" that Mayor Biagio DiLieto chose to respond when Novick showed him that New Haven's AIDS epidemic had become a disease of primarily African American intravenous drug users.[61] The impetus for action within the white community in the interest of the black community was not entirely benevolent, but it did lead to the creation of culturally relevant and life-saving institutions and programs.

The unwillingness to acknowledge or confront the problem remains in New Haven's African American community, but the African American community has proven easier to reach, and quicker to react, than the city's Latino community.

III. The Hispanic Community, Culture & AIDS

The unique features of the city's Latino community made it difficult for professionals and paraprofessionals within the city government and AIDS service organizations to reach out to educate and serve the community. There were parallels between the difficulties serving the African American and the Latino communities, among them a lack of awareness. A long-term Latino outreach worker recalled, "'I do a lot of reading and keep up with the news, but I knew very little about this epidemic, other than what I heard about gay men in San Francisco."[62] In many ways, the Latino

[61] Chi, *Early Response*, 21.
[62] Ibid.,, 28-29.

community refused to face the reality of the disease's impact on their city. The same Latino outreach worker noted "'the Latino community has always been a challenge. In the beginning of the epidemic, people did not want to hear about it. They still don't want to hear about it.'"[63] This resistance stems, in part, from a refusal to believe that the disease did, in fact, impact them. In line with the media framing of HIV/AIDS, the disease was viewed as a "'white gay problem, and they [Latinos] didn't have those kind of problems.'"[64] In addition, as previously mentioned, the mainstream media failed to provide the community with adequate, relevant information.[65] The number of news stories in print and on television focused on analyzing the epidemic in African-American and Hispanic communities "lagged behind those stories in which gay men were central, and lagged drastically behind the number of stories examining the threat of AIDS to 'the general population.'"[66] Thus, just as in the African American community, the Hispanic community's resistance to AIDS information and the threat it posed to the community was not simply a result of a stereotypical homophobia. In the African American community, homophobia was grounded both in the church and the community's history of being stereotyped as sexually deviant. Their additional resistance to AIDS resulted from a failure of the mainstream and black media to provide timely and accurate information.[67] The Hispanic community confronted the same lack of appropriate information and an equally deep-seated homophobia rooted in Christianity. One of the founders of AIDS Project New Haven, Alvin Novick, noted that it was difficult for the predominantly

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[63] Ibid., 12.
[64] Ibid., 29.
[65] C. Cohen, *Boundaries*.
[66] Ibid., 149.
[67] Ibid.

white organization to reach out to the Latino community, as they "'were very homophobic'"[68] and this prejudice also infected leaders and influential organizations within the Latino community.

The same resistance Elsie Cofield faced in some of the black churches was echoed in the predominantly Latino churches – "churches didn't want to know anything about it. They felt that God could heal the individual, so there was no need for us."[69] Like black churches, Hispanic churches faced two options when confronting AIDS – service or willful ignorance based in Christian scripture. It appears that the Hispanic churches, like many of New Haven's black churches, initially chose to remain ignorant and uninvolved with direct action. Their premise, however, was different. While many black churches chose inaction based upon condemnation of the mode of transmission, the resistance within the Hispanic church appears based in a belief the God, not individuals, was in the position to help those infected. The Latino community's fear also derived from a lack of knowledge, as "[p]eople felt that the hugging and the kissing and the mosquitoes, all that things, were related to the epidemic, so there was a lot of unknown things."[70] Critically important organizations within the city, such as Junta for Progressive Action, Inc., the city's oldest Hispanic organization that provides education and service programs, such as English as a Second Language and family advocacy and case management and Centro San Jose, a Catholic service organization that provides behavioral health and addiction services and other services, such as group and grief therapy, refused to

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[68] Chi, *Early Response*, 27.
[69] Interview, January 14, 2009.
[70] Ibid.

recognize the impact AIDS had on their community.[71] A Latino outreach worker explained that this, too, could be traced to an often all-consuming homophobia: "'If we [Latinos] began to address it, we will be identified as gay. This is going to cause a lot of problems, so let's deny that it's happening and not deal with it.'"[72] Aware of this culture-wide denial yet armed with the facts of the disease in New Haven, city professionals and private citizens prepared to face the crisis in the Latino community, and to work to persuade them to do the same.

The difficulty in dealing with the Latino community extended beyond the lack of information and embedded biases that were also seen in the African American community. There were often basic communication problems, particularly as the city welcomed more Latino immigrants who arrived speaking little or no English. As one employee of the Hispanic-focused AIDS organization in New Haven, Hispanos Unidos, noted, "when you cannot communicate, you are lost" and this is especially true when addressing an already overwhelming situation, such as AIDS.[73] In a study of HIV and AIDS infected women in London, Feldman and Crowley find that "a lack of opportunity to find out how the community care system works…is very disempowering for many service users" and that the failure to complain or demand care is caused by practical language, not cultural, barriers; these are the same practical barriers which have challenged the Latino community's response to HIV/AIDS from the beginning.[74] Other organizations have addressed some of the

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[71] Junta for Progressive Action, "Junta: Junta for Progressive Action," *Junta for Progressive Action*, http://www.juntainc.org/en (accessed April 6, 2009), Superpages, "Centro San Jose CATH Charities in New Haven, CT," *Xmlproxy Yellow Pages by Superpages.com*, http://www.superpages.com/bp/New-Haven_CT/Centro-San-Jose-CATH-Carities-L0001201320.htm (accessed April 6, 2009).
[72] Chi, *Early Response*, 29.
[73] Interview, January 14, 2009.
[74] Rayah Feldman and Colm Crowley, "HIV Services for Women in East London: the Match Between

practical barriers facing the Latino community's access to HIV/AIDS preventative and treatment services. The needle exchange program has bilingual and bicultural outreach workers on staff, and Yale-New Haven Hospital is capable of providing translators for dozens of languages, including Spanish and Spanish dialects.[75] The city's other hospital, the Hospital of Saint Raphael, also provides bilingual services.[76] These organizations are equipped with the practical tools needed to assist this community; however, none of them shared both a common linguistic and cultural foundation with the Hispanic community.

Dealing with these non-English speaking Latinos can be a challenge, but the communication difficulties extend beyond the language barrier. A Latino outreach worker explained, "'When I went into the community to talk to educate Latinos, I couldn't talk about HIV/AIDS. I needed to talk about the culture and who we were as a culture. It was like a hook. Then you were able to talk about HIV/AIDS. You just don't talk openly about sex and IDUs [intravenous drug users] with our people."[77] This "'hook'" served as a critical education tool to reach a largely resistant community. As one community educator at AIDS Project New Haven explained, "you can present an idea but you have to show people the relationship to them, it's not just something out there that could happen. You have to actually help them see something in the realm of possibility to them."[78] The use of community insiders to address the Hispanic community's vulnerability to HIV/AIDS provided these

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Provision and Needs," in *AIDS Activism and Alliances*, ed. Peter Aggleton, Peter Davies and Graham hart (Bristol, PA: Taylor and Francis, Inc., 1997): 137.
[75] Interview, December 19, 2008, Interview January 14, 2009.
[76] Hospital of Saint Raphael, "About Us," *Hospital of Saint Raphael*, http://www.srhs.org/body.cfm?id=52 (accessed April 6, 2009).
[77] Chi, *Early Response*, 33.
[78] Interview, October 23, 2008.

educators with intangible qualities that gave them credibility and respect within the community, thus providing their message with increased authority. This could only be successfully achieved by a member of the Hispanic community; no outsider, regardless of how culturally sensitive and knowledgeable they may be, could possess the intangibles needed to properly address the taboo topic of HIV/AIDS with the Hispanic community. The city's community of HIV/AIDS service providers demonstrated cultural sensitivity and knowledge by relying on Latinos to reach out to their community and educate them in a linguistically and culturally sensitive manner.

IV. The Role of Stereotypes: Attitudes Toward Race & Mode of Transmission

Racial misconceptions are not one-sided and the common modes of transmission among minorities created opportunities for animosity among the New Haven community toward these services and these circumstances further marginalized an already outcast culture. In New Haven, the race of the individual infected is linked to the mode of transmission, which can further complicate efforts to address the unique needs of minorities. In the initial framing of the disease, men having sex with men (MSMs) were more prominent, and the stereotypes and negative attitudes surrounding homosexuality make reaching minorities difficult. Yet many minorities in New Haven contracted HIV/AIDS through illegal intravenous drug use, adding a further stereotype to an already stigmatizing disease.

Race and mode of transmission cannot be separated when explaining the epidemic in New Haven. Despite the early dominant image of HIV/AIDS as a "gay disease," only 10.8% of African Americans and 11.8% of Hispanics who were infected with HIV/AIDS in New Haven between 1980 and the end of 2008 were

infected through homosexual intercourse, compared to 39.4% of white men who were infected with the disease through homosexual intercourse over the same time period. Instead, 46.5% of African Americans and 46.5% of Hispanics who became infected with HIV/AIDS while living in New Haven between 1980 and 2008 contracted the disease via intravenous drug use.[79]

The prevalence of infection through intravenous drug use is not surprising, as studies have shown that between all the major cities along the Interstate 91/Interstate 95 and Interstate 84 corridor between Washington D.C., and Boston there are almost one million intravenous drug users, yet the debilitating effect of the mode of transmission on the ability to reach minorities remains.[80] Many HIV/AIDS patients who are previously bound by social stereotypes must examine the ramifications of their new diagnosis on their socially stigmatized identity; New Haven's minority communities, already facing the stigmas attached to inner city poverty and racism, faced battling a disease whose stigma was strong enough to outweigh preexisting stereotypes.[81] Furthermore, their drug use allows society to paint these minority intravenous drug users as "social 'deviants'…. as objects of threat and repulsion, ostracism and discrimination [which] can be justified by those who are 'normal' (Goss and Adam-Smith, 1995; Marquet, Hubert and Campenhoudt, 1995)."[82] This allows society at large to disregard these people, to paraphrase an earlier comment, to let these infected citizens be someone else's problem. It also complicates the work of

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[79] Connecticut Department of Public Health, "New Haven Total HIV/AIDS by Risk, Sex, Race and Age Group (1980-December 31, 2008)," *Connecticut Department of Public Health HIV/AIDS Surveillance Program*, http://www.ct.gov/dph/lib/dph/aids_and_chronic/surveillance/city_and_county/city_new_haven_total_hivaids_table.pdf (accessed February 9, 2009).
[80] Interview, December 19, 2008.
[81] Small, "Suffering in Silence," 18.

city employees and community workers who hope to reach out and treat these minorities.

The intersection of race and mode of transmission made it easy not only to ignore the infected African American drug users who were at the heart of the city's epidemic, but it was possible to not recognize a need even existed. As City Director of Health, William Quinn, noted, "no one really recognized it [HIV/AIDS] because the population infected was not in the mainstream."[83] These individuals were "outsider constituencies" with no connection to influential city institutions.[84] Unlike their white gay male counterparts, these individuals did not have a relationship with influential classes that may have provided them with access to the ear of the most influential city leaders.[85] Minority activists did not have the social network or privileges to directly approach the Mayor with their concerns. Nor could they automatically rely upon medical professionals at Yale-New Haven Hospital for assistance. This lack of access to medical personnel often stemmed from a lack of medical insurance and, in some cases, a desire to avoid medical care for fear of being caught abusing drugs. They also lacked the financial resources or knowledge on how to obtain funding. These constituents were invisible and dying rapidly. Even if most of the minority communities had chosen to protest, they would have been bound by their pre-existing relationship with established power and without a relationship to

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[82] Adam-Smith and Goss, "Opportunity Lost," 30.
[83] William Quinn, Comments at Town Hall Meeting, October 29, 2008.
[84] Bonita Roth, "Where Does the Grassroots End? Blurring the Boundaries Between Inside and Outside in Social Movement Activism," *American Sociological Association Meeting*, August 2007, http://www.allacademic,com//meta/p_mla_apa_research_citation/1/7/4/6/1/pages174611/p174611-1.php (accessed February 9, 2009).
[85] Cohen, *Love and Anger*.

exploit. They would have also faced the barriers of racism and, in some instances, drug use; they were left with few avenues for which to protest their circumstances. [86]

V. Race & AIDS Service Organizations

The identity of key organization's founders, and their target clientele, set these organizations - AIDS Project New Haven, AIDS Interfaith Network and Hispanos Unidos - on separate trajectories. The critical role of the founders of New Haven's three main service organizations can be understood by examining these three organizations.

A. AIDS Project New Haven

The founders and original purpose of New Haven's first AIDS organization, AIDS Project New Haven, put the organization on a long-term path that allowed the organization a certain level of privilege while limiting their ability to serve the New Haven community as the demographics of the epidemic shifted. The organization's founders, Sabella and Novick, had the privilege, as gay white men, of existing "both inside and outside of [the] dominant culture."[87] Both men enjoyed privileged social standing and could have opted to "integrate and 'pass'" as straight men. Yet they chose to utilize their role as "insiders" with social connections and influence to act on behalf of their community of "outsiders," stigmatized by their sexuality and now facing the additional stigma of AIDS. Many gay white men took this course of action in the early 1980s, such as the white professional gay men who helped found and run the often radical AIDS activism group AIDS Coalition to Unleash Power, or ACTUP,

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[86] Benita Roth, "Where Does the Grassroots End? Blurring the Boundaries Between Inside and Outside in Social Movement Activism." Paper presented at the American Sociological meeting, New York City, New York, August 11-14, 2007.
[87] Cohen, *Love and Anger*, 11.

which had a large and active chapter in New York City.[88] In spite of the stigmas attached to their homosexuality and their connection to the equally stigmatized disease, Novick and Sabella were quick to respond to the community's need.

The need for a gay-focused AIDS organization was brought to Novick's attention while attending a 1983 Gay Pride parade in Hartford. Throughout the day "'people shared that they were beginning discussions about how there should be services in Connecticut, particularly for gay men, about education and prevention.'"[89] Additionally, friends of an upper middle class white man dying of AIDS at Yale-New Haven Hospital told the two men that there needed to be a "service organization to mark the way for change."[90] Men of good social standing with ties in the New Haven community, Novick and Sabella responded. As gay white men, Sabella and Novick could have blended into society as straight men, ignoring the stigma of homosexuality. This put them in a privileged position. Unlike the minority communities who would soon be affected by HIV/AIDS, Novick and Sabella had a *choice* to accept or reject a stigmatizing aspect of their identity. The two communities, one stigmatized by sexual orientation, another by race, shared the consequences of being socially marginalized and medically vulnerable to HIV/AIDS. However, the *choice* to publicly accept the stigma put Novick and Sabella in a unique and inherently privileged position. They chose to not only embrace this stigma, but confront the stigma of HIV/AIDS because "for some, [HIV/AIDS] adds further urgency and intensity to the need for affirmation."[91]

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[88] Ibid., 11.
[89] Chi, *Early Response*, 8.
[90] Ibid., 14.
[91] Small, "Suffering in Silence," 17.

AIDS Project New Haven's inception and early mission did not stray from its roots in the gay community. The organization, the first AIDS organization in the state, was officially founded by a group of eighteen gay men, Novick and Sabella included, and two straight women who met in the summer of 1983 at Partners Café, a gay bar in New Haven. The founders took their cue from fellow gay AIDS activists and christened their organization AIDS Project New Haven, after AIDS Project Los Angeles.[92] Despite their respectable standing, the founders of AIDS Project New Haven found their new organization was not immune from the community's fear of AIDS.

One incident the year the organization was founded demonstrates the difficulties they encountered, regardless of their social or human capital. AIDS Project New Haven applied for a grant from the New Haven Foundation, a local philanthropic organization, requesting $65,000 for the administrative purposes of running a non-profit organization, as the group did not have any source of income and needed such basics as an office, a telephone, the material needed to write, print, and distribute a newsletter, and the funds to pay an executive director a "modest salary."[93] The group's knowledge of funding sources and their ability to write a grant proposal demonstrates the significant resource advantage the group, headed by white male professionals, had compared to other minorities service organizations. For example, the founder of AIDS Interfaith Network, an organization that began in the city's black churches, did not know how to write a grant proposal when the organization first became independent.[94] This privilege did not isolate AIDS Project New Haven from

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[92] Chi, *Early Response*, 15.
[93] Ibid., 15-16.
[94] Interview, January 26, 2009.

the controversy surrounding the epidemic. Although the New Haven Foundation's executive director told Novick it was "'the best proposal he had ever received,'" the application was denied "on the basis of three profound and basic problems." The Foundation "questioned the importance and relevance" of funding AIDS outreach, they believed that AIDS was not an issue that should be addressed by non-medical professionals or the community at large, and lastly, the organization required that AIDS Project New Haven's "board of trustees have the usual leaders of New Haven," such as local religious leaders, heads of community-based organizations, such as the Boy Scouts, and business leaders, such as the President of the now-defunct Southern New England Telephone company.[95] These were people, Novick commented, who "'won't even come into a room with us [homosexuals]….They probably think we all have AIDS.'"[96]

These difficulties, however, were easier for Novick and Sabella to overcome. They were able to rely upon their personal resources and those of their newly established board to develop into a full-fledged organization. In late 1983 an area physician gave the group evening and nighttime access to an alcove in his office, allowing them to have their first meeting and kicking off what would prove to be a very active speaker's bureau.[97] In late 1985 the organization rented New Haven's Shubert Theater for the evening, raising $19,000 and gaining the ability to hire a half-time staff member for the first time.[98] Although the sum raised is paltry in comparison to many large-scale fundraisers, it demonstrated that AIDS Project New

[95] Chi, *Early Response*, 15-16.
[96] Ibid., 15-16.
[97] Ibid., 17.
[98] Ibid., 19.

