

A TANGLED PATHOLOGY:
HOW AIDS BECAME A “FAMILY DISEASE” IN NEWARK, NEW JERSEY

1970-1997

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Abstract

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As AIDS proliferated in Newark, New Jersey through the 1980s, local AIDS-care advocates conceptualized AIDS in ways that reflected the disease’s impact on Newarkers. In reframing a problem that was predominately cast as a “gay disease” in North America, AIDS activists in Newark sought to highlight the growing prevalence of HIV and AIDS among urban communities of color. These efforts sought to direct national attention and resources towards affected “at risk” Newarkers by self-consciously portraying HIV and AIDS as a disease of the family. The lynchpin in this discourse was the pediatric AIDS patient. Discussions of HIV-positive children, and the “family disease” frame, became normalizing shorthand for addressing the complex biological transmission of the disease. By the late 1980s, advocates for Newark recognized the political utility in characterizing AIDS as a family disease at a time when the federal government was preparing to allocate funds for the areas hardest hit by the epidemic. This unique discourse was particularly useful in not only drawing attention to the problem of AIDS, but also to the societal “ills” associated with the disease’s prevalence among impoverished communities of color in Newark. As the family disease discourse evolved, Newark came to represent the ubiquitous, albeit insidious, urban problems that contributed to and exacerbated the

epidemic in similar U.S. cities. Reserved almost exclusively to descriptions of families of color, the family disease discourse must be understood as—an implicit, if not explicit—response to mainstream perceptions of the inner city. Efforts to cope with AIDS in Newark benefited from the family disease script. Yet the legacy of the family disease discourse perhaps further encumbered cultural perceptions of inner city families as well. The family disease discourse thus inextricably linked the AIDS epidemic in impoverished communities color, and inner city families, to the pernicious social pathologies narrative that had over-determined perceptions of Newark since the late 1960s.

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On December 8, 1989, five-year-old Cynthia Givens died from complications due to AIDS. Cynthia was in Newark's Children's Hospital for ten weeks before she returned to her foster home, where she passed away in her sleep. Cynthia had been the poster child for the Urban League's Pediatric AIDS Foster Care program: she appeared on local public service announcements, which spoke of both the Urban League's program and the problem of orphaned AIDS children like her. Cynthia also represented one of thousands of children of color infected with HIV and AIDS in the United States by the end of the 1980s. Cynthia's life with, and death from, AIDS was also symbolic in highlighting the fact that AIDS among children was fast becoming a tragic complication of entrenched neglect in American cities—particularly where the majority of citizens were people of color. Newark, New Jersey, the city in which she lived, saw “one out of 22 babies born” with the disease.¹ In many ways, Cynthia's story stands as a microcosm for the AIDS epidemic in poor urban communities of color in the 1980s and 1990s. Her story elucidated how these communities remained vulnerable to the conditions of the inner city. Perceptions of “neglect,” as well as health care and socioeconomic disparities, implicitly framed Cynthia's story. Yet her story is perhaps further instructive. Cynthia's situation, like that of other high profile pediatric AIDS patients, came to symbolize, in Newark and other cities, a normalizing narrative through which the AIDS epidemic could be constructively discussed in impoverished urban communities of color.

The HIV-positive child undoubtedly epitomized the “innocent victims” of the AIDS epidemic during the 1980s and 1990s. Advocates for these children often cast them

¹ Janice Phipps, “Girl star of AIDS public service ads dies at age 5,” *Star-Ledger*, December 9, 1989. The conditions of Cynthia's abandonment were not detailed in the article.

as innocent victims of long intractable social ills that were fueling the spread of AIDS in urban America. Depending on who you asked, those “ills” included not only AIDS, but also poverty, illicit drug use, inadequate health care services, and the pervasive misinformation and denial that accompanied each of these subjects. How the “problems” of impoverished cities intersected with minority populations affected by HIV quickly emerged as the dominant theme surrounding Newark’s AIDS epidemic. Within such conversations, the presence of the HIV-positive child, perhaps more than any class of affected individual, factored prominently in how the disease was framed within these communities because it allowed for a public discourse about AIDS, and the social determinates of health among urban families of color.²

By the late 1980s, advocates for cities like Newark characterized AIDS as a disease of the family, and the lynchpin in such descriptions was the pediatric AIDS patient. Towards the end of the decade, the AIDS epidemic among African Americans and Hispanics garnered national attention.³ In 1989, Wayne Duncan, who was a coordinator for the National Minority Outreach Initiative Grant Program, at the Centers for Disease Control (CDC), overtly expressed Newark’s “distinctive” AIDS-related phenomenon. “In cities like Newark,” Duncan pointed out, “AIDS has become a disease of the family... We’re talking about women, children, men. It’s not skipping over anyone.” Duncan’s remarks encapsulated a growing discourse, which emerged in the

² This is informed by Cathy Cohen’s *The Boundaries of Blackness: Aids and the Breakdown of Black Politics* (Chicago: University of Chicago Press, 1999).

³ Cohen, *The Boundaries of Blackness*, 105; Daniel Fox, “The Politics of HIV Infection: 1989-1990 as Years of Change,” in *AIDS: The Making of a Chronic Disease*, ed. Elizabeth Fee and Daniel M. Fox (Berkeley: University of California Press, 1992), 125-143.

1980s, that sought to delineate the “unique” difference in the epidemiology and demographics of the disease among impoverished urban communities of color. Such efforts often described the disease’s prevalence in these communities as affecting “mainly drug addicts [IV drug users], their sexual partners and babies,” rather than “homosexual men.” Descriptions of “AIDS as a family disease” thus represented for some an explanatory device for both the affects HIV and AIDS had on urban communities of color, as well as the social ills, particularly IV drug use, associated with the disease’s prevalence.⁴ The IV drug user permeated the subtext of this new AIDS discourse. For many AIDS-advocates, the IV drug user was a critical vector of HIV infection among families of color. The family disease narrative sought, in part, to address this pernicious and intractable HIV/AIDS-related problem.

The rise and eventual decline of the family disease discourse became ensnared in culturally and politically complicated discussions of the AIDS epidemic’s relationship to purported urban problems. The history of this unique discourse ultimately reveals the benefits and limitations in casting HIV and AIDS as a family disease among urban communities of color.⁵ The evolution of the family disease frame began in the early

⁴ Lena Williams, “Inner City under Siege,” *The New York Times*, February 6, 1989.

⁵ Historical understanding of the family disease frame offers an additional perspective to the already rich historiography that focused on “disease models” in order to contextualize the AIDS epidemic. Brandt clearly deploys the venereal disease model of analysis for AIDS: “AIDS makes explicit, as few disease could, the complex interaction of social, cultural, and biological forces. Given the social history of venereal disease in the United States, this is hardly surprising.” Allan Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880* (Oxford: Oxford University Press, 1987), 163; 147-168 “AIDS is not syphilis, and the historical moment has shifted. But one thing is certain: The response to AIDS, as can already be seen, will not be determined strictly by the disease’s biological character; rather, that response will be deeply influenced by our social and cultural understanding of disease and its victims,” 163; Allan Brandt, “The Syphilis Epidemic and its Relation to AIDS” *Science*, New Series, Vol. 239, No. 4838 (Jan. 22, 1988), pp. 375-380; Gilman, Sander L. *Disease and Representation: Images of Illness from Madness to AIDS* (Ithaca: Cornell University Press, 1988.), 245-271; Rosenberg, “What is an Epidemic? AIDS in Historical Perspective,” *Explaining Epidemics and Other Studies in the History of Medicine* (Cambridge ; New York: Cambridge University Press, 1992), 278-292; Elizabeth Fee “Sin Versus Science:

1980s when medical researchers and physicians in Newark and other cities identified their first pediatric AIDS cases among families of color.⁶ As the disease began to proliferate in Newark through the 1980s, health care professionals, politicians, public health officials, AIDS advocates, and public health policy-makers, began to conceptualize and describe HIV and AIDS as a disease of the family in explicit terms. The family disease discourse also factored prominently in the changing politics, public health agendas, AIDS advocacy, and medical decision-making that surrounded the disease in the late 1980s and early 1990s. The infected child, and the “family,” thus became politically potent shorthand for those trying to communicate, navigate, and address both the complex biological transmission of the disease, as well as highly stigmatized individuals seen as closely associated with the spread of the HIV. During this period, the family disease narrative proved successful in raising AIDS awareness in urban