Haven was capable of successfully running and profiting from a fundraiser, thus allowing the organization to built its bankroll and expand its staff and services.

Once firmly established, the organization continued to focus on the gay community and continued to be identified as a gay organization as late as 1988, although the demographics of the disease in New Haven had already shifted, leaving minority intravenous drug users most at risk.[99] The organization did provide AIDS education to the general AIDS community, and they wrote and distributed brochures for intravenous drug users and minorities on how to avoid HIV/AIDS infection. They agency did not intend to restrict its services to the homosexual community; however, Novick recognized when the infections demographics changed, that minority intravenous drug users were a "'population of people that we don't serve. Except to hate them. And to stigmatize and ostracize them."[100] Despite these changes, Novick and Sabella's continued focus on the gay community made sense in light of Castells analysis of San Francisco's Mission District, which in the late 1960s and early 1970s was part of the Model Cities Program in an effort to improve the largely impoverished neighborhood. Castells finds that the Mission District "had to learn to rely on its own economy and organization before it could engage in wider confrontations that might bring general acceptance."[101] AIDS Project New Haven had to successfully serve their target population before they could reach out to unfamiliar segments of the spreading epidemic who, in the 1980s, the organization was simply unequipped to serve.

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[99] Ibid., 18.
[100] Ibid., 20, 18.
[101] Manuel Castells, *The City and the Grassroots: A Cross-Cultural Theory of Urban Social Movements* (Berkeley and Los Angeles: University of California Press, 1983): 119.

This difficulty in serving African American and Hispanic communities rests upon misconceptions by all of those involved. As Novick demonstrated, New Haven's minorities, particular minority drug users, were not groups that the white professionals who founded AIDS Project New Haven were comfortable with approaching. These professionals were already confronting a largely unexplained disease that threatened themselves and their friends. Now they had to address the needs of a community that even they, a group who were already stigmatized for their sexuality and affiliation with the stigmatized disease, perceived as untouchable. White, law-abiding professionals were uncomfortable dealing with minority drug users while, at the same time, these minority drug users were uncomfortable with the idea of HIV/AIDS and homosexuality. Both sides were bounded by their misconceptions and fears, misconceptions and fears that were often reinforced by the culture in which they lived. These constraints led to discomfort but could have also manifested an unwillingness to approach the stigmatized group. There is no evidence, based upon Novick's comments, which indicates that AIDS Project New Haven was unwilling to deal with minority intravenous drug users. His comments do indicate, however, that he was aware of, and perhaps shared, the negative stereotypes attached to minority drug users. Nor is there any direct evidence that minority intravenous drug users refused to deal with AIDS Project New Haven. However, the creation of AIDS Interfaith Network and Hispanos Unidos indicates that there remained a chasm that neither side could completely heal.

In the first decade of the twenty-first century, AIDS Project New Haven remains at the forefront of the AIDS crisis in New Haven, although both Sabella and Novick have passed on. The organization resides in a nicely renovated and furnished

home on Chapel Street in the city's hospital neighborhood (personal observation] and is open during business hours Monday through Friday.[102] The clients have evolved from primarily gay men to include people of every race, socioeconomic background and sexual orientation. The organization runs community-based interventions directed at a specific at-risk population, such as S.I.S.T.A., or Sisters Informing Sisters on Topics on AIDS. Funded by the Centers for Disease Control, S.I.S.T.A. is a culturally competent intervention targeting women of color and has been adapted to serve the Latina population.[103] The original emphasis on community education remains, although they have extended to offer comprehensive services, such as case management, emergency financial services, mental health and nutritional counseling, support groups and meal delivery and transportation programs.[104] In addition, they have expanded to serve the greater New Haven area. Although the organization does not engage in political action, they keep their clients and the community aware of important developments, such as funding cuts, and urge action.[105] The organization's evolution has given them a better opportunity to serve the community; the early inability to reach beyond their target clientele, however, prompted the creation of other AIDS Service Organizations in the city focused on other at-risk and affected groups and each organization's origins set them on a unique path.

B. AIDS Interfaith Network

The AIDS epidemic had been devastating to the African American community, yet with the mutual discomfort between AIDS Project New Haven and

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[102] AIDS Project New Haven, "AIDS Project New Haven," http://www.apnh.org (accessed February 9, 2009).
[103] Interview, October 23, 2008.
[104] Chi, *Early Response*, 15.
[105] AIDS Project New Haven, "AIDS Project New Haven," http://www.apnh.org (accessed February 9,

the African American community, there was no where for these infected African Americans to turn, particularly when many of their own churches shunned them. Elsie Cofield's background made her an ideal person to respond to the AIDS crisis in her own community, and her experiences as a minister's wife and her perception of people set her organization on the unique path it still follows today. In the 1980's, Cofield's husband, the late Reverend Curtis Cofield, was the only minister in New Haven willing to work with African American AIDS patients, regardless of their particular denomination.[106] A Yale University Divinity student approached Cofield in 1987, shortly after she retired from 31 years of teaching, urging her to respond to the crisis within the African American community. Cofield explained that she would "pray on it" and would contact the student if she was willing to take on this responsibility; after two weeks of prayer, she agreed and AIDS Interfaith Network was born.[107] Despite AIDS Project New Haven's discomfort with the African American community, Cofield turned to them to educate herself through their AIDS 101 course and the newly formed organization was designated by AIDS Project New Haven's then-director, Jean Hess, as a part of their organization.[108]

Cofield did more than simply form an organization within an organization - she would work directly with clients, often staying out late at night caring for the sickest of her clients.[109] In addition to directly tending to those in need, Cofield addressed the leaders of the black churches in an attempt to educate them and to urge them to join her in her new life's work. In the beginning, she stood before leaders of

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2009).
[106] Chi, *Early Response*, 34.
[107] Interview, January 26, 2009.
[108] Chi, *Early Response*, 36.
[109] Interview, January 26, 2009.

the black church and gave a lecture on "'How to use a Condom,'" reminding them that she had been teaching the Bible for years but now "[w]e are going to learn how to use a condom.'"[110] That night, Cofield began to see progress as a young African American man in attendance announced his own homosexuality and the black church was "talking about homosexuality, condoms, and AIDS."[111] The organization's focus on educating the black churches remained one of Cofield's primary purposes during the organization's first years as she reached out to dozens of ministers and parishes within the African American community. At first, their responses were "luke-warm at best" but she refused to be deterred from her mission.[112] Although Cofield is a religious woman, she "never had a problem" with the behavior of those she served: "All I thought about was these people who needed help…I never thought about who was gay and who wasn't or who had AIDS because of sex or drugs."[113] Quite simply, Cofield's philosophy is based on her assertion that, "I'm not God. I don't judge."[114] Cofield's hands-on approach to caring for her clients influenced the shape the organization took, the services it offered and the services it continues to offer to this day.

Now located across the street from AIDS Project New Haven on Chapel Street, AIDS Interfaith Network is an independent organization with a different approach to serving the city's infected and affected. Cofield agreed to establish AIDS Interfaith Network, but while the organization was run out of the basement of her husband's church, the organization did not have any funding until she attended a

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[110] Chi, *Early Response*, 37.
[111] Ibid., 37.
[112] Ibid., 38.
[113] Interview, January 26, 2009.
[114] Ibid.

meeting at AIDS Project New Haven, where she was presented with a check for $12,000. She recalls, "that was unbelievable, and I didn't know how to take the check – what strings would be attached if I did?"[115] Cofield did accept the check, and two weeks later AIDS Project New Haven's executive director visited her at home, and it was during this visit that the "strings" were revealed. The executive director told Cofield, "we [AIDS Project New Haven] were glad to give you a check and now you're a part of us and you can't do anything on your own. You're going to have to say, 'I am Elsie Cofield, AIDS Interfaith Network from AIDS Project New Haven' and I had to write that on all the material I sent out."[116] In addition, she was expected to submit a report every two weeks and AIDS Project New Haven would respond. After about a year and a half, "it got to be a little rocky with AIDS Project New Haven because it's hard to be doing as much work as I was doing and…the only thing they did [to] help me was to get $20,000 from the Community Foundation every year," although she later learned that AIDS Project New Haven received a grant for $40,000 and gave her half.[117]

Despite the "rocky" relationship, the partnership lasted approximately two and a half more years. By then, Cofield recalls, "I wasn't wanting to do all of that work and have them get all the credit. I couldn't write a grant, I couldn't do anything I needed to, and I don't work like that."[118] The final break between the two organizations came when a young representative from AIDS Project New Haven visited Cofield. He told her "'you know, you're all doing so well, we're working so well together, we just have to see, you know, what you think is going to make it

[115] Ibid.
[116] Ibid.
[117] Ibid.

better for us, and all that,' and I thought he really meant it."[119] However, two weeks later Cofield received a letter from that same young man, telling her that "'we haven't been able to mesh', M-E-S-H in parentheses, 'and because we can't mesh, I want you to be free and independent by March 13 in '91.'"[120] Cofield, both shocked and concerned, would not allow AIDS Project New Haven to determine the circumstances of her independence and called a press conference three days before the March 13, 1991 deadline to announce that AIDS Interfaith Network was now an independent entity.[121] Nearly two decades after establishing AIDS Interfaith Network as an independent agency, Cofield does not fully understand what caused AIDS Project New Haven to abruptly decide to end the relationship between the two organizations. When asked if she believed race was involved, she said, "I never saw that, I never saw the racial thing with him, not with Doctor Novick anyway."[122]

No longer an entity of AIDS Project New Haven, independence was not always an easy road for AIDS Interfaith Network. Originally run out of the basement of her husband's church, Cofield's organization spread out into multiple rooms of the church before moving to various locations throughout the city. Eventually, Cofield went to then-Governor John Rowland and the state bonding commission to explain the situation and "how I had so many clients, I couldn't handle them in that building."[123] Much to Cofield's surprise, Rowland was familiar with Cofield's work and told her to "'go back to New Haven, choose anything you want, [and] come back

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[118] Ibid.
[119] Ibid.
[120] Ibid.
[121] Ibid.
[122] Ibid.
[123] Ibid.

to the bonding commission', and that's what we did."[124] Cofield eventually chose the renovated multi-family home on Chapel Street because it had a kitchen – she wanted "clients to be able to come and spend the day and get breakfast and lunch….I wanted to make sure they had breakfast and lunch…"[125] She also selected the building because it offered an elevator and she recognized that an elevator would be a necessity. Ironically, after abruptly breaking their ties with AIDS Project New Haven, a while after AIDS Interfaith Network was settled into and had fixed up their current location on Chapel Street, AIDS Project New Haven moved from "way across town" to a house directly across the street from AIDS Interfaith Network. At the time, Cofield recalls "it was so upsetting to me…why would they move right in front of me?"[126] Despite this earlier development, Cofield considers herself "blessed" and is grateful for all of the assistance they received throughout the years.[127]

AIDS Interfaith Network welcomes clients with brightly colored walls – the paint and painting services were donated – and struggles on a shoe-string budget.[128] In contrast to AIDS Project New Haven's waiting room, which offers comfortable chairs, a table covered with AIDS-related magazines and multiple types of AIDS-related literature and pamphlets, the waiting room at AIDS Interfaith Network is sparse. There are plastic folding chairs and a handful of AIDS-related magazines. Instead AIDS Interfaith Network's most friendly, comfortable rooms are those reserved for clients who often spend their entire days within the organization's building. AIDS Interfaith Network is, in many ways, more than a service

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[124] Ibid.
[125] Ibid.
[126] Ibid.
[127] Ibid.
[128] Ibid.

organization, it is a service center. Some clients come in every day, and although there is no place for clients to sleep at AIDS Interfaith Network, they do serve breakfast and lunch and offer a day center with a flat screen television and in the afternoon the center plays movies and the organization provides snacks.[129]

Cofield's tolerance continues to drive the organization's approach as it nears twenty-one years of operation. The race, religious and, in some cases, socioeconomic background of the clientele have changed - Cofield recalls, in the early days, how the organization served lots of young children and babies. The organization now sees predominantly single people, and Cofield muses, "I don't know why that is."[130] Yet there remains, as one of the organization's case managers explains, "a tolerance for everything here, there's no separation of anything."[131] While none of the city's AIDS service organizations discriminate based upon a client's race, gender, sexual orientation or religious belief, the organizations did originate to serve a specific community and this initial separation has created structurally different organizations. While all three AIDS service organizations provide a waiting room for clients, clients at AIDS Project New Haven and Hispanos Unidos sit in a waiting room furnished with comfortable chairs along with a receptionist desk. While waiting to be seen at Hispanos Unidos, clients may even watch television on the waiting room's television screen. In contrast, while a receptionist does buzz you in to AIDS Interfaith Network, visitors wait in a sparsely furnished room separate from the receptionist. While magazines and a few children's toys are provided, there is a clear aesthetic difference. These differences seem to emphasize the different services provided by these

[129] Interview, October 24, 2008.
[130] Interview, January 26, 2009.
[131] Interview, October 24, 2008.

organizations. AIDS Interfaith Network provides a day center with a large television and sofas and they also provide lunch and snacks. Subsequently, most of the organization's clients spend their time in the day center and generally it is visitors not receiving services who sit in the waiting room. In contrast, AIDS Project New Haven and Hispanos Unidos provide case management, as does AIDS Interfaith Network, in addition to other types of counseling, education and financial assistance. Thus, their clients spend less time at the agency and tend to spend more time in the reception area waiting to meet with their counselors. While no organization differentiates or sorts clients, there appears to be more intermingling amongst AIDS Interfaith Networks clients, based largely upon the nature of their visits to the agency. Although all of the city's AIDS service organizations have clients who are struggling financially, representatives from AIDS Interfaith Network emphasize their service to those who are homeless and in shelters. Based upon this focus on the most at need – a focus in line with the role of the black church at the heart of the African American community - AIDS Interfaith Network attempts to actively address their clientele's unique concerns and needs by providing a unique alternative to the services of AIDS Project New Haven and Hispanos Unidos. In 2002, AIDS Interfaith Network's then-director, Joyce Poole, echoed what statistics already prove – "'AIDS has become the disease of the poor'" and noted that "'80 to 90% of our clients are living below the poverty level, 15% are homeless, most have not worked in years. Half are dually diagnosed with HIV and hepatitis C….[and] [m]ost of our clients have had at least one encounter with the Department of Corrections."[132] In light of these facts, the

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[132] Vulliamy, "U.S. in Denial."

structural differences between the organizations, specifically the unique features of AIDS Interfaith Network, are logical. AIDS Interfaith Network makes a point of responding to these unique needs. They provide food baskets for Thanksgiving, in addition to holding a Thanksgiving dinner the day before Thanksgiving and providing clients who live in shelters with a plate to take to the shelter so they have a special dinner on Thanksgiving. They also take Christmas wish lists from their clients with families and reach out to community organizations to fulfill these wishes. In addition, at Christmas time the organization gives their single clients a small gift, such as a sweatshirt or a sweat suit, to open on Christmas day.[133]

C. Hispanos Unidos

The pervasive homophobia and unique challenges of the Hispanic community led to a Hispanic-focused AIDS service organization with unique origins and unique services. Hispanos Unidos Contra el SIDA, furthermore Hispanos Unidos, was the state's first Hispanic AIDS organization.[134] Unlike AIDS Project New Haven, which was begun by professionals, or AIDS Interfaith Network, which originated as a community-based organization within a community-based organization, Hispanos Unidos is a community based organization that originated with three Latino members of the New Haven Mayor's Task Force on AIDS. The organization was formed with the purpose of providing linguistically and culturally appropriate services to the Latino population, factors "which makes a difference."[135] One of the founders and Task Force members was an outreach worker with the Health Department's AIDS

[133] Interview, October 24, 2008.
[134] Chi, *Early Response*, 31.
[135] Interview, January 14, 2009.