Venereal Disease in Twentieth-Century Baltimore,” in Elizabeth Fee and Daniel M. Fox. *AIDS: The Burdens of History* (Berkeley: University of California Press, 1988); David. McBride, *From TB to AIDS: Epidemics among Urban Blacks since 1900* (Albany: State University of New York Press, 1991). With respect to the racialization of disease and framing of disease, this work is informed, in part, by the following scholarship: Keith Wailoo’s, *Dying in the City of the Blues: Sickle Cell Anemia and the Politics of Race and Health*, (Chapel Hill: University of North Carolina Press, 2001) and *How Cancer Crossed the Color Line* (Oxford: Oxford University Press, 2011); Samuel Roberts’, *Infectious Fear: Politics, Disease, and the Health Effects of Segregation*, Studies in Social Medicine (Chapel Hill: University of North Carolina Press, 2009); Jonathan Metzl’s *The Protest Psychosis: How Schizophrenia Became a Black Disease* (Boston, MA: Beacon Press, 2009).

⁶ The framing disease interpretive perspective is derived from Charles Rosenberg’s “Framing Disease: Illness, Society and History,” *Framing Disease: Studies in Cultural History* eds. Charles Rosenberg and Janet Golden (New Brunswick: Rutgers University Press). The essay is also found in Charles Rosenberg, *Explaining Epidemics*, 305-318. The original essay, “Disease in History: Frames and Framers,” appeared in *The Milbank Quarterly*, Vol. 67, Suppl. 1, (1989). Rosenberg avoided using the social construction of disease terminology in the essay and chose “less programmatically charged metaphor ‘frame’ rather than ‘construct’ to describe the fashioning of explanatory and classificatory schemes of particular diseases. Biology, significantly, often shapes the variety of choices available to societies in framing conceptual and institutional responses to disease; tuberculosis and cholera, for example, offer different pictures to frame for a society’s would-be framers.” (XV)

communities of color, and it aided in the acquisition of resources to help mitigate the effects of the disease. However, within the context of new AIDS medications and the calls by AIDS advocates for statewide needle exchange programs in the mid to late 1990s, the family disease frame would eventually lose its political usefulness. More importantly, this framing was almost exclusively reserved to descriptions of HIV and AIDS-related issues in Newark's communities of color. Although those who adopted the family disease language did not speak specifically in terms of social pathologies, this unique AIDS discourse further reveals how the real and imagined cultural and social perceptions of the urban environment became inseparable from discussions surrounding how AIDS in cities like Newark affected families of color.

Newark's "Urban Decline" and the Roots of the Social Pathologies Narrative

In the decades before the first reported cases of AIDS, Newark experienced a period of drastic change. Newark grew from a Puritan village in 1666, into a hub for manufacturing during and after the industrial revolution. However, during the 20th century, Newark encountered a "perfect storm" of "urban troubles." According to the journalist Brad R. Tuttle, Newark experienced "deeply entrenched corruption, industrial abandonment, white flight, racial conflict, soaring crime rates, fiscal insolvency, [and] dire poverty."⁷ These phenomena were exacerbated after the 1967 civil unrest and, by the

⁷ Brad R. Tuttle, *How Newark Became Newark: The Rise Fall and Rebirth of an American City* (New Brunswick: Rutgers University Press, 2009), 11.

1970s, Newark had hit “rock bottom.”⁸ During the 1970s, it became clear that years of urban neglect had taken its toll on Newark’s communities of color. This resulted in intractable social “ills,” such as poverty, drug use, and social dislocation that came to characterize Newark’s image during this era. For Tuttle, Newark’s “urban jungle” image was the byproduct of inner city blight, “distorted media coverage,” and mainstream perceptions of the city’s communities of color.⁹

Such urban declension narratives factored prominently in the response to AIDS in Newark. Many of the entrenched problems and racialized inequalities of the late 1960s and 1970s persisted as the AIDS epidemic emerged in Newark. As AIDS advocates began responding to the epidemic they grafted the problem of AIDS onto this preexisting urban decline story. Discussions of the intractability of HIV and AIDS were thus intermingled with discussions of the intractability of urban problems, which predated the epidemic, and later became associated with the disease’s prevalence. Here, urban landscape in cities like Newark came to represent the “diseased” environment in which AIDS would flourish and affect communities of color.