Division.[136] He had previously worked as a substance abuse counselor at a substance abuse center tailored to Latinos in New Haven.[137]

From its inception and establishment in 1987, the organization's focus was on the Hispanic population, and its structure and goals were planned without the knowledge of city AIDS activists and free from the influence of fellow Task Members.[138] The organization's Hispanic founders were "protective of the group for fear of a negative reaction from the Hispanic community."[139] As one of the founders, also a Hispanic outreach worker, recalls, "'Anything that had to do with HIV/AIDS at that time was printed in the press immediately….We felt the need to protect the group. We knew that if the press found out that we were doing this, that we would be bombarded with the press.''[140] The organization began as "an organization of education and prevention of HIV/AIDS" but, as a minority-focused service organization, similar to AIDS Interfaith Network, the organization has evolved into more of a community service organization as opposed to a solely AIDS service organization.[141] In the beginning, however, one long-time employee of Hispanos Unidos recalls how people "were afraid. People were not wanting to be identified with us because of the epidemic" and consequently they did not "want to come into the agency because we had a store front on Grand Avenue and everybody knew what was going on there, so they didn't want to be seen coming in."[142]

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[136] Rierden, "New Haven Sends Needles Into Battle."
[137] Chi, *Early Response*, 5, 28.
[138] Hispanos Unidos, Inc., "Hispanos Unidos, Inc., Who We Are," *Hispanos Unidos Inc*., http://www.hispanos-unidos.org (accessed February 9, 2009), Chi, *Early Response*, 28-30.
[139] Chi, *Early Response*, 30.
[140] Ibid., 30.
[141] Hispanos Unidos, Inc., "Hispanos Unidos, Inc.: Mission," *Hispanos Unidos, Inc*., http://www.hispanos-unidos.org (accessed February 9, 2009), Interview January 14, 2009.
[142] Interview, January 14, 2009.

The stigma surrounding HIV/AIDS within the Hispanic community remained even years after the organization was established. One high-ranking member of the organization recalls, "when I was working my other job here [in New Haven] before I came to work for Hispanos Unidos [in 1992], I was inquiring why the position was still open after six months and they told me nobody wanted to work there because they didn't want to work with those people, they didn't want to work with gays" and, despite the organization's push for education and advocacy, misinformation and ignorance remained:

> there was a lot of not resistance but the unknown. People were afraid of the epidemic; they didn't know how you get it. They thought that by touching you or coming in or talking to you, you would get infected. So, at the beginning, people didn't have the information necessary to accept us.[143]

As the epidemic has evolved, and the organization has become one of the main Hispanic organizations in the city, Hispanos Unidos has changed both locations and focus. Like their fellow AIDS service organizations, Hispanos Unidos has bounced around city locations. Moving from their storefront on Grand Avenue, they moved "like halfway up toward Chapel [Street]" and, when that building was sold and the organization was forced to leave, the owner of Griswold Special Care, who had shared the Chapel Street building with Hispanos Unidos, bought a building on Sherman Avenue and invited the organization to join her there.[144] As a high-ranking official of Hispanos Unidos recalls, "she offered me the upstairs or the downstairs and we chose the downstairs because of the facility for people to come in" and they

[143] Ibid.
[144] Ibid.

also built a ramp to accommodate their handicapped clients.[145] The same official explains that their current location "is a good spot for us because the bus stop's here [points directly outside the building], the hospital's [The Hospital of Saint Raphael's] across the street, so people will come for services when they got to the hospital, they come here, and we try to give them as many services [as we can]."[146]

As an important organization within an often struggling community, Hispanos Unidos has expanded its services and focuses as the epidemic shifts from a short-term death sentence into a long-term chronic illness. In the early years of the twenty-first century, the organization became licensed to provide mental health care and began the process of becoming licensed to treat substance abuse for the city's entire Hispanic population because there is "a great need to have bilingual, bicultural services of mental health and substance abuse."[147] The organization is also examining how they can address other issues within the Hispanic community, such as asthma, diabetes and obesity.[148]

VI. Conclusion

What can the intersection of race, socioeconomic status and HIV/AIDS in New Haven tell us? Although the disease did not discriminate based on race or ethnic background, the stigma surrounding the disease was too polarizing and, at times, too specific to a minority community to allow for there to be a successful one-size-fits-all approach to addressing the disease across New Haven's diverse population. Friendships formed between those who responded to HIV/AIDS in New Haven, crossing the boundaries of race, sexual orientation and religious preference. Yet it

[145] Ibid.
[146] Ibid.
[147] Ibid.

remained too difficult for AIDS Project New Haven to effectively and appropriately respond to the epidemic when it first began to ravage the African American and Hispanic communities.

The three groups most at risk for contracting HIV/AIDS in the 1980s had needs that were too specific, and blinded by stereotypes often embedded into their very culture, to be properly served by a less tailored organization. This trend toward one specific clientele, we have seen, has deteriorated as the organizations approach the second decade of the twenty-first century, but this can be understood in terms of the context of the epidemic. While it is still fatal, HIV/AIDS is rarely the immediate death sentence it once was and, although some stereotypes will never be fully overcome, minorities are far more likely now to recognize that HIV/AIDS is more than just a gay man's disease. For example, the revelation in the early 1990s that former professional basketball player Earvin 'Magic' Johnson, a rich, successful, straight black man, was HIV-positive made that abundantly clear.[149] The key distinction throughout these three organizations and targeted responses is not what the organizations were providing or preaching – the same general rules on how to avoid or treat HIV/AIDS apply regardless of one's sexual orientation or race – but the culturally-relevant manner in which the information is being presented. Perhaps this is a result of our multicultural society, that we are a country proud of ourselves and our heritage, and as a result one size will never fit all.

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[148] Ibid.
[149] Interview, October 30, 2008.

Chapter Two: The Role of the City Government

The New Haven government's response to AIDS has been innovative and demonstrated a remarkable level of cooperation between departments within the city government. The government's services have also corresponded with the community's needs and complimented services provided by community based organizations. The chapter opens with an explanation of the city's entry into the battle against HIV/AIDS. A pivotal force in convincing the city government to become involved was a respected community leader who had already formed a private organization to respond to HIV/AIDS. By accepting that the city had a role to play in the HIV/AIDS crisis, then-Mayor Biago DiLieto initiated a response that would put New Haven at the forefront of the response to HIV/AIDS.

An examination of the Mayor's Task Force on AIDS, the first institution within the city government designed to respond to AIDS**,** follows. The Task Force's composition and relationship with different mayoral administrations are discussed. There is also an in-depth discussion of the Task Force's paramount accomplishment, the innovative needle exchange program.

Interwoven throughout the chapter is a comparison to the response of New York City's government to the HIV/AIDS crisis. This is a relevant comparison for several reasons. New York City's high AIDS rate can be attributed to several factors that also account for a large percentage of cases in New Haven, such as the high level of drug use in New York City and extensive poverty.[150] As was previously discussed, HIV/AIDS disproportionately affects minorities in New Haven and the situation is no

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[150] Joshua Brustein, "AIDS in New York City," *Gotham Gazette*, March 28, 2005,

different in New York City. In New York City, African Americans are three times as likely to be HIV-positive than their white counterparts, while Hispanics are twice more likely than whites to be HIV-positive.[151] Specifically, by the end of 2006, 46.3% of the city's cases were African American and 32% were Hispanic.[152] There are also significant parallels between the drug problems in New Haven and New York City, which are particularly relevant to the discussion of New Haven's needle exchange program. Both cities lie on the I-95 drug corridor between Washington, D.C., and Boston and "though the number of drug users in New York City is vastly greater, with 200,000 in a population of more than seven million, the proportion is roughly equal to that of New Haven, which has 130,000 residents."[153] Thus the critical parallels between the two east coast cities create an opportunity to demonstrate New Haven's innovative response.

I. The Creation of the Mayor's Task Force: an Unique Response

New Haven's government did not lead the city's response to HIV/AIDS. They entered the battle after several community based organizations had already formed. HIV/AIDS was a politically dangerous topic in the 1980's, and the city's leaders were not immune. A city government official acknowledged, "[i]t's always the voluntary agencies that are out there first, recognizing what the issues are and then putting pressure on the government to get involved."[154] In the end, it would be a voluntary

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http://www.gothamgazette.com/article//20050328/200/1361 (accessed March 24, 2009).
[151] Ibid.
[152] New York State Department of Health, Bureau of HIV/AIDS Epidemiology, *New York State HIV/AIDS Surveillance Annual Report for Cases Diagnosed Through December 2006*. (New York City, May 2008).
[153] Kirk Johnson, "New Haven Plans to Give Addicts New Needles," *The New York Times*, May 24, 1990
[154] William Quinn, Comments at Town Hall Meeting, October 29, 2008.

organization affiliated with the city that would drive the city's policy towards HIV/AIDS.

In the 1980s, AIDS was highly visible nationally and it was, in the words of a former employee of the New Haven Health Department, "the most compelling health issue of the day."[155] The medical urgency could not completely eclipse the political risks associated with addressing the disease; for example, President Ronald Reagan did not even say "AIDS" publicly until 1987.[156] New Haven's young AIDS organizations were able to garner the attention of local leaders and begin to gain influence. This was not an easy accomplishment in a hostile political environment but it was achieved by the actions of a "resourceful and institutionalized contender" with "direct access to policy makers."[157] Novick directly approached then-Mayor Biagio DiLieto with details on New Haven's AIDS epidemic. Novick had scientific expertise as a medical doctor and professor of biology at Yale University and the experience as founder of the city's first AIDS service organization, AIDS Project New Haven. This knowledge gave him considerable influence with the Mayor. DiLieto was the former New Haven Chief of Police and a conservative Democrat. DiLieto accepted the risks associated with AIDS and heeded Novick's "emphasis on the political importance of the information. 'If you don't move, it will be seen as a failure on your part.'"[158]

Novick's decision to approach DiLieto on behalf of the movement of AIDS service organizations casts doubt on Koopmans claim that "movements must face the task of influencing those whom they do *not* have bonds of co-operation and

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[155] Interview, October 30, 2008
[156] Gay Men's Health Crisis. *GMHC: Gay Men's Health Crisis*. http://www.gmhc.org (accessed April 18, 2006)
[157] Ruud Koopmans, "Movements and Media: Selection Processes and Evolutionary Dynamics in the Public Sphere," in *Theory and Society 13* (2004): 371.

solidarity."[159] New Haven's AIDS organizations succeeded because an influential member of their movement demonstrated to the city that the government and the movement had a common pragmatic and moral purpose. DiLieto responded by forming an innovative program to respond the needs of those infected or at high risk. This response began with the creation of the New Haven Mayor's Task Force on AIDS in 1986.

The Mayor's Task Force on AIDS developed into one of the city's large-scale responses to the AIDS epidemic. The organization was formed to cultivate a community-based response to HIV/AIDS and to raise awareness within the government. The Task Force began with "specific goals because we were the only game in town."[160] The group chose to focus on advocacy, education, research, public policy and the coordination of city AIDS services.[161] The Task Force's goals have changed as private organizations have developed and adopted many of the group's original projects. In the first decade of the twenty-first century, the group focuses on advocacy and "keeping a pulse on what's happening and to be proactive rather than reactive."[162] The Task Force is also the Mayor's primary advisory board on AIDS-related policy and events. Their annual meetings have changed into hosting "something consumer based, like the town hall meeting."[163] The Director of the Health Department's AIDS Division is the Task Force's one mandated member and coordinates case management through a consortium of five community AIDS service

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[158] Chi, *Early Response*, 21.
[159] Koopmans, "Movements and Media," 385.
[160] June Holmes, Interview, November 14, 2008.
[161] Jill Max, "Turning the Tide of AIDS in New Haven, in a collaborative style," *Yale Medicine* Spring 2005, Alumni (2005), Interview, November 14, 2008.
[162] June Holmes, Interview, November 14, 2008.
[163] Ibid.

organizations.[164] The Mayor's Task Force also helps to facilitate inter-organizational communication between AIDS service organizations and other critical agencies addressing AIDS in New Haven. AIDS service organizations along with Yale-New Haven Hospital, the Hospital of Saint Raphael and local housing agencies are represented on the Mayor's Task Force. The inter-organizational relationships cultivated through the Mayor's Task Force has helped improve communication and decreased the risk of overlap between service organizations. For example, if a client is unhappy at AIDS Interfaith Network, the consortium provides the client with a smooth transition to Hispanos Unidos.[165] This has eased case managers' burdens and improved services. However, this is a result of the Task Force's unique composition and their role as the first part of the city government's response to HIV/AIDS.

The city government's response to the epidemic has not been adversarial, unlike the response of other city governments addressing HIV/AIDS. Instead, the New Haven Mayor's Task Force on AIDS laid the foundation for a collaborative relationship between the city and AIDS service organizations and activists. From its inception, the Mayor's Task Force on AIDS has had a unique composition. It is a wholly voluntary, bi-partisan agency and "there's no real criteria" for membership.[166] From the beginning, the Task Force has "included representatives of diverse constituencies in New Haven."[167] Many organizations and agencies have had representatives on the Task Force for years, some since the very beginning. The three major AIDS service organizations in New Haven have representatives, as do other

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[164] Max, "Turning the Tide."
[165] Interviews November 14, 2008 & October 24, 2008.
[166] Interview November 14, 2008.
[167] Edward Kaplan and Elaine O'Keefe, "Let the Needles Do the Talking! Evaluating the New Haven Needle Exchange," *Interfaces* 23, no. 1 (1993):9.

community health and service organizations. Among these are the Visiting Nurses and Planned Parenthood.[168] Other members of the Task Force include New Haven residents living with HIV/AIDS.

The Mayor's Task Force is better able to serve the city's infected and at risk residents due to the freedom granted by the mayor. As one long-term member of the Task Force explained, "[w]e don't have any rules…we're one of the few, if any, groups that are not mandated to sit around that table on a regular basis…it's great, we don't have rules."[169] This allows the Task Force to provide honest, nonpartisan recommendations and evaluations. Their independence granted them the right to directly challenge a city policy early in its existence. The Mayor's Task Force threatened to sue the city of New Haven and School Superintendent John Dow, Jr., if he did not allow HIV-positive and AIDS infected children back into the mainstream school system. At the time of the lawsuit, these children were being educated in the basement of a city church. Faced with the potential legal challenge, the Superintendent conceded before the Task Force pursued legal action. The Task Force also helped design a nonpartisan, non-ideological HIV/AIDS education program in the schools and overcame parental protests to implement the program.[170] This nonpartisan approach to responding to the epidemic, including the design of an HIV/AIDS curriculum, is one of the features that sets New Haven's response apart from other city's more adversarial responses – for example, the ideologically driven debate of HIV/AIDS education in New York City public schools.

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[168] June Holmes, Interview, November 14, 2008.
[169] Ibid.
[170] Ibid.

In the late 1980s and early 1990s a group of adolescent AIDS activists from a New York City group called Youth Education Life Line, or YELL, fought religious conservatives and other city leaders over HIV/AIDS sex education in city schools. In contrast to Cofield's focus on treating the needs of those infected in New Haven rather than condemning the route of transmission, religious conservatives in New York City "invoked old stereotypes of gay and lesbian people as the main cause of the epidemic, professing that the AIDS epidemic was God's punishment for homosexual indulgence."[171] New York City conservatives adeptly manipulated the political process to "discourage federal sponsorship of programs that would explicitly address human sexuality, including those intended to study HIV/AIDS prevention among student."[172] Conservatives used the epidemic as a "new cultural prism through which…[they] could initiate an attempt to control social relations." The adolescent activists united and broadened the groups activism as the fight for HIV/AIDS education had "become a struggle to preserve their gay and lesbian identity."[173] New York City's School Board is a public entity, and the City's mayor did not voice his opinion during the public debate. Instead, he allowed the situation to become a battle over ideology rather than a consensus response to a significant health threat.[174] The ideological debate ran so deep that the first chair of the New York City Board of Education's AIDS Advisory Council announced, "'The homosexuals are not going to get our children. We don't want homophobia; we don't hate anybody, but we hate the acts of homosexuality.'"[175] It is not surprising that the YELL activists perceived the

[171] Elbaz, "Adolescent Activism," 152.
[172] Ibid., 152.
[173] Ibid., 152.
[174] Ibid.
[175] Ibid., 165

religious conservatives to be threatening their identity. They also received mixed signals from the city school system. While the School Board condemned them, school administrators and police did little to stop their illegal in-school distribution of condoms and HIV/AIDS information.[176]

In sharp contrast, New Haven's approach to HIV/AIDS education remained bipartisan. While the Task Force faced parental protests regarding HIV/AIDS education and the free distribution of condoms in city schools, the debate never raised to the level of debate seen in New York City. New Haven's response can be understood, in part, by the liberal nature of the city itself. "We're a bunch of liberals here in New Haven," explained a long-time member of the Task Force.[177] The Democratic party has an overwhelming majority in New Haven. In 1987, when DiLieto last ran for office, Democrats outnumbered Republicans nine-to-one.[178] Although DiLieto was a conservative Democrat, his emphasis on improving the city may account for his willingness to address AIDS. DiLieto's administration revived the city's railroad station and improved the area around Yale University. He cited that the number of the city's welfare cases had been cut in half by 1987.[179] DiLieto's cooperation with HIV/AIDS activists may be a result of his concern with the city's quality of life and improved image. His behavior may have been influenced by the "liberals" that dominate the city. These liberal tendencies cannot fully explain the cooperative relationship between the city government and the AIDS community across multiple mayoral administrations.

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[176] Ibid., 160
[177] June Holmes, Interview, November 14, 2008
[178] Nick Ravo, "In New Haven, Election is Mayor's Least Worry," *The New York Times*, September 11, 1987.
[179] Ibid.

The cooperative nature of the Mayor's Task Force has benefited the organizations whose members work with the Task Force. Throughout its existence, the different city mayors have used the Task Force to continue an open line of communication with HIV/AIDS activists and organizations. The mayor, particularly the current Mayor of New Haven John DeStefano, has an open door policy regarding communication with the Task Force. This policy has allowed multiple city constituencies to raise their concerns regarding the epidemic directly with the Mayor's office.[180] The city's three primary AIDS service organizations – AIDS Project New Haven, AIDS Interfaith Network and Hispanos Unidos – consistently have representatives on the Task Force. This provides the organizations a direct method of sharing their concerns and challenges with the Mayor.[181] Yet the Task Force's unique composition gives it additional access to the Mayor and to the political process.

Their status as a nonpartisan advisory board has allowed the Task Force contact with mayoral candidates. This was particularly important during the Task Force's campaign for a needle exchange program, one of the city's most extensive AIDS programs to date. The Task Force advocated for the program during the 1989 mayoral election and met with candidates during the campaign. They raised "AIDS-related issues, including needle exchange, with all of the mayoral candidates" in a successful bid to gain all of the candidates support for the establishment of a needle exchange program in New Haven.[182]

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[180] Interview, November 14, 2008
[181] Interviews November 14, 2008, January 14, 2009 & January 26, 2009.
[182] Kaplan & O'Keefe, "Let the Needles Do the Talking!" 9

The open nature of the Mayor's Task Force on AIDS provides both the Task Force members and the mayor the option to increase or decrease their level of involvement. In New Haven, the political and social context and the Mayor himself affect the amount of communication and coordination between the Mayor's office and the AIDS community. For example, one long-time Task Force member commented, "[former] Mayor Daniels was less involved than [current] Mayor DeStefano."[183] The difference between the two men and how their administrations responded can be understood, in part, by their personalities and backgrounds. Both are Democrats; however, Daniels was a conservative Democrat while DeStefano is considered liberal. Furthermore, DeStefano interacted with and advocated for key members of the city's AIDS community prior to becoming mayor. While DiLieto's chief administrative officer, DeStefano worked with Novick to help craft the city's initial response. In addition, he was among the first to sit on the Mayor's Task Force Advisory Committee. He has been characterized by a long-time Task Force member as "very supportive…he's been a very strong advocate."[184]. Cofield, founder of AIDS Interfaith Network and a former Task Force member, recalls, "[e]verytime I see DeStefano, he asks 'what do you have? You alright? You alright? Let me know if you're not doing alright…DeStefano's my friend, always has been.'" Cofield added, however, that "[a]ll the mayors in New Haven were our friends, they would work to help us with what we wanted to do or whatever."[185]

DeStefano's emphatic support of the Mayor's Task Force on AIDS and the city's AIDS service organizations can be understood, in part, by the context of his

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[183] Interview, November 14, 2008.
[184] Ibid

mayoral terms. He came to office in 1993, a dozen years after the epidemic first appeared in New Haven and years after the city's most controversial programs were established.[186] The social and political circumstances of Daniels term were less stable. Daniels, the city's first African American mayor, ran for the first of his two terms in 1989, during the debate over establishing New Haven's needle exchange program. He had objected to the decriminalization of syringes and the establishment of a needle exchange program when a member of the state legislature.[187] However, Daniels chose to support the program after Novick took him to visit all of the HIV-positive and AIDS-infected babies in the neonatal intensive care unit at Yale-New Haven Hospital. After the visit, he had a better understanding of the consequences of contracting HIV/AIDS through the sharing of needles.[188] Daniels then focused his political energy on the logistical and political aspects of establishing a needle exchange program. He recalled how "[i]t took hard work. I got a lot of heat from other elected officials, the Board of Alders [Aldermen], church groups and community members." Once the pilot program was established, he confronted the problem that New Haven's "program will draw addicts from other communities and they will drain New Haven's resources." Although the state increased the needle exchange's funding once it was proven successful, Daniels asserted that "other communities must also commit to protecting addicts and develop programs of their own."[189] While DeStefano may be more involved in the daily aspects of battling

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[185] Interview, January 26, 2009.
[186] City of New Haven, "Welcome to the New Haven Mayor's Office," *City of New Haven, Connecticut Government: Office of the Mayor*, http://www.cityofnewhaven.com/Mayor/index.asp (accessed March 24, 2009).
[187] Jones, "Needle Exchange in New Haven," 5.
[188] Ibid., 5.
[189] Ibid., 5.

HIV/AIDS, Daniels undertook the enormous responsibility of coordinating across city departments and creating ties with private city organizations to establish the crux of New Haven's direct service-based response to HIV/AIDS – the needle exchange program.

II. The Needle Exchange Program

New Haven campaigned for and ultimately succeeded in its "Herculean undertaking" to establish a needle exchange program to curb the spread of HIV/AIDS.[190] The innovative approach and coordinated implementation of New Haven's needle exchange program created the first successful government-sponsored needle exchange program in America. It was the nature of New Haven's strategy that set it apart from the nation's first government sponsored needle exchange program, a failed program in New York City.

The nation's first government-sponsored needle exchange program began in New York City in 1988 and quickly failed.[191] The program started in November 1988 after two years of political pressure. It was established through an emergency decree from the City's Health Commissioner; subsequently, it did not undergo "full legislative scrutiny."[192] Tight boundaries were placed on the program. Pressured by neighborhood groups, the Mayor prohibited the needle exchange program from operating within a thousand feet of a school or day care center. Under these regulations, the City Health Department in lower Manhattan was the only permitted

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[190] Interview, October 30, 2008.
[191] Rierden, "New Haven Sends Needles Into Battle."
[192] Lawrence Gostin, "Dimensions of HIV Prevention: Needle Exchange," *Needle Exchange Law & Policy* (1993), http://www.aegis.com/law/journals/1993/ALAW0004.html (accessed January 29, 2009); Johnson, "New Haven Plans."

location.[193] This site, however, was "adjacent to a city jail, the courts, and central police headquarters."[194] It was a peculiar location for a program that sought to bring in illegal drug users in an attempt to keep them free from HIV/AIDS. During its short life, the program would never enroll more than three hundred people. As one commentator notes, the low enrollment is "not surprising, given the program's inaccessibility to most drug users and their fear of arrest and prosecution for possession of drug paraphernalia."[195] Potential needle exchange program clients were too afraid of arrest and prosecution to visit the exchange and learn that the State's Health Commissioner granted the program a waiver from New York's needle prescription law.[196] The program was also limited to exchange, as City Health Commissioner Woodrow A. Myers "eliminated a program to teach addicts about sterilization."[197]

Ideological objections within the city government also doomed New York City's needle exchange program. There had been political debate over a potential needle exchange program for years prior to its establishment, and the dispute continued throughout the program's existence. A member of the City Council compared the exchange "to genocide of [the] black and Hispanic people who are a majority of the city's drug users."[198] Liberal Democrat David Dinkins' opposition was particularly influential. He believed that "giving needles to addicts does nothing to stop drug use and in fact promotes it." This argument overlooks the purpose of needle exchange, which is to stop the spread of HIV/AIDS among intravenous drug

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[193] Gostin, "Dimensions of HIV Prevention," Johnson, "New Haven Plans."
[194] Gostin, "Dimensions of HIV Prevention."
[195] Rierden, "New Haven Sends Needles Into Battle."; Gostin, "Dimensions of HIV Prevention."
[196] Gostin, "Dimensions of HIV Prevention."
[197] Johnson, "New Haven Plans."

users and their law-abiding lovers and children.[199] Dinkins became New York City's first African American mayor in 1990 and cancelled all of the city's needle exchanges.[200] Several important lessons can be taken from the experiences of New York City's needle exchange program. Among the most critical was the "importance of harmonizing the objectives of law enforcement and public health. The probability of success of needle and syringe exchange also depends on the cooperation of city and state law-enforcement officials."[201] These were principles that guided the design of New Haven's needle exchange program.

The creation and implementation of New Haven's needle exchange program centered on cooperation across critical city departments and addressing the vital needs of at-risk populations. From its inception, "[a] main tenet is that [New Haven's needle exchange program] will not be anything like the New York exchange."[202] The Mayor's Task Force on AIDS observed the shift in the demographics of the infected population in New Haven and pushed for the program.[203] The epidemic's demographics changed early in New Haven and the Health Department "made it a priority to target IDUs [intravenous drug users] with aggressive prevention efforts." The city was one of the first in the nation to allot public funds to prevention efforts targeting intravenous drug users.[204] Since they were uncommitted to any policy or party, the Mayor's Task Force on AIDS recognized that a politically dangerous legal needle exchange was "the logical intervention." Members of the Task Force were

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[198] Rierden, "New Haven Sends Needles into Battle."
[199] Johnson, "New Haven Plans."
[200] Tom Cannell, "The Struggle to Implement Needle Exchange in Three Cities," *The Yale Journal of Public Health* 1, no. 2 (2004); Gostin, "Dimensions of HIV Prevention."
[201] Gostin, "Dimensions of HIV Prevention."
[202] Johnson, "New Haven Plans."
[203] Kaplan and O'Keefe, "Let the Needles Do the Talking," 8.

aware that local activists already illegally distributed clean needles to intravenous drug users.[205] A former employee of the AIDS Division and past member of the Mayor's Task Force on AIDS explained, "[w]e couldn't give out needles, we just couldn't do it, but we knew there were others who were doing it….others were doing the work because we weren't."[206] The Mayor's Task Force responded by asking the newly established city-sponsored street outreach team to survey drug addicts to determine why they continued to share needles with the threat of contracting HIV/AIDS. The outreach team disseminated HIV/AIDS information, condoms and bleach for addicts to clean their needles with – they were the "first line of defense" against HIV/AIDS that the city's AIDS Division could legally offer.[207] In addition to this service, their work provided the Mayor's Task Force and the city government with the a crucial understanding of "why they [drug addicts] were sharing needles and what that [had] to do with access."[208] Specifically, drug addicts shared needles "'because of economics or fear of arrest, not because they are on a suicide mission or because sharing needles is part of some social ritual.'"[209] Based upon this direct feedback from area drug users, the city began designing an all-encompassing program that would be created not only by the city but also by the program's future clients.

The needle exchange program resulted from a collaboration of diverse people. Each participant represented an integral component of the needle exchange program. The program's formation began in the summer of 1990 when the Health Department formed a Protocol Committee to help shape a pilot of the needle exchange

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[204] Jones, "Needle Exchange in New Haven," 3.
[205] Kaplan and O'Keefe, "Let the Needles Do the Talking," 8.
[206] Interview, October 30, 2008.
[207] Ibid.
[208] Kaplan and O'Keefe, "Let the Needles Do the Talking," 8.

program.[210] Multiple organizations and affected populations were represented on the committee. There were high-ranking officials from several city departments, such as the Director of the New Haven Health Department, the City's Chief of Police, the Director of the City's AIDS Division, the chair of the Mayor's Task Force on AIDS and representatives of the Mayor's office. The committee also included members familiar with the epidemic and the target population, such as Connecticut's Chief AIDS epidemiologist, drug treatment professionals, city health outreach workers, community activists and representatives from the city's AIDS organizations. Surprisingly, the committee included members of the city's underground needle exchange. The committee also included Yale University Professor Edward Kaplan, who designed and evaluated the effectiveness of New Haven's pilot needle exchange.[211] Each member represented a unique constituency and special interests that needed to be incorporated for a successful program. The presence of city health outreach workers was particularly critical. They had been in the field, engaged in general outreach work with intravenous drug users. Based upon their work with the program's target population, they "understood more about why they [intravenous drug users] were sharing needles and what that had to do with access." The input of health outreach workers led to a program design which "was really informed to a large degree by the people who ultimately used the program" – the city's intravenous drug users.[212]

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[209] Rierden, "New Haven Sends Needles into Battle."
[210] Kaplan and O'Keefe, "Let the Needles do the Talking," 10; Jones, "Needle Exchange in New Haven," 6.
[211] Kaplan and O'Keefe, "Let the Needles do the Talking," 10; Jones, "Needle Exchange in New Haven," 6.

[212] Interview, October 30, 2008.

Efforts to keep the needle exchange program based, driven and focused on the community extended beyond the program's design. After the program was designed, the city formed an Advisory Committee to supervise and support the program. The new committee's members held diverse views on AIDS and drug abuse in New Haven. Some members of the group were familiar with the medical aspects of AIDS and drug abuse, such as state and city public health officials and drug treatment providers. Other members had first-hand experiences with drug abuse in New Haven, including members of the underground needle exchange and former drug users. AIDS organizations and organizations serving people of color were also represented. The committee also included political leaders and city professionals, such as the City Police Chief and principal investigator Kaplan.[213] The innovative composition of both the Protocol and Advisory Committees resulted in a non-ideological program that did not favor one city department or private organization. The groups' voluntary collaborations were one factor in the program's success. The other critical reasons for the program's success were the innovative work of Kaplan and New Haven's Police Chief.

The partnership between the Health Department and the New Haven Police Department was a critical component of the needle exchange's success. Gostin noted that, in battling AIDS, "there needs to be a social contract among city government departments that explicitly favors public health goals over law enforcement goals."[214] Cannell concurred, observing that "[p]olice officers are a critical part of any functioning needle exchange, and they must be convinced of the importance of the

[213] Jones, "Needle Exchange in New Haven," 6, 12.
[214] Gostin, "Dimensions of HIV Prevention."

programs' benefits not only to public health, but also to the fight against drug abuse itself."[215] Tension between law enforcement and needle exchange is better understood in context – most needle exchange programs, including the one in New Haven, began with the illegal distribution of needles to drug addicts. As of 2004, approximately a quarter of America's needle exchanges occurred illegally.[216] Based upon the extraordinary partnership between the Health Department and the Police Department, New Haven has focused on public health concerns.

The cooperation between the Police Department and the needle exchange is based upon a shared understanding of both organization's roles and the Police Department's dedication to community policing. The partnership originated from former Police Chief Nicholas Pastore's community policing philosophy. Pastore served as Chief of Police from 1990 to 1997.[217] He entered office as the Health Department was lobbying for state approval to implement a pilot needle exchange program. From the beginning of his tenure, Pastore enthusiastically supported the program. He offered to help design the program and testified before the Connecticut General Assembly on the city's behalf.[218] Program supporters admitted his enthusiasm was "crucial to gaining [the] support" of state legislators.[219] Pastore's support was based on his belief that the "'1990's is calling for some new thinking in dealing with these issues [drug addiction]…I think we can be law-enforcement people. But I like to see the Police Department's moving toward a social-engineering

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[215] Cannell, "The Struggle to Implement."
[216] Ibid.
[217] National Families in Action, "Nicolas Pastore - Drug Legalization," *National Families in Action A Guide to the Drug-Legalization Movement*, http://www.nationalfamilies.org/legalization/npastore.html (accessed February 9, 2009).
[218] Jones, "Needle Exchange in New Haven," 4; Johnson, "New Haven Plans."
[219] Johnson, "New Haven Plans."

role.'"[220] He believed ''the war on drugs…have been mean spirited and beat on the already oppressed. This program [needle exchange] is a step away from the mean spirited policing that has led to these mean spirited streets.'"[221] The current Director of the Health Department's AIDS Division explained that Chief Pastore "was interested in making sure people got services as opposed to being punished."[222] Additionally, Pastore supported the program because "'it opened communications between drug users and police. It lets them know that the system cares about them changing their lifestyle. That's a nice subliminal message –that police officers do care.'"[223]

Pastore implemented changes in his Police Department to create a force that was amicable with the needle exchange program. The Police Department created a training seminar for the New Haven Police Academy addressing police interaction with needle exchange programs. Outreach workers briefed the Police Department and explained their work and "the public health basis for the program."[224] The police-program partnership has had difficulties. Occasionally officers still confiscate or break participant's syringes, but participants are provided new syringes. While Chief, Pastore acknowledged "'we had our problems along the way, but I was notified and they were dealt with.'" Incidents of harassment have not completely disappeared, but "in every case a meeting with the chief has cleared up the trouble," including meetings with Pastore's successors.[225] Other police-program relations cannot be considered cooperative, including other Connecticut programs established after New

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[220] Ibid.
[221] Johnson, "New Haven Plans."; Jones, "Needle Exchange in New Haven," 11.
[222] Interview, December 19, 2008.
[223] Jones, "Needle Exchange in New Haven," 11.
[224] Ibid., 11.