During most of the 20th century, people of color in Newark, especially African Americans, were encumbered by neglect. As African Americans migrated from the South during the first half of the century in search of the “promise land,” they quickly found themselves underemployed and concentrated in urban slums. This phenomenon became

⁸ Tuttle, *How Newark Became Newark*, 9. For 1967 rebellion in Newark see, for example, Kevin Mumford, *Newark: A History of Race, Rights, and Riots in America* (New York: New York University Press, 2007); Komozi Woodard, *A Nation Within a Nation: Amiri Baraka (LeRoi Jones) & Black Power Politics* (Chapel Hill: University of North Carolina Press, 1999); Tom Hayden, *Rebellion in Newark: Official Violence and Ghetto Response* (New York: Vintage Books, 1967).

⁹ Tuttle, *How Newark Became Newark*, 213.

more pronounced between 1945 and 1970. These conditions, historian Kenneth Jackson argued, were due in part to the "inferior quality and segregation of housing and persistent discrimination in employment."¹⁰ These conditions were not unique to Newark, however. The city's post-war problems were part of a larger urban-American declination narrative, which historians and journalists have stressed. Historian Thomas J. Sugrue argued that "the bleak landscape and unremitting poverty of Detroit in the 1970s and 1980s are the legacies of the transformation of the city's economy in the wake of World War II, and the politics and culture of race that have their origins in...housing and workplace discrimination of the postwar decades."¹¹ This characterization, as Tuttle and others have argued, applied to Newark as well by the 1970s. During this decade unemployment rose, non-Newark residents held two-thirds of jobs in the city, public education slumped, and Newark was rated as having some of the poorest housing conditions in the country. In addition, Newark lost 50,000 residents between 1970s and 1980.¹² The seemingly insurmountable set of social, economic, and political issues facing communities of color in Newark, Detroit, and other American cities became a particularly contentious issue as advocates for these communities provided analyses regarding the perceived underlying problems of the inner city.

¹⁰ Kenneth Jackson, "The Black Experience in Newark: The Growth of the Ghetto, 1870-1970.," *New Jersey Since 1860: New Findings and Interpretations*, William C. Wright ed. Papers Presented at the Third Annual New Jersey History Symposium-1971, 36-56; quotes on 55 and 37 respectively.

¹¹ Thomas Sugrue *Origins of the Urban Crisis: Race and Inequality in Postwar Detroit* (Princeton: Princeton University Press, 1996); quote from 271. For racial discrimination in Newark's housing see also Mumford, *Newark*, 51-75.

¹² Tuttle, *How Newark Became Newark*, 212-213.

Mainstream conceptualizations of inner city communities of color factored in efforts to address and understand the growing problems during the post-war period. In 1965, Patrick Moynihan, a sociologist and Assistant Secretary of Labor in the Lyndon Johnson administration, provided his analyses of the problems urban African American families faced in a controversial report: *The Negro Family: The Case for National Actions* (or simply the Moynihan Report). In the report, Moynihan interpreted the historical and sociological factors that led to the impoverished conditions in these communities. Speaking specifically about the certain social ills that intersected African American families in the 1960s, Moynihan claimed that a “tangle of pathology” led to the “deterioration” of black communities in the United States.