Haven's needle exchange. Specifically, approximately twenty miles west in Bridgeport "there has never been the concord between exchange and city police that exists in New Haven." A former director of Bridgeport's needle exchange recalls an incident when "unmarked police cars [were] pulling up next to the exchange van and shouting, 'We're going to make sure you can't do shit!'" Participants who prefer to exchange their needles at Bridgeport's needle exchange office are deterred by police cars parked outside of the exchange's office.[226] Generally the partnership in New Haven continues to be a sharp contrast to Bridgeport. Current AIDS Division director, Matthew Lopes, explains "'the police have been very good here in New Haven'" and the police "have even changed their rounds so that they aren't present when the vans are and risk scaring away clients."[227] He acknowledges that it is helpful that "essentially most of the police know and give us a bye and, of course, we're [the needle exchange van] a city vehicle, so we can park most places." Lopes makes an additional point that highlights the city's emphasis on public health over law enforcement, stating that "a lot of police actually refer people to us so they can get them into treatment."[228]

The needle exchange program also tries to assist the Police Department. Prior to the state's decriminalization of syringe possession in July 1992, the Health Department issued identification cards to newly enrolled participants. The card allowed them to prove their enrollment to law enforcement officials and justify their syringe possession and their exemption from "state statutes concerning the possession

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[225] Jones, "Needle Exchange in New Haven," 11; Cannell, "The Struggle to Implement."
[226] Cannell, "The Struggle to Implement."
[227] Julia Dahl, "Senator seeks to end needle exchange," *Yale Herald*, January 31, 1997.
[228] Interview, December 19, 2008.

of needles and syringes."[229] The Health Department also created a letter for the police to confirm a participant's program enrollment if he or she was arrested without their identification card. Prior to July 1992, non-participants could still be arrested for illegal possession of needles and syringes.[230]

The police-program partnership has allowed New Haven's needle exchange program to thrive. This was not the only important city partnership. New Haven's unique role as a leader in addressing HIV/AIDS in America can also be attributed to the city's partnership with Yale University. Specifically, it was the work of Yale University Professor Kaplan and his innovative work that led to a permanent needle exchange program in New Haven. Kaplan's work also laid the foundation for future needle exchange programs.

III. The Needle Exchange Program: "Let the Needles Do the Talking!"

As was previously mentioned, possession of a syringe or needle without a prescription was illegal in Connecticut until 1992. When the state legislature granted New Haven permission to start a program in 1990, the legislation provided the program and participants a waiver from the law. In return, the state required a program evaluation. Kaplan, a Professor at both the Yale School of Medicine and the Yale School of Organization and Management, designed and performed the program evaluation.[231] Previous needle exchange program evaluations were primarily based upon "surveys of program participants to determine the frequency of various risk behaviors…before and during the implementation of needle exchange" to determine whether the program successfully reduced the incidence of HIV/AIDS among

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[229] Kaplan and O'Keefe, "Let the Needles Do the Talking," 14; Jones, "Needle Exchange in New Haven," 8.
[230] Jones, "Needle Exchange in New Haven," 11.

intravenous drug users. These earlier evaluations were criticized for multiple flaws. "First, it is not possible to verify self-reported behavior. Second, even if the self-reports are accurate, it is not clear how the changes reported translate to reduction of HIV incidence. Third, an analysis based solely on self-reports does not incorporate the actual operations of needle exchange, yet surely the success or failure of a program depends on the needle distribution and return rates achieved."[232] Kaplan's new, innovative approach would set New Haven apart.

Kaplan proposed a new theory of needle exchange evaluation that validated the work of New Haven's needle exchange. His work relied on the principle that "the mechanics of needle exchange require that the behavior of *needles* must change [emphasis added]" and he proposed a circulation theory of needle exchange.[233] He argued

> by making needles available on an exchange basis, it is not the number of needles among program participants that will change, for a law of conservation of needles applies…[instead there will be] an increase in the turn-around of needles. This is equivalent to reducing the time needles spend circulating in the population. As needles circulate for shorter periods of time…needles share fewer people. This lowers the number of infected needles in the pool of circulating needles, which in turn lowers the chance that an IDU becomes infected when injecting with a previously used needle.[234]

Based upon Kaplan's theory, the number of new HIV-positive intravenous drug users will continue to fall "in proportion to the lowered level of infection in the needles circulating among needle exchange participants" even without behavioral

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[231] Kaplan and O'Keefe, "Let the Needles Do the Talking," 10.
[232] Ibid., 11.
[233] Ibid., 11.
[234] Ibid, 11-12.

modification among drug users.[235] Kaplan created a system based upon this definitive theory. His system allowed New Haven to authenticate needle exchange's benefits.

Kaplan's design rejected unreliable self-reported data and allowed scientists at Yale-New Haven Hospital and Yale University to gather data from the most reliable source in the cycle – the needles. Needle exchange participants were not asked to provide any identifying information and were given a unique code name. The distributed syringes each had a tracking code and when a needle was exchanged, the outreach worker recorded multiple pieces of information. The outreach worker recorded the date and location of the exchange, the client's code name and the new needle's tracking code on a log sheet. Clients placed their dirty needles into a canistesr, and the worker attached a label with the date and location of the exchange and the code name of the client to the canister. The exchanged needles and corresponding data were taken to Yale University, where the information from the labels was collected and a sample of the returned needles was tested for HIV.[236] By directly "talking" to the needles, Kaplan proved that needle exchange effectively curbed the spread of HIV/AIDS among the population most at risk. When the program began, they tested needles found on the street and in shooting galleries, which are places where intravenous drug users can purchase their drugs and rent the necessary drug paraphernalia from the gallery owners and "often the needles have been used previously."[237] These initial tests were troubling. 91.7% of the forty-eight shooting gallery needles were positive for HIV. 67.5% of the 160 tested street needles also tested positive for the virus. In the program's first five months, 50.3% of the

[235] Ibid., 12.
[236] Ibid., 11-13.
[237] Ibid., 12-13.

distributed needles tested positive for HIV, a decline that "is consistent with what the circulation theory suggests."[238] More importantly, the "statistical significance of the different infection levels is beyond question, [thus] policy experts found these data alone quite persuasive."[239]

Kaplan's research convinced the state legislature to decriminalize needles and New Haven's needle exchange was made permanent. The program evolved into the city's primary form of direct service to the city's HIV/AIDS-positive and at-risk populations. The city remains responsive to the needs and wants of the general community and the program's target population. The needle exchange remains a mobile program, and clients can call and arrange home delivery. The exchange is prohibited from working within five-hundred feet of any of the city's fifty schools and the program adjusts when it is necessary. For example, a stop on Congress Avenue was taken off of the day time rotation due to the building of a new school. However, the van visits these stops during their nighttime rotation because schools are not in session. During their rotations, clients can flag down the van and receive services. The program also makes an effort to provide clients with the products they like in an effort to keep them enrolled. For example, "clients particularly like B&D syringes, and we have two sizes, one cc and one half cc syringes….we try to be user friendly, obviously it makes sense to. We had other needles, they were less expensive, people didn't like their action and so forth. We still use B&D because we just learned what people prefer."[240] The program continues to provide condoms - "we have female condoms, we have male condoms, we have flavored condoms. We have all kinds of

[238] Ibid., 12-13.
[239] Ibid., 12-13.

things."[241] The needle exchange program also accommodates non-participants in the neighborhoods they serve. For example, in the first ten months of the program's operation, the Health Department received one complaint from a property owner concerned with the location of one of the van stops, and the site was relocated a few blocks down the street.[242] The needle exchange program's history of cooperating within and outside of the city government is a reason for the program's success. This is one of the policies required for the successful implementation of another needle exchange program.

IV. The Needle Exchange Program: Beyond New Haven

The Mayor's Task Force on AIDS successful campaign for needle exchange had far-reaching consequences. The full implications of Kaplan's work extends beyond the focus on HIV/AIDS in New Haven.

Kaplan and O'Keefe have demonstrated the significant financial impact needle exchange could have on the public health system. Kaplan's calculations "suggest the avoidance of five infections over the first year of the program, rising to 20 over the first two years." In 1993 the estimated lifetime hospital cost of treating an HIV-positive person was anywhere from $50,000 to $100,000. Based upon Kaplan's calculations and these estimates, the program saved approximately $1 million to $2 million in public health expenditures during the first two years.[243] These results mean that duplicating New Haven's model in another city could have significant public health and financial ramifications. Kaplan and O'Keefe discussed this. If New Haven's results "can be extrapolated elsewhere, then in New York, with an estimated

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[240] Interview, December 19, 2008.
[241] Ibid.
[242] Jones, "Needle Exchange in New Haven," 6.

200,000 IDUs, a network of needle exchange reaching only 25 percent of the IDU population could avert over 1,000 infections in the first year of operation, avoiding between $50 million and $100 million in public health care costs."[244] Kaplan conclusively demonstrated needle exchange's effectiveness in stopping the spread of HIV/AIDS in intravenous drug users and proved that it was also cost-effective, which is an implicit incentive for other cities to implement a similar program.

Kaplan's pioneering technique was the critical component of the city's innovative approach to addressing HIV/AIDS. New Haven's response to HIV/AIDS creates a unique and successful model that other cities could follow. None of the city's mayors considered HIV/AIDS a political issue; even Mayor Daniels supported the politically dangerous needle exchange program once he understood the realities of HIV/AIDS and intravenous drug use. DiLieto established the city's place in the battle against HIV/AIDS, and his hands-off approach resulted in greater ingenuity in the city's response. DiLieto created the New Haven Mayor's Task Force on AIDS but did not enforce any boundaries on the members or their work. The open nature of the Task Force led diverse groups and interests to band together and share information that may have remained separated. The Task Force's focus on HIV/AIDS as a medical issue rather than an ideological issue allowed them to shape the city's pragmatic, bi-partisan programs and policies. Yet while the mayor's response and the city's policies may have been bi-partisan, there was no movement towards instituting a needle exchange program until the Mayor's Task Force started the campaign. The Mayor's Task Force devoted a significant amount of energy to convincing the city

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[243] Kaplan and O'Keefe, "Let the Needles Do the Talking," 14.
[244] Ibid., 14.

and state to permit the establishment of a pilot program. The all-inclusive nature of the team that designed the program resulted in an effective program that all of those involved accepted. This abnormal level of cooperation across city departments and Kaplan's inventive design created a needle exchange program that also addressed HIV/AIDS and drug addiction as a medical issue rather than a social stigma. It is a lesson that many cities could learn.

V. New Haven Responds: Beyond Needle Exchange

New Haven's response to HIV/AIDS extends beyond the needle exchange program and includes partnerships with community organizations. The Health Department has partnerships with non-professionals in the community. Along with Yale-New Haven Hospital, the Health Department supports a community health van that travels with the needle exchange program. The Department has also partnered with businesses in each of the city's five neighborhoods who distribute materials on behalf of the outreach team. Outreach workers visit "drug sites, beauty parlors and even soccer fields on the weekends to help disseminate information…and going to schools to promote harm reduction."[245] When the needle exchange program first began, the Health Department conducted community briefings on the program to community based organizations, groups and other city departments. They held "over 100 [briefings] during the program's first year of operation."[246] The Health Department continues to maintain community dialogue and gain community support as the epidemic approaches the second decade of the twenty-first century. For example, in December 2008, the Mayor's Task Force on AIDS sponsored "New

[245] Jones, "Needle Exchange in New Haven," 12; Max, "Turning the Tide."
[246] Jones, "Needle Exchange in New Haven," 12.

Haven Unites to End AIDS: A Community Conversation on HIV/AIDS: It's about Us: Our Past, Our Present, Our Future!" The Mayor's Task Force on AIDS and the city frequently host events on World AIDS Day, December 1st, including an event organized by the Health Department in 2004 at the Center Church in the New Haven Green.[247]

VI. Conclusion

New Haven's response to AIDS cannot be understood without an examination of private AIDS service organizations. However, it was the city's extraordinary response to HIV/AIDS that created a successful model for other cities. The innovation began with the New Haven Mayor's Task Force on AIDS. The wholly voluntary organization was given the independence needed to craft a comprehensive, pragmatic response. It is unlikely that New Haven would have had a needle exchange program without the Mayor's Task Force. The group's autonomy and their powerful members and allies allowed them to challenge societal norms and take political risks. In the absence of the Mayor's Task Force on AIDS, it is unlikely New Haven would have demonstrated the same leadership in HIV/AIDS services. The Mayor's Task Force on AIDS brought together a unique combination of nonpartisan individuals who collectively had substantial political and social clout. Their brazen leadership and level of preparation convinced city and state officials to put aside political concerns and focus on public health. The Mayor's Task Force on AIDS is the nexus of the city's response to HIV/AIDS and the center of the city's innovative and life-saving needle exchange program. If other cities are willing to put aside political

[247] Personal Observation, October 29, 2008; Max, "Turning the Tide."

differences, New Haven's models of the Mayor's Task Force and the needle exchange program could be successfully implemented with life-saving results.

Chapter Three: Social Movements

New Haven's comprehensive response to HIV/AIDS resulted from a partnership between city department's and private organizations, an effort that originated at the grass-roots level. Private organizations, specifically AIDS Project New Haven, AIDS Interfaith Network and Hispanos Unidos, were at the forefront of New Haven's need, filling the city's void. New Haven's multilateral response was a social movement that falls under the umbrella of a nationwide movement to deal with the HIV/AIDS crisis.

This chapter begins with an examination of the political and social context of the 1980s. There is also a discussion of how these factors influenced the response to HIV/AIDS in New Haven and nationally. The response in New Haven culminated to form a social movement. Work by Manuel Castells and Doug McAdam provide an understanding of social movements. New Haven's social movement was a new social movement. Joseph R. Gusfield's work is used to define a new social movement and first-hand accounts and other documentation are used to conclude that the work in New Haven fits the contours of a new social movement.

I. The 1980s – The Age of Reagan

AIDS was not the only issue jarring America's political and social landscape in the 1980s and the ascendency of Ronald Reagan to the Presidency and the shift in party control in Congress would profoundly influence the political landscape.

Reagan easily defeated Democratic incumbent Jimmy Carter in the 1980 Presidential election with significant help from the emerging New Right and the fundamentalist Christian Right. The Republicans also defeated nine incumbent

Democratic Senators, including liberal Senator George McGovern, and picked up seats in the House of Representatives during the same election cycle. In addition to winning the Presidency, the Senatorial victories gave the Republicans the Senate Majority for the first time in nearly thirty years. The Reverend Jerry Falwell, Reagan supporter and founder of the recently created political action group the Moral Majority, credited conservative Christians for the Republican victories. The Moral Majority and other Christian Right organizations earned significant public attention for their successful grassroots organizing abilities and voter turn out campaigns. These victories and the newly tapped power of the Christian Right fundamentally shifted the American political landscape.[248]

Reagan actively courted the Christian Right and other conservative elements of the Republican Party during his Presidential campaign and his administration embraced conservative social values and "waged an all-out war on those who did not conform to his [Reagan's] view of morality."[249] Reagan appointed those who shared his conservative ideas to his administration, such as his pick for Surgeon General, C. Everett Koop. Koop was a pro-life Evangelical Christian.[250] Koop had also repeatedly stated his belief that homosexuality was a sin, making him the Christian Right's ideal Surgeon General.[251] The Christian Right was further encouraged when Reagan appointed Gary Bauer as a domestic policy advisor. Bauer was an associate of James Dobson, the president of the conservative Focus on the Family and a Reagan

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[248] Craig A. Rimmerman, From *Identity to Politics: The Lesbian and Gay Movements in the United States* (Philadelphia: Temple University Press, 2002), 131.
[249] Ibid., 132.
[250] Frontline, "The Age of AIDS." *Frontline: The Age of AIDS*, http://www.pbs.org/wgbh/pages/frontline/aids/ (accessed April 7, 2009).
[251] Rimmerman, *From Identity*, 134.

supporter.[252] Further evidence of the Christian Right's influence on politics was shown through successfully registering Christian voters and recruiting people to become active in Republican politics. This success and subsequent influence led not only to Reagan's election and the appointment of a conservative-leaning administration, but allowed the new modern conservative movement to push their social agenda onto Congress and the President. This included abortion, school prayer, and homosexuality.[253]

The conservative's successful campaigning provided an ideal environment for a renewed attack on lesbian and gay rights. For example, Senator Roger Jepsen (R-Iowa) introduced the "Family Protection Act" in 1981 that would prohibit lesbians and gays from receiving Social Security, veterans or welfare benefits and was endorsed by President Reagan. The House of Representatives also passed legislation in 1981 "'prohibiting the Legal Services Corporation from accepting discrimination cases filed" by lesbians and gays.[254] Conservative, pro-family organizations also developed and sharply attacked lesbians and gays. The conservative Family Research Institute was particularly aggressive in attacking homosexuality. The organization distributed multiple pamphlets that connected a variety of social ills to homosexuality - one such flyer "identified gay sex as a 'crime against humanity.'"[255] The organization's director, Paul Cameron earned publicity for multiple studies that tried to prove "'that gay men brought AIDS on themselves and the rest of the world.'" He claimed AIDS originated with "promiscuous American gay men" who "engaged in

[252] Ibid., 132.
[253] Ibid., 132.
[254] Ibid., 132.
[255] Ibid., 134.

'unsanitary' sexual practices as they enjoyed 'world wide sex tours.'"[256] Cameron supported universal HIV testing and quarantining everyone who tested positive for HIV antibodies. Rimmerman notes, "That Cameron's shoddy research and bizarre theories received widespread public attention and entered into mainstream conservative thought says something about the reactionary tenor of the times."[257]

In the midst of a significant shift in national party control, New Haven remained firmly Democratic. As was previously discussed, New Haven elected their first African American Mayor in 1989, succeeding fellow Democrat Biagio DiLieto, who had served as Mayor for ten years. The Democrat's secure hold over city politics isolated the city from much of the politically-charged debate that would develop over AIDS. Without an actively hostile conservative movement to oppose, New Haven's AIDS social movement would lack much of the antagonism seen in other parts of the nation.

II. The 1980s – Lesbian and Gay Rights

The Conservative political regime actively attacked homosexuality, yet in the 1980s lesbian and gay rights activists witnessed significant progress, significant defeats and, as previously mentioned, worked to redefine themselves in response to AIDS. While there had been local lesbian and gay rights movements for decades, gay rights activists became far more active in national mainstream politics in the 1980s.[258] The rise of the Conservatives as a national political force threatened the gay right movements' accomplishments and the public arrival of AIDS forced lesbian and gay

[256] Ibid., 134.
[257] Ibid., 134.
[258] Ibid., 28.

rights activists to acknowledge the need to become involved in national mainstream politics.[259]

Lesbians, gay men and their supporters began to openly enter mainstream politics in the years leading up to Reagan's 1980 Presidential election. The Log Cabin Republicans, a group that, unlike their conservative counterparts, supported gay rights, began in California in the 1970s and continues today. [260] Harvey Milk, an openly gay man, won a seat on San Francisco's Board of Supervisors in 1977 and successfully mobilized gay and lesbian activists throughout California to defeat Proposition 6. Proposition 6 had been proposed by conservative State Senator John Briggs and would have expelled homosexual teachers from the state's school system. Milk was murdered in November 1978.[261]

Openly homosexual politicians had emerged after Milk's assassination. California Governor Brown appointed Mary Morgan, an openly gay woman, to on the San Francisco Municipal Court in 1981.[262] Gay politics and politicians also began to emerge nationally. Massachusetts Representative Barney Frank became the first openly gay Congressman when he was elected to the House of Representatives in 1981.[263] Lesbians and gays would also find they had an ally in Representative Henry A. Waxman, California Democrat from Los Angeles who has served since 1974.[264]

The 1980s saw further activism, advances and defeats for lesbian and gay rights. In 1982 Wisconsin became the first state to outlaw discrimination based on sexual

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[259] Ibid., 28.
[260] Log Cabin Republicans, http://online.logcabin.org/ (accessed April 8, 2009).
[261] Oakland Museum of California. *Picture This: Post Vietnam Era*, http://www.museumca.org/picturethis/6_9.html accessed (April 8, 2009).
[262] Ibid.
[263] Congressman Barney Frank. "Congressman Barney Frank – MA-04," *United States House of Representatives*, http://www.house.gov/frank/ (accessed April 8, 2009).

orientation.[265]. The same activists in the California Bay Area whom Milk successfully mobilized to defeat the Briggs Imitative in 1978 joined forces once again in 1986 to defeat Proposition 64, Lyndon LaRouche's initiative to quarantine people with AIDS.[266] Gay rights activists also successfully organized a march on Washington D.C. for Lesbian and Gay Rights in October 1987, further bringing attention to their demands.[267]

The movement would experience significant setbacks, however. In addition to the devastating medical and emotional damage dealt by the AIDS epidemic, and the conservative's hostile attitude towards both homosexuality and AIDS, the United States Supreme Court significantly damaged gay rights in their 1986 decision in *Bowers v. Hardwick*. The majority's opinion legitimized the Christian Right's agenda, "especially since the Supreme Court had previously avoided ruling definitely on the issue of sodomy laws." This decision continues to be the foundation on which courts deny lesbian and gays their basic rights.[268] In this political environment, where the nation's highest court refuses to protect gays and lesbians' fundamental rights, the connection between HIV/AIDS and homosexuality laid the groundwork for a nationally combustible political reaction. However, the political landscape under Reagan also proved hostile to the other population most vulnerable to AIDS – intravenous drug users – further pushing HIV/AIDS from a medical issue into a political problem.

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[264] Rep. Harry A. Waxman. "Rep. Henry A. Waxman – 30th District of California," *United States House of Representatives*, http://waxman.house.gov/ (accessed April 8, 2009).
[265] 365gay. "An American Gay History timeline: 1903-2008." *Feature Story on 365gay.com*, http://www.365gay.com/uncategorized/an-american-gay-history-timeline-1903-2008/ (accessed April 8, 2009).
[266] Oakland Museum of California.
[267] Rimmerman, *From Identity*, 32.

III. The 1980s – "Just Say No!"

The conservative pro-family agenda was not the only important issue on President Reagan's domestic agenda. On October 2, 1982, Reagan declared the "'War on Drugs" with the goal of a "Drug-Free America" by 1995.[269] Two years later, in 1984, First Lady Nancy Reagan introduced the "Just Say No!" campaign, an anti-drug use campaign aimed at white, middle-class children and paid for by corporate and private donations.[270] Despite these efforts, and the emphasis on cracking down on drugs and related crimes, events throughout the decade continued to indicate the extent of the nation's drug problem. *The New York Times* ran a cover story in November of 1985 spotlighting the explosion of crack abuse in New York City. Less than a year later, on June 19, 1986, college basketball player Len Bias died from a cocaine overdose which further emphasized drugs as a political issue. On October 27, 1986, Reagan signed the Anti-Drug Abuse Act of 1986, allotting $1.7 billion dollars to fighting drug abuse; of that, $97 million went to constructing new prisons. These prisons would be particularly relevant once the mandatory minimum sentences laid out in the bill went into effect. The bill's mandatory minimum sentences included tougher penalties for crack-related offenses.[271] The emphasis on battling crack had specific socioeconomic implications. Crack is cheaper to purchase than cocaine and "the majority of crack users are lower income."[272] The social implications of the war

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[268] Ibid., 135.
[269] Steven Wisotsky, "A Society of Suspects: The War on Drugs and Civil Liberties," *the Cato Institute, The Cato Institute Policy Analysis no. 180* http://www.cato.org/pubs/pas/pa-180es.html (accessed April 8, 2009).
[270] Frontline. "Frontline: Drug Wars: Thirty Years of America's Drug War" *Frontline: Drug Wars: Thirty Years of America's Drug War.* http://www.pbs.org/wgbh/pages/frontline/shows/drugs/cron/ (accessed April 8, 2009).
[271] Ibid.
[272] National Public Radio. "Timeline: America's War on Drugs," *NPR: The Forgotten War on Drugs: Timeline: America's War on Drugs.* http://www.npr.org/templates/story/story.php?storyId=9252490

on drugs continued after Reagan left office in 1989. President George H.W. Bush established the Office of National Drug Control Policy and created the first "drug czar." Bush appointed William Bennett to the position and Bennett sought "to make drug use socially unacceptable."[273] Public opinion polls indicate that Reagan succeeded in raising public concern over drug use. Polls taken by the Roper Center at the University of Connecticut between June 1980 and May 1984 indicate an increase in the percentage of respondents who felt that the federal government should be making a "major effort" to solve the problems of crime and drugs. In June 1980, 77% felt the government should make a major effort; in May 1981 the number increased to 80% and remained at 80% in a poll taken in June 1983. By May 1984, however, 84% of respondents indicated that the federal government should be making a major effort to solve problems of crime and drugs.[274] In an ABC News Poll taken two years later in August of 1986, 62% of respondents said they believed that drug use among Americans in general poses a serious problem to society, compared to 36% of those who said they did not know.[275] That same year, 79% of those who were asked in a Wall Street Journal poll said they believed the increased use of illegal drugs threatens the future of the American Dream.[276] Drug abuse was not a medical problem, nor was it merely a threat to security; the war on drugs had created a society where drug use threatened the secure fabric of society. These were challenging circumstances for intravenous drug users vulnerable to acquiring HIV.

IV. The 1980s – Politics, Ideology & AIDS

(accessed April 8, 2009).
[273] "Timeline: America's War on Drugs."
[274] Roper Center for Public Opinion Resarch. "Search i-Poll." *iPoll Databank @ The Roper Center for Public Opinion Research*. http://www.ropercenter.uconn.edu/ (accessed April 8, 2008).
[275] Ibid.

Conservative politics, the gay rights movement and the War on Drugs collided nationally with the emergence of AIDS. Based upon the starkly contrasting interests of each interest group, it is not surprising that the federal government's response to AIDS was neither fast nor unified.

AIDS presented the newly empowered Conservative branch of the Republican Party a prime opportunity to advocate for their agenda. AIDS was "the tool, and gay men the target, for the politics of fear, hate and discrimination." For example, Reagan supporter and founder of the political action group, The Moral Majority, Jerry Falwell believed that "AIDS is the wrath of God upon homosexuals."[277] The Moral Majority, along with other Christian Right organizations, "exploited AIDS hysteria as a central element of their political organizing and fundraising strategies." [278] The exploitation of HIV/AIDS and vulnerable populations continued into the later half of the 1980s. In 1987, North Carolina's Republican Senator Jesse Helms responded to an explicit same-sex brochure issued by the Gay Men's Health Crisis by calling for an amendment banning federal funds for educational material that "'promotes or encourages homosexual activities.'" The legislation passed and the policy continues to this day.[279]

Members of Reagan's administration were also uninterested or unmotivated in properly, promptly addressing AIDS and assisting those most at-risk. Cathy Cohen discusses how inferior social status – such as the social standing of the most vulnerable populations – "negatively affects the responsiveness of dominant

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[276] Ibid.
[277] Allen White, "Reagan's AIDS Legacy/Silence equals death." *SFGate*, June 8, 2004, http://www.sfgate.com/cgi-bin/article.cgi?file=/chronicle/archive/2004/06/08/EDG777163F1.DTL (accessed April 7, 2009).
[278] Rimmerman, "From Identity," 132.

institutions that control the distribution of information and resources needed by marginal group members" and this can be seen in the government's response.[280] The President's Communications Director Pat Buchanan "argued that AIDS is 'nature's revenge on gay men.'"[281] In March of 1983 Reagan appointed former Massachusetts Republican Congresswoman Margaret Heckler Secretary of Health and Human Services. While she claimed AIDS was her top priority, she opposed increasing the budget of public health organizations addressing the epidemic. Later she explained, "'this was not a problem that money could solve; it was a problem that scientists could solve, and so one had to balance the various segments of the AIDS dilemma."[282] The following year Heckler reinforced this message, speaking before Congress and arguing, "I really don't think there is another dollar that would make a difference."[283] However, there were contradictory opinions and attitudes toward addressing AIDS within the government. For example, on the same day Heckler testified before Congress in 1984, dismissing the idea of additional funding, an epidemiologist at the Centers for Disease Control and Prevention told his superior, Dr. Walter Dowdle, "The inadequate funding to date has seriously restricted our work and has presumably deepened the invasion of this disease into the American population. In addition, the time wasted pursuing money from Washington has cast an air of despair over AIDS workers throughout the country.'"[284] This contradictory attitude extended into the administration. Specifically, the nation's highest ranking physician, Surgeon General Koop, later claimed he was prohibited from discussing

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[279] Frontline, "The Age of AIDS."
[280] Cathy Cohen, *Boundaries*, 51.
[281] Allen White, "Reagan's AIDS Legacy."
[282] Frontline, "The Age of AIDS."
[283] Ibid.

AIDS during the administration's first five years – Reagan would not publicly address AIDS until 1987. Koop claimed he was not allowed to discuss the matter due to "'intradepartmental politics…because transmission of AIDS was understood to be primarily in the homosexual population and those who abused intravenous drugs. The President's advisers, said Koop, 'took the stand, 'They are only getting what they justly deserve.'"[285] Even when the administration did publicly address the AIDS medical crisis, the circumstances were extremely political. The speechwriter who wrote one of Reagan's first major AIDS speech recalls how the speech was "subject to an intense back-and-forth political debate within the White House. 'It didn't really make much sense to have the White House staff second-guessing a medical doctor, but that happened.'"[286]

President Reagan's public discussion of AIDS intersected with his political philosophies. In his second major speech on AIDS, in May of 1987, Reagan mentioned, among other things, how the disease was not discovered until June of 1981 and how "a drug treatment, AZT, has been brought to market in record time."[287] It is interesting to note that the President acknowledges the largely misunderstood and dangerous epidemic appeared in 1981, yet he did not give a major public address on the issue until the spring of 1987. In addition, as is discussed later, it is largely due to AIDS activists that AIDS drugs became available so quickly. In the same speech, Reagan goes on to remind his audience that "We [the government] can do any

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[284] Ibid.
[285] Allen White, "Reagan's AIDS Legacy."
[286] Frontline, "The Age of AIDS."
[287] Frontline, "President Reagan's amFAR Speech." *Frontline: The Age of AIDS* http://www.pbs.org/wgbh/pages/frontline/aids/docs/amfar.html (accessed April 8, 2009).

number of things. But only medical science can ever truly defeat AIDS."[288] Reagan's in-depth comments on AIDS appeared shift the topic from a political to a medical problem by stating that it is the medical establishment, not the government, who was best situated to end the epidemic. Reagan's attempt to redefine AIDS as a medical problem is interesting in light of New Haven's response; from the onset, due to the activism of Novick and those within the city's Health Department, the city addressed AIDS as a medical, rather than social or political, crisis. During the same speech, the President also calls for communities, religious organizations, schools and parents to provide AIDS education but hopes that it "will not be value-neutral."[289] As previously discussed, New York City engaged in an ideological battle over sex and AIDS education.[290] Again, in contrast to the events in New York City and the President's public hopes, New Haven's non-partisan Mayor's Task Force created and implemented a neutral AIDS education curriculum.[291]

In the May 1987 speech, Reagan also maintained his own moral stance while contradicting the beliefs and statements of fellow conservatives, including those within his own administration. While Christian Right groups have exploited AIDS and scorned those who are infected and most vulnerable, the President urged his audience, "This is a battle against disease, not against our fellow Americans. We mustn't allow those with the AIDS virus to suffer discrimination."[292] Reagan delivered the speech in 1987, two years after his friend and fellow actor Rock Hudson

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[288] Frontline, "The Age of AIDS."
[289] Frontline, "President Reagan's amFAR speech."
[290] Elbaz, "Adolescent Activism."
[291] Interview, November 14, 2008.
[292] Frontline, "President Reagan's amFAR speech."

died of AIDS, which partially accounts for his divergence.[293] Another factor was Ryan White, a hemophiliac who contracted AIDS through a tainted blood donation and in 1985 was barred from attending public school.[294] The White case earned both publicity and presented the nation with a sympathetic portrait of a "blameless" AIDS victim. In light of these events, Reagan continued to portray the epidemic as a moral issue in a different sense than that proposed by the Christian Right. The President reminded his audience, "As individuals, we have a moral obligation not to endanger others...If a person has a reason to believe that he or she may be a carrier [of HIV], that person has a moral duty to be tested for AIDS, human decency requires it...Innocent people are being infected by this virus, and some of them are going to acquire AIDS and die."[295] This "morality" is the basis of the President's intrusive proposal to require universal HIV/AIDS testing. He ordered HIV/AIDS added to the list of contagious diseases for which immigrants and aliens can be denied entry into the country and asked the Department of Justice to test all federal prisoners. Reagan explained, "While recognizing the individual's choice, I encourage states to offer routine testing for those who seek marriage licenses and for those who visit sexually transmitted disease or drug abuse clinics. And I encourage states to require routine testing in state and local prisons."[296] The President's attempt to establish universal testing baffled many. A June 2, 1987 editorial in *The New York Times* questions the President's decisions - "What's less evident is why he ignores the best advice of public health officials and recommends compulsory AIDS testing that has little relevance to the incidence of the disease." The author goes on to note that one of the

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[293] White, “Reagan’s AIDS Legacy.”
[294] Frontline, “The Age of AIDS.”
[295] Frontline, “President Reagan’s amFAR speech.”

best options for curbing the spread of AIDS is a widespread education program, "something the Federal Government is ideally situated to conduct. Yet Mr. Reagan seems willing to leave that task to the ad hoc efforts of states, schools and private businesses."[297] Reagan's choice to entrust sex education to other institutions is reasonable in light of his Conservative beliefs in small government; however, it is contradictory to most of his Presidency, in which he significantly increased the size of the federal government.

There were some substantial advances made in addressing AIDS during Reagan's presidency. After five years of silence, Koop issued a report on AIDS in 1986, urging parents and schools to speak frankly to children and teenagers about AIDS. The report also dispels the myth that AIDS can be spread through mosquitoes and recommends against pursuing mandatory HIV/AIDS testing or quarantining those who test positive. A condensed version of Koop's report, called "Understanding AIDS," was mailed to every American household in 1988. Before he left office, Reagan reversed the government's previous legal position and "mandated that all AIDS patients – symptomatic or asymptomatic – would now be protected against discrimination by the entities receiving federal assistance. It was one of the recommendations that had been made by Reagan's special commission on AIDS," created in 1987.[298] The larger political landscape of the 1980s, however, remained particularly unsympathetic towards homosexuals, intravenous drug users, and especially those infected with AIDS. It was the ideal setting for the emergence of the

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[296] Ibid.
[297] "Mr. Reagan's AIDS Test," *The New York Times*, June 2, 1987 Section a pg. 26.
[298] Frontline, "The Age of AIDS."

creation of a new social identity, and the emergence of AIDS activism that created the larger AIDS social movement.