Central to Moynihan's “tangle of pathology” assessment was the assumption that African American families were unstable and that federal intervention was necessary. According to Moynihan, a number of conditions and social pathologies—such as poverty, unstable marriages, illegitimate pregnancies, crime, drug use, under employment, “absent fathers,” and female-headed households—were some of the factors underlying the dislocation of black communities. “At the center of the tangle of pathology,” Moynihan wrote, “is the weakness of the family structure.” Moynihan attempted to explain how racial segregation, and discrimination, coupled with unemployment in the black community ultimately weakened the family structure. Yet his culturally insensitive approach characterized the African American family as culpable in the persistence of the social pathologies that led to the declining conditions these communities faced by the end of the 1960s. Such perceptions of inner city communities of color engendered a cultural

and political backlash towards Moynihan and his report—which remained a contentious topic for decades after the release of the Report.¹³

In this respect, Moynihan’s analysis of African American families represented a particularly salient cultural artifact that demonstrated how certain advocates came to view people of color in post-World War II urban environments. The legacy of Moynihan’s assessment of the African American family loomed large in the construction of the family disease discourse. The Report represented a marker, a script, by which the real and imagined conditions of urban black America were understood, perceived, and discussed since the mid-1960s. In many ways, The Report channeled mainstream social and cultural interpretations of urban families of color. Such interpretations persisted decades after Moynihan’s analysis was made public—as did critiques of these cultural assumptions about urban populations of color. Though many were compelled to discuss how certain social pathologies have intersected inner city families of color, such perceptions seemed inadequate when discussing urban problems in the age of AIDS.

Moynihan’s analysis, however well intentioned, elucidated the cultural shortsightedness present in such “outsider” advocacy related to growing concerns of urban neglect in America. As cultural, political, and social critiques of the Moynihan Report continued into the late 1960s, urban neglect persisted in cities like Newark. Yet if there was a silver lining to the seemingly insurmountable set of social and socioeconomic

¹³ Lee Rainwater and William L. Yancey, *The Moynihan Report and the Politics of Controversy; a Trans-Action Social Science and Public Policy Report* (Cambridge, Mass.: M. I. T. Press, 1967), 47-93; quote on 78. Douglass S. Massey and Robert J. Sampson “Moynihan Redux: Legacies and Lessons” *The Annals of the American Academy of Political Science*, 621 (January 2009), 10-12; Michael Katz, “Underclass as Metaphor” in *The Under Class Debate*, ed. Michael B. Katz, (Princeton: Princeton University Press, 1993), 13; William J. Wilson, *The Truly Disadvantaged: The Inner City, the Underclass, and Public Policy*. (Chicago: University of Chicago Press, 1987), 20; James T. Patterson *Freedom is Not Enough: The Moynihan Report and America’s Struggle over Black Family Life—From LBJ to Obama* (New York: Basic Books, 2010) 145-165.

issues facing African Americans and Hispanics in Newark, it was the emergence of grassroots political change that took place in the late 1960s and early 1970s.

In Newark, a combination of political activism and community passion for political change led to the election of the city's first black mayor, Kenneth Gibson (1970-1986). The election of Gibson was due in part to the emerging black empowerment movement that sought to challenge, and change, the predominantly white power structures and institutional racism in the city. This grassroots political movement, with the help of local leaders such as Imamu Amiri Baraka created enthusiasm for political change.¹⁴ According to the historian Komozi Woodard, "Black self-determination was the fruit of the Black Power experiment in Newark; it reflected the political consciousness of masses of African American and Puerto Rican people mobilized in a life-and-death struggle against white racism and internal colonialism." In addition to influencing the polity of the city, these grassroots leaders, Woodard argued, strived to "develop parallel black institutions in the void left by the urban crisis, emphasizing the failure of the American government and mainstream economy in providing basic services."¹⁵ However, the political triumph and fervor surrounding the election of the city's first black mayor was short lived.

By the mid-1970s and early 1980s, efforts by elected and non-elected African Americans leaders faltered in the wake of racial strife, political impasse, and the intractable structural problems in the city. By 1974, efforts of Black Power leaders essentially "inherited" the problems of the inner city, which made grassroots efforts to

¹⁴ Woodard, *A Nation Within a Nation*, 2-44.

¹⁵ *Ibid.*, 91-217; quotes on 153 and 8 respectively.

improve the living conditions for people of color more difficult—if not improbable.