V. The 1980s – Anger, Activism and the Creation of a Social Movement

In the 1980s, the United States government was hesitant to attack AIDS head-on and preached an attitude that belittled homosexuals and drug users, the two groups most at risk. Although these groups remained caricatures within the public mindset, the paranoia associated with AIDS in the 1980s created an even stronger social stigma. These men and women were marginalized because of their sexual orientation or drug problem, but, more powerfully, because they *might* be infected with AIDS – as previously mentioned, Novick recalled being denied a grant to fund AIDS Project New Haven shortly after its inception, musing that those who ran the grant foundation probably believed that all homosexuals had AIDS.[299] AIDS was the primary stigma; in the political climate, homosexuality and drug use were maligned, but AIDS was too stigmatized to be publicly discussed. These men and women needed to be their own voice and find their own allies. This pushed their identity as AIDS infected or affected men and women to the forefront and pushed them into action.

The late 1970s and early 1980s witnessed a modest advancement in the rights of lesbians and gay men. Although belittled by conservatives and the Christian Right, homosexuals began to gain a voice in politics, ranging from local politician Harvey Milk to the election of Barney Frank and those supportive of gay rights, such as Henry A. Waxman, to the House of Representatives. AIDS arrived in gay communities as a puzzling and frightening medical problem, one that rapidly killed friends and loved ones. Yet for all of their earlier progress, the fear associated with

AIDS only bred further contempt for homosexuals and the government's paradoxical response – aggressive attempts to violate the rights of those infected by many Republicans in Congress, while the Republican President remained mum – turned AIDS from an urgent medical crisis to an intensely political problem. Furthermore, the government's powerful voice and the increasing influence of the Conservatives and the Christian Right had the power to spread ideologies that supported and validated marginalizing those with AIDS.[300] As Cathy Cohen notes, when dealing with AIDS, "ideologies and definitions of deviance and abnormality have been used to position many with HIV and AIDS outside not only the traditional health-care system but also the larger 'moral fabric' of the country."[301] This further highlighted the perception that individuals associated with AIDS were all alike in their deviance and their behavior endangered society. This portrayal forced the social category of AIDS onto those infected and affected and the newly created social group responded.

The creation of AIDS as a new, stigmatizing identity resulted from the government and public reaction to the disease. As mentioned earlier, the Reagan administration was disinterested in publicly addressing the issue or increasing funding. Many school systems, including New Haven's, refused to educate HIV-positive or AIDS-infected children in mainstream schools. The confusion over *what* AIDS was and, most critically, *how* it spread collided with the dominant stereotypes against homosexuals, minorities and drug users to create a new, stigmatized identity. "The stigmatization of an identity results from a process of social construction that defines certain behaviors, beliefs, or physical characteristics as abnormal or deficient.

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[299] Chi, *Early Response*, 16.
[300] C. Cohen, *Boundaries*, 45.
[301] Ibid., 43.

Marginal groups exist within a societal framework in which one or more of their primary identities has come to signal inherent inferiority."[302] Those most affected early in the AIDS epidemic were doubly stigmatized. Prior to the emergence of AIDS, many of these individuals were already members of a marginalized group based upon their sexuality, race or drug problem. AIDS not only created its own stigma, it seemed to many to further signal these groups "inherent inferiority." As previously marginalized groups, these diverse constituents were now marginalized based upon the same criteria. Marginalization "constrain[ed] the opportunities and rights afforded community members, helping to solidify their secondary status."[303]

The stigmatization of those infected and affected by AIDS as a group unified otherwise diverse constituencies. They shared a common experience as people marginalized by the same social perception and this reinforced the importance of this stigma in defining common interests. When dealing with AIDS, the group's stigma and the limited resources of the populations most infected often limited the opportunities to respond. There were, however, many stigmatized by AIDS who previously belonged to the dominant class. Since the "construction of what is normal evolves over time," many of those first infected with AIDS were white professional men who had sex with other men.[304] These men enjoyed the social and economic privileges inherent in their race, gender and professions and were not necessarily defined by their sexuality, as it was a less obvious characteristic of their identity. The threat of AIDS – whether to themselves or watching a loved one suffer and die – made it impossible to ignore their sexuality. Thus, their identity as homosexuals led

[302] Ibid., 38.
[303] Ibid., 38.
[304] Ibid., 39.

to the stigmatized identity of AIDS. Since AIDS was not categorized as "normal," these men's privileged identities were challenged.[305] This led many white gay men to form organizations at the heart of the AIDS social movement, such as the AIDS Coalition to Unleash Power (ACT UP) and AIDS Project New Haven. Ultimately, however, "these identities would serve as the basis for much of the community mobilization witnessed in response to HIV and AIDS."[306] As demonstrated in New Haven, the movement's strength often lay in pulling together previously diverse identities under the stigmatized social category of AIDS.

Men and women across the country were denied the protection and attention of the dominant institutions in the early years of the epidemic. Subsequently, they took action that would help lay the groundwork for an emerging movement. In 1981, after reading the first *New York Times* article chronicling the disease, gay activist and playwright Larry Kramer held the first AIDS fundraiser in his apartment.[307] ACT UP's New York City chapter was particularly active in public protest and subsequently attacking the political landscape and dominant ideology. As one ACT UP – NY member explained, the members were no longer able to follow the traditional route of lobbying their congressional representative to make progress and thus had to use radical tactics.[308] For example, in 1988 the group sponsored the "'Seize the FDA'" demonstration at the FDA headquarters in Rockville, Maryland.[309] Approximately 1,000 protesters successfully shut down the building by blocking the

[305] Ibid., 39.
[306] Ibid., 40-41.
[307] Frontline, "The Age of AIDS."
[308] P. Cohen, *Love and Anger*, 22.
[309] Ibid., 30.

entrances.[310] Although 176 activists were arrested, the effects were almost immediate; within a year four new AIDS drugs had been licensed by the FDA and four others were available through expanded access programs.[311] The demonstration had other profound effects. The Head of the National Institute of Allergy and Infectious Diseases, Dr. Anthony Fauci, recalls how he "began to get beyond the rhetoric and the theater of the demonstrations….to really listen to what it is they were saying…it became clear to me, quite quickly, that most of what they said made absolute sense, was very logical and needed to be paid attention to. ... Interacting with the constituencies was probably one of the most important things that I had done in my professional career.""[312] Not all of ACT UP's protests were as productive. On December 10, 1989, ACT UP New York held "Stop the Church" day, protesting inside New York City's Saint Patrick's Cathedral.[313] Their actions included "civil disobedience during [Cardinal John] O'Connor's sermon and one activist's crumbling of a communion host."[314]

Less dramatic and less political activities were taking place in New Haven. In addition to the creation of the previously mentioned AIDS service organizations, members of New Haven's branch of ACT UP would loiter outside the discos until they closed, cornering those who were leaving to distribute condoms and educate

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[310] Frontline, "The Age of AIDS."
[311] P. Cohen, *Love and Anger*, 30-31.
[312] Frontline, "The Age of AIDS."
[313] ACT UP-NY specifically chose to interrupt Cardinal O'Connor's sermon to protest the Cardinal's positions on gay rights, abortion and condoms.
[314] P. Cohen, *Love and Anger*, 21.

them about AIDS.[315] Individuals were also illegally distributing syringes to intravenous drug users.[316]

VI. What is a Social Movement?

A social movement must be defined before the activism that resulted from the creation of an AIDS-identity can be called such. In *Political Process and the Development of Black Insurgency, 1930-1970* Doug McAdam defines the political process model of mobilization, which assumes that a social movement is the product of both internal and external factors.[317] Specifically, social movements are an ongoing process of interplay between movement groups and "the larger sociopolitical environment they seek to change."[318]

One component in the emergence of a social movement, McAdam argues, is shifting political conditions. Political opportunities can shift due to an event or social process that challenges the political establishment.[319] These events may either undermine the entire political system or, as in the case with AIDS activism, provide the activists with increased political leverage.[320] In practical terms, these events have improved the activists bargaining power and created new opportunities for the group to pursue their goals.[321] Political opportunities for AIDS activists changed nationally in 1985 with actor Rock Hudson's death from AIDS and the case of Ryan White, whose "guiltless" infection with AIDS brought sympathy to the cause. In later years, the announcement that professional basketball star Magic Johnson was HIV-positive

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[315] Comments, Town Hall Meeting, October 29, 2008.
[316] Interview, October 30, 2008.
[317] Doug McAdam, *Political Process and the Development of Black Insurgency, 1930-1970* (Chicago: University of Chicago Press, 1999), 50.
[318] Ibid., 40.
[319] Ibid., 41.
[320] Ibid., 42.

brought further attention to the cause and pressured political leaders to act.[322] On a smaller scale, events in New Haven shifted political conditions in favor of AIDS activists, such as when Novick brought the alarming shift in the demographics of the most vulnerable population to DiLieto's attention, or when Novick took Daniels on a tour of the AIDS-infected babies at Yale-New Haven Hospital.[323] These events earned the cause of AIDS sympathy with politicians and opened opportunities for activists. Furthermore, activists' increased leverage proportionately increased the cost of repressing them because they have become "a more formidable opponent." Subsequently, repressing the group "involves a greater risk of political reprisal…and is thus less likely to be attempted even in the face of an increased threat to member interests." The increased strength of the movement is also increased because collective action is encouraged as the risks associated with movement participation decrease.[324]

Improved political conditions are only one ingredient necessary for the emergence of a social movement. The marginalized group needs the resources to exploit the increased political opportunities.[325] Activists must "'convert'" the political opportunities into "an organized campaign of social protest" and "indigenous structures frequently provide the organizational base out of which social movements emerge."[326] McAdam argues that these organizations are critical for four crucial

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[321] Ibid., 43.
[322] Interview, October 30, 2008.
[323] Chi, *Early Response*.
[324] McAdam, *Political Process*, 43.
[325] Ibid., 43.
[326] Ibid., 44.

resources they provide activists – members, an established structure of solidarity incentives, a communications network, and community leaders.[327]

Indigenous organizations must first exist before an emerging social movement may draw upon their resources. AIDS activists did have indigenous organizations to rely upon while creating a social movement. In New York City, the movement emerged from such indigenous organizations created by and largely serving gay white men, such as ACT UP and Gay Men's Health Crisis. Activists in Los Angeles relied upon the resources of existing organizations such as AIDS Project Los Angeles, which, like AIDS Project New Haven, was originally founded to serve the gay and lesbian community. In New Haven, the social movement emerged from existing indigenous organizations such as AIDS Project New Haven, AIDS Interfaith Network and Hispanos Unidos.

Members are the basis of any social movement and they are frequently recruited from pre-established formal and informal lines of interaction. Existing organizations provide activists an opportunity to meet and recruit individuals who may already be inclined to join. These organizations may be the foundation of the emerging movement and members may be recruited based upon the organization's association with the movement. Or, members may be absorbed into the movement if the movement is the result of the merger of existing organizations.[328] Both methods of recruitment can be seen in New Haven. Novick and Sabella joined the emerging AIDS social movement after discovering from their friends that a fellow homosexual had acquired AIDS.[329] Similarly, Cofield became involved after another member of

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[327] Ibid., 44.
[328] Ibid., 44-45.
[329] Chi, *Early Response*.

the religious community, a student at Yale University's Divinity School, brought the crisis in the African American community to her attention.[330] At the same time, the movement in New Haven resulted from the unification of various organizations and interests groups in addressing the same disease and coming together formally in the New Haven Mayor's Task Force on AIDS.

The creation of a movement also depends upon the "'established structures of solidarity incentives' provided by indigenous organizations. These incentives are the salient interpersonal rewards that motivate participation in pre-existing organizations."[331] Movement activists can successfully recruit members by appropriating these incentives by equating movement participation with organizational membership and the movement absorbs the rewards previously associated with group participation.[332]

The communications network provided by established community organizations are also critical for an emerging social movement. The network provides an established avenue for dissemination of the movement's ideology and goals to their target population.[333] The strength of the preexisting communication infrastructure is critical to a new movement's expansion and survival; in fact, "the failure of a new movement to take hold and the rapid spread of insurgent action have been credited to the presence or absence of such an infrastructure."[334] The significance of a communication network can be seen in New Haven. For example, in

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[330] Interview, January 26, 2009.
[331] McAdam, *Political Process*, 45.
[332] Ibid., 46.
[333] Ibid., 47.
[334] Ibid., 46.

New Haven, it was Novick's access to the Mayor and his colleagues at Yale that initiated a large-scale response.

Leadership is the last critical resource social movements need from preexisting organizations. These individuals are especially critical – "in the context of political opportunity and widespread discontent there still remains a need for the centralized direction and coordination of recognized leadership."[335] Existing organizations provide established and known leaders who can provide the movement with organization and prestige. Based upon their privileged position within the marginalized community, "it may well be that established leaders are among the first to join a new movement."[336] Organizational leadership played a key role in the AIDS social movement. In New Haven, Novick and Cofield both enjoyed privileged positions within their respective communities and organizations and successfully galvanized their communities and the greater New Haven community to action. In cities such as Los Angeles, the AIDS movement drew on the prestige and influence of celebrities such as Elizabeth Taylor, Elton John and Michael Jackson.[337]

Expanding political opportunities and the existence of indigenous organizations are necessary for the creation of a social movement, but insufficient without the subjective meanings people attach to their situations.[338] Social movements require a majority of the marginalized group to recognize a favorable political landscape and this recognition is more likely to occur in light of "improved political conditions and existent organizations."[339] The political significance may be

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[335] Ibid., 47.
[336] Ibid., 47.
[337] Frontline, "The Age of AIDS."
[338] McAdam, *Political Process*, 48.
[339] Ibid., 48.

obvious; however, when they are less apparent, McAdam claims they "will invariably be made 'available'…through subtle cues communicated by other groups. The expectation is that as conditions shift in favor of a particular challenger, members will display a certain increased symbolic responsiveness."[340] The induced change in "the symbolic content of member/challenger relations, shifting political conditions supply a crucial impetus to the process of cognitive liberation" – the last required component in McAdam's political process of mobilization.[341] This "cognitive liberation" that leads to the development of an insurgent consciousness is assisted by existing organizations "not simply [because of] the extent and speed with which insurgency is spread but the very cognitions on which it depends are conditioned by the strength of the integrative ties within the movement's mass base."[342]

Cognitive liberation is evident in AIDS activism in New Haven and elsewhere. Members of ACT UP-New York shared a belief that the system was not serving them and that radical politics was the solution. They also shared common enemies in institutions such as the Catholic Church and government agencies. While they did not consistently wait for political opportunities, many of their public demonstrations affected government and societal institutions and helped create more favorable political opportunities for later activists. In New Haven, cognitive liberation is seen within the creation of the individual organization and their unified programs. AIDS Interfaith Network, AIDS Project New Haven, and Hispanos Unidos were each indigenous organizations, founded by and originally serving a distinct marginalized community. Their common enemy, however, helped create a group

[340] Ibid., 48-49.
[341] Ibid., 49.
[342] Ibid., 49.

consciousness and belief in the appropriate course of action. The cognitive liberation in New Haven is further evidenced by the inclusion in the Mayor's Task Force on AIDS of nontraditional, occasionally criminal, members. Their group consciousness allowed them to forgo societal norms to solve an urgent medical problem.

VII. How to Characterize the Movement? New Social Movements

Identity is critical to the definition and understanding of new social movements, but these movements do not, as many older social movements tended to do, fall strictly upon class lines. New social movements are often centered on the "collective search for identity" and these are frequently "new or formally weak dimensions of identity."[343] These movements are "focus for [the] individual's" self-definition and movement activity is "a complex mix of the collective and individual confirmation of identity."[344] New social movements also tend to involve "personal and intimate aspects of human life," such as the gay right's movement and the movements in favor of or in opposition to abortion.[345] These movements conceptualize participant's concerns over identity and changes in identity are credited as being "manifestations of macro social change."[346] With new social movements often grounded in identity, participants are not mobilized by economic grievances but are galvanized by "cultural and symbolic issues that are associated with sentiments of belonging to a differentiated social group." As members of a group discriminated against in society, these participants share beliefs, common values and meanings that

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[343] Gusfield, "Reflexivity," 10, Hank Johnston, Enrique Larana and Joseph R Gusfield, "Identities, Grievances," in *New Social Movements* edited by Hank Johnston, Enrique Larana and Joseph R. Gusfield (Philadelphia: Temple University Press, 1994),. *7*-8.
[344] Johnston, Larana and Gusfield, "Identities, Grievances," 7-8.
[345] Ibid., 8.
[346] Scott A. Hunt, Robert D. Benford and David A. Snow, "Identity Fields: Framing Processes and the Social Construction of Movement Identities," in *New Social Movements* edited by Hank Johnston,

are associated with the feeling of being deemed socially different. Additionally, these movements are "likely to have subcultural orientations that challenge the dominant system."[347] Identity cannot be separated from a thorough understanding of new social movements, particularly as new understandings of identity continue to develop in the first decade of the twenty-first century.

New social movements can be understood in terms other than identity. Since they "transcend traditional class divisions and corresponding struggles for control of state and economic institutions," participants are generally connected through "rather diffuse social statuses," such as age or sexual orientation.[348] Their principles are often as diffuse as their socioeconomic backgrounds, as they represent multiple ideas and values while they also tend to have "pragmatic orientations."[349] Unlike their older, traditional social movement counterparts, their actions are focused on "transformations of civil society and life worlds."[350] The decentralized nature of many new social movements means that this movement may be "'acted out' in individual actions rather than through or among mobilized groups" and group mobilizations tend to utilize nonviolent tactics, such as civil disobedience.[351] The formation and centralization of a movement may be helped by a shared "grievance base," something that is common among many of the most frequently discussed new social movements. Johnston notes that when movements are being established, "the

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Enrique Larana and Joseph R. Gusfield (Philadelphia: Temple University Press, 1994), 188.
[347] Johnston, Larana and Gusfield, "Identities, Grievances," 7-10.
[348] Hunt, Benford and Snow, "Identity Fields," 188, Johnston, Larana and Gusfield, "Identities, Grievances," 6.
[349] Johnston, Larana and Gusfield, "Identities, Grievances," 6-7.
[350] Hunt, Benford and Snow, "Identity Fields," 188.
[351] Johnston, Larana and Gusfield, "Identities, Grievances," 7-8.

collective expression of grievances represents the emergency of collectivity-cum-movement and a primary source of initial coordination."[352]

Identity played a key role in the emergence of an HIV/AIDS social movement in New Haven. New social movements are grounded in a search for identity, particularly for a better understanding of a new or formerly weak aspect of a one's self-conception. This is evident in the emergence of one of the movement's central organizations, AIDS Project New Haven. As the first AIDS service organization in New Haven, AIDS Project New Haven essentially kicked off what would evolve into a social movement, and the creation of this organization was intimately related to the strengthening of a formerly weak aspect of the founder's identity – his homosexuality. The creation of the organization also involves, like many new social movements, the intimate part of participants life, as Novick, a gay man, was driven by concerns over the health and safety of his homosexual friends.[353] AIDS Project New Haven allowed Novick and his friends a place not only to deal with their homosexuality, a component of their character already deemed deviant by society at large, but confront the possibility of contracting a terminal and stigmatizing disease. It is this new identity, or potential identity – that of an infected or affected individual – that, in part, drove the creation of all three of the movement's organizations.

These organizations were founded in the 1980s, when their mere existence, as previously shown, often challenged the dominant system, a common characteristic of new social movements.[354] Two of these organizations - AIDS Interfaith Network and Hispanos Unidos - addressed HIV/AIDS when their respective subcultures adopted

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[352] Johnston, "New Social Movements and Old Regional Nationalism," 284.
[353] Chi, *Early Response*.
[354] Johnston, Larana and Gusfield, "Identities, Grievances," 7-8.

the same discriminating stance toward the issue as was seen in the public at large. Cofield, for example, faced resistance from leaders in the black church community, a community where she was known due to her husband's role as minister at Emanuel Baptist Church, from other church leaders who refused to shake the hands of, or even bury, HIV/AIDS infected parishioners. The founders of Hispanos Unidos faced even greater hostility from their peers in the Hispanic community, who often refused to even acknowledge that HIV/AIDS could be, and already was, an issue within their community.[355] Yet these organization's founders pushed on, despite the risk of being stigmatized by the specific subcultures they meant to serve. Their work affected the dominant values and norms within their own subculture and the community at large. Cofield convinced the leaders in the black churches, and in other various churches in the area, that HIV/AIDS was an issue, that people needed to be served and it was their obligation to do so.[356] Additionally, as a member of the Mayor's Task Force on AIDS, she helped convince the Board of Alderman and the School Board to distribute condoms.[357] Hispanos Unidos focused on challenging the dominant beliefs within the Hispanic community; it is a community that continues to be difficult to serve, but the organization's mere existence reminds the Hispanic community that they are at risk and there is an organization to serve them. Although AIDS Project New Haven aimed specifically to target the area's homosexual population, they greatly influenced the community by their establishment as the first AIDS service organization in Connecticut and by bringing HIV/AIDS to the attention of the city government. It was Novick's influence that prompted DiLieto to address the politically hot topic

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[355] Chi, *Early Response*.
[356] Chi, *Early Response*, Interview January 26, 2009.
[357] Interview, January 26, 2009, Chi, *Early Response.*

with the creation of the Mayor's Task Force on AIDS, which ultimately influenced Mayor Daniels to take on the even riskier idea of needle exchange in New Haven.

In their often unintentional quest to challenge the dominant culture through service to those in need, these organizations were joined by common beliefs and values. Early in their existences, when many of those infected and affected were homosexuals or intravenous drug users, these organizations shared a mentality that these were not deviants but individuals that needed to be served. When asked about how she reconciled her Christian faith with Biblical stances towards homosexuality and the immoral perception of drug abuse, Cofield was quick to answer – "I never even thought about it. All I thought about was these people who needed help. I've never thought about who was gay and who wasn't or who had AIDS because of sex or drugs."[358] AIDS Project New Haven, founded by a group of homosexual men, easily reached out to the needs they saw within the homosexual community, but even Novick noted a changed mentality when it became apparent that the disease had hit minority intravenous drug users especially hard. He recalled his response, upon learning that the demographics had shifted significantly – "'this is a population of people that we don't serve. Except to hate them. And to stigmatize and to ostracize them.'" Yet his reaction did not merely end with an evaluation of the troubled population; instead he noted how society had "neglected them in health care, and now we'll certainly neglect them in prevention and care services. So it's crucial that we move!'"[359] Thus, Novick overcame the perception of the new demographic as deviants. Like Cofield, Novick focused on the need to serve. Novick also

[358] Interview, January 26, 2009.
[359] Chi, *Early Response*, 20.

acknowledged that this new group of infected and at-risk citizens would be particularly challenging for AIDS Project New Haven to serve; instead, he went to Mayor DiLieto to explain the development, leading to the creation of the New Haven Mayor's Task Force on AIDS.[360]

The shared beliefs and values are especially evident in the early work of the Mayor's Task Force on AIDS. All the founders of the city's AIDS service organizations sat on the first Mayor's Task Force and contributed to a comprehensive report the Task Force issued in January 1987, reporting on the status of HIV/AIDS in New Haven. The report did not recommend that police further efforts to crack down on intravenous drug use. They emphasized the need to address the needs of those infected and, perhaps more importantly, work to protect and educate the largely marginalized population that was most at risk. Specifically, they urged the creation of a team of outreach workers to hit the streets to find and help those most at risk. This report also brought to the government's attention, specifically the attention of the Board of Aldermen, the need to establish an AIDS Division to further address the needs of often overlooked and scorned populations.[361] Thus these were organizations founded not to judge their clients or reinforce the predominantly negative image of HIV/AIDS patients. They shared a foundation of acceptance and a desire to help those infected, affected and at risk with the belief that these people were to be valued as much as anyone else, and the shared hope that their efforts could curb the spread of HIV/AIDS in New Haven.

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[360] Ibid., 20-21.
[361] Ibid., 22.

While New Haven's individual AIDS service organizations were founded on shared identities among the founders and most of their initial clients, the social movement as a whole is composed of a variety of socioeconomic and racial backgrounds, all of which influenced the movement. Instead, this movement was unified by common values and beliefs, as well as a shared complaint that their specific subcultures and communities had not adequately addressed the unfolding crisis. A quick glance at the founders and original clientele of these major organizations reveals no commonality aside from frustration over the lack of the community's response to HIV/AIDS. As was previously discussed, the founders of AIDS Project New Haven were gay white professional men, and their status as white men allowed them implicit social privileges that were unavailable to other organizations. Additionally, their original board of directors was composed of fellow professionals with a special interest in HIV/AIDS.[362] In contrast, Cofield, the wife of a minister of a major black church, did not enjoy the same social privileges. Much of her staff and volunteers in the beginning were parishioners at her husband's church and they served the young and financially disadvantaged – often, in the early days, Cofield would face the difficulty of finding the funds to arrange a client's burial.[363] Hispanos Unidos shared AIDS Interfaith Network's lack of social capital, as the Hispanic founders dealt with a hostile Hispanic community and the challenges of working not only with a language barrier but addressing the tricky dance of properly serving a community of undocumented workers.[364] These distinct lines have, to some extent, blurred as the epidemic has evolved and the organizations have solidified a

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[362] Chi, *Early Response*.
[363] Interview, January 26, 2009.
[364] Interview, January 14, 2009.

partnership, particularly the distinct socioeconomic and racial boundaries that dominated AIDS Project New Haven and AIDS Interfaith Network's early days.[365] Yet, the HIV/AIDS movement in New Haven remains a movement of devout Christians, recovering drug addicts, urban and suburban professionals, homosexuals and multiple ethnicities. This is a diverse group unified by priceless intangibles.

From their diverse backgrounds, these organizations were formed and a social movement coalesced around the belief that not enough was being done within their communities and the community at large regarding HIV/AIDS. Cofield recalls how people were dying and no one was doing anything about it. Novick and Sabella began their organization at the urging of friends who told them how white male urban professionals were dying, but healthcare and educational services were lacking.[366] Hispanos Unidos meant to address the Hispanic community's resistance to acknowledging and learning about the epidemic as well as addressing the barriers to treatment.[367] The Mayor's Task Force on AIDS, a focal point of the social movement and the tangible manifestation of the organization's partnerships, also shared the grievances of the organization's founders. Outside of the founders of the city's AIDS service organizations, other members of the original Mayor's Task Force included a high-ranking employee of the Health Department.[368] The former Health Department employee recognized that the epidemic would be overwhelming and that a new division within the Department was needed to channel all the resources, funding, staff and expertise needed to properly address HIV/AIDS.[369] Thus, in the context of a mid-

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[365] Interview, October 24, 2008, Interview, October 23, 2009.
[366] Interview, January 26, 2009, Chi, *Early Response*, 8.
[367] Interview, January 26, 2009, Chi, *Early Response*, 8, 27.
[368] Interview, October 30, 2008.
[369] Ibid.

sized city struggling under the weight of a potential health disaster, social differences were successfully pushed aside and these unique individuals and specifically tailored groups joined together against a common enemy with a shared set of values and complaints.

New Haven's AIDS service organizations provided their clients with a forum for the validation of a joint identity. Novick and his homosexual friends found validation and support for their identity as at-risk, infected or affected individuals through the formation of AIDS Project New Haven. The organization's initial focus on homosexuals in the New Haven community provided other gay men and women in the community a non-judgmental source of crucial information. They also provided these at-risk, infected and affected individuals with a support group of those who faced the same social stigmas. Clients can find the same safe space for confirmation of identity at AIDS Interfaith Network. As one case worker explained, their clients are spread across race and socioeconomic background. Frequently, their middle class clients will visit to donate goods or funds and to be around other people facing the same medical and social implications of HIV/AIDS.[370]

VIII. Conclusion

New Haven's response to HIV/AIDS can be considered a new social movement under the umbrella of the AIDS movement that emerged nationally. The movement formed in response to a disease that forced many to reconsider their identity or feel that their identity, whether individually or their identification with a specific group, was threatened. The identities of many of the most vulnerable populations, specifically homosexuals, were openly threatened during the first years

of the epidemic, not only by AIDS but by the dominant political coalition. The pressure of facing a mysterious disease and the hostile political environment helped solidify the activists' identity as people infected or affected by AIDS. The creation of this identity brought together multiple constituencies and helped define the emerging social movement.

The movement in New Haven was grounded in three indigenous organizations, each of which originally began to serve a particular aspect of their client's identity. Despite the distinct groups they initially targeted, the organizations worked together, in conjunction with the city government, based upon a shared set of beliefs and goals. Every major figure within the movement witnessed first hand how the epidemic affected citizens of New Haven, and everyone involved acknowledged that HIV/AIDS was not an issue of politics or culture. Instead, they viewed HIV/AIDS as a medical issue that permeated multiple aspects of people's lives. These organizations and city departments were already bound by a shared belief that there was a need and people needed information and services. The movement's identity-based concerns, along with their explicit focus on providing services based upon a shared understanding and common set of beliefs, fulfill the guidelines of the abovementioned understanding of new social movements.

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[370] Interview, October 24, 2008.

Conclusion

Why is New Haven's reaction to HIV/AIDS important? The city is anchored to New York City by more than the eighty mile Metro-North Railroad track that runs between them. The disease originally appeared in New York City in 1981; however, New Haven instituted a successful program to address AIDS earlier than New York City. The city's response saved lives within city limits and laid the groundwork for a strategy that could be replicated elsewhere with financial and public health benefits.

The discussion of AIDS policy in New Haven began with the complex issue of race. The demographics of the disease in New Haven are similar to the diseases' demographics in other urban areas. The connection between race and socioeconomic status are evident in the statistics of the disease, demonstrating that it is predominantly the least empowered who are most impacted. Race influenced the private response to the disease, including the particulars of the city's primary AIDS service organizations. Organizations were founded to target specific, marginalized communities. While they successfully reached their designated clientele, their exclusive focus could also be a shortcoming. For example, AIDS Project New Haven's original focus on homosexual men left the organization unable to properly address the epidemic as it began to infect intravenous drug users and African Americans.

There are distinct racial trends in the public arena. White professionals, especially within city agencies, worked to compensate for racial and cultural differences. These professionals acknowledged the cultural barriers between themselves and their minority clients. They hired employees from within the minority

community and specifically designed organizations to serve the city's minorities. New Haven's experience further shows that the difficulties in addressing race are also evident in the suspicions many minority groups have of HIV/AIDS, particularly in the beginning of the epidemic. There is an additional difficulty in targeting these populations due to the misconceptions specific minority groups have of other minority groups.

An examination of the role of the city government demonstrates the importance of considering AIDS in terms of public health policy as opposed to any legal or moral implications associated with mode of transmission or impacted population. The city government's response was successful due to an inclusive, multilateral governmental solution. In New Haven, this included cooperation between the Police Department, the Department of Health and the Mayor's Office. The city's success demonstrates that this collaboration is possible when all the relevant departments focus on community health. The actions of former Mayor Biagio DiLieto also indicate that politicians can adopt a hands-off approach to AIDS while still being effective. While there is little evidence of DiLieto's involvement in the Mayor's Task Force on AIDS that he created, his acceptance that AIDS needed to be addressed and his decision to entrust the matter with a knowledgeable professional allowed him to initiate a city response. Ultimately, DiLieto's decision to trust the city's AIDS policy not to politicians but professionals removed AIDS from politics. By neutralizing AIDS as a political issue, the city government was in a better position to properly respond to the disease.

The last chapter discusses the political and social context of the 1980s. There is a discussion of social movements as a whole and considers the actions in New

Haven in light of this definition. New Haven demonstrates how social movements can occur when diverse constituencies unite in the face of a common challenge. It also shows how a social movement can successfully align with the local government.

What can be taken away from the experience in New Haven? What is most apparent is that race matters, and not only demographically. Race's significance is unremarkable; what is noteworthy is how and why it matters. Race has previously been shown to influence who is infected with the disease. In New Haven, however, it has shown an impact on who addresses the epidemic. White professionals were aware that they lacked the cultural sensitivity to reach several of the most vulnerable populations. This leads to the discovery that race impacts the most effective means to reach an at-risk population. Since race influences both who is involved and the means of serving the community, it logically follows that ethnicity also influences the development of specific AIDS organizations. Although each specific organization fights the same general enemy, the tools and general approach are notably different.

This leads to a larger, more significant implication. The experiences in New Haven demonstrate that the most effective solution comes from within the targeted community. This is demonstrated by the success of New Haven's AIDS service organizations. A more powerful illustration is the design of the city's needle exchange program. The city had the benefit of learning from New York City's failed attempt at needle exchange, but this was not the ultimate strength of their program. New Haven utilized case workers to survey drug addicts to learn why they shared needles and what incentives they could provide to stop the practice. Even more remarkable is the inclusion of former drug users and those who had illegally distributed needles on the committees that planned the needle exchange program.

The other enduring lesson from New Haven's policy and programs is that the most effective way to address HIV/AIDS is to remove the politics and consider the epidemic a public health issue. DiLieto's actions in the early 1980's demonstrate that this can be accomplished. Former Police Chief Pastore's philosophy that needle exchange could *assist* police in their efforts to keep their constituents safe further supports the fact that AIDS can be addressed in an apolitical fashion. This is based upon a multilateral acceptance that AIDS was not a matter of morals, politics or legality and that it was in the best interest of the community, particularly those most vulnerable, to focus on public health.

New Haven's actions have significant implications on an understanding of AIDS and provide a design for a comprehensive, successful response to the disease.

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