"Consider the grotesque logic," Woodard posits, "suburban whites have abandoned the cities and then assigned black and Latinos the awesome responsibility for healing urban decay."¹⁶ By the end of the 1970s, the city's finances were dwindling. Gibson sought outside state and federal funds to help keep Newark afloat. In an effort to "improve" the city—and the image of the city—Gibson instituted "urban renewal projects" such as the construction of I-78 and improvements to the downtown business district. These efforts, however, did little in improving the overall condition of the city. The construction of a major highway through sections of Newark resulted in the loss of "thousands" of homes, and created neighborhood dislocation.¹⁷ The AIDS epidemic entered Newark during this continued period of urban problems.

The social dislocation in Newark's minority communities, underscored by intractable poverty, set the stage for a number of issues related to the emergence of the AIDS epidemic in the city during the 1980s. The attenuated community and socioeconomic structures in the city provided the basis for the prevalence of IV drug use such as heroin—perceived as a pernicious culprit in the inner city AIDS epidemic.¹⁸ According to historian Caroline Acker, structural change in the urban landscape such as “residential segregation,” concentrated poverty, neighborhood-dislocation, and urban

¹⁶ Woodard, *A Nation Within a Nation*, 220-254; quote on 263.

¹⁷ Tuttle, *How Newark Became Newark*, 212-213

¹⁸ Charles Perrow and Mauro F. Guillen, *The AIDS Disaster: The Failure of Organizations in New York and the Nation* (New Haven: Yale University Press, 1990), 91.

renewal created, in part, “natural sites for the sale of illicit commodities like heroin.”¹⁹ The relatively easy access to drugs, such as heroin, which combined, Acker states, with “structural barriers to economic opportunity, encouraged generations lacking significant career prospects,” ultimately led to the high prevalence of AIDS in African American communities. For cities like Newark, IV drug use became the “hub” of the disease’s transmission, particularly among women and newborn children.²⁰ The prevalence of IV drug use represented one of many social systems that was intertwined with the emergence and spread of AIDS in poor urban communities of color.

The prevalence of particular social conditions and social ills became, for some, the culprits in the inner city AIDS epidemic. The problems of the inner city thus became essential for AIDS advocates in Newark as a way to explain the structural issues and social determinates of health related to the proliferation and intractability of AIDS. For these advocates the disease became a public health problem, a social problem, a political issue, and sometimes all three at once. Yet these perceived distinctive conditions and demographics also came to characterize how the problem of AIDS was different from other communities. Here, IV drug use was seen as a particularly pernicious, and unique, vector for the disease among urban families of color. AIDS-care advocates in Newark thus sought a counter narrative that challenged the culturally dominant “gay disease”

¹⁹ Caroline J. Acker, *Creating the American Junkie: Addiction Research in the Classic Era of Narcotic Control* (Baltimore: The Johns, Hopkins University Press, 2002), 225. Kenneth Jackson posited in 1971 that “not surprising,” that “heroin drops along Springfield Avenue are known even to children, and the rate of narcotics addiction is among the highest in the United States; Jackson, “The Black Experience in Newark,” 37.

²⁰ Acker, *Creating the American Junkie*, 225; Mc Bride, *From TB to AIDS*, 160.

discourse of the early to mid-1980s. The pediatric AIDS patient was essential to their preferred counter narratives.

The “Most Defenseless Victims”: Pediatric Patients and the Changing AIDS Script in the “Gay Disease” Era

Early reports of AIDS among children of color were overshadowed by the intensified news media and public health coverage of a new syndrome affecting homosexual men in the United States. Shortly after the first reported cases of AIDS in 1981, physicians caring for children of color alerted the nation’s public health and scientific communities about the increasing numbers of AIDS cases among their patients.

²¹ During this period, numerous gay activist groups and gay health organizations, particularly the Gay Men's Health Crisis and Kaposi's Sarcoma Research and Education Foundation, began to organize and push for action surrounding the disease, as well as provide care for those infected. Through their efforts, the sociologist Steven Epstein argued, the gay community began to "claim the epidemic."²² AIDS became a “gay

²¹ Centers for Disease Control, “Pneumocystis Pneumonia --- Los Angeles,” *Morbidity and Mortality Weekly Report (MMWR)* 30(21) (June 5, 1981), 1-3, <http://www.cdc.gov/mmwr/preview/mmwrhtml/june> (accessed May 20, 2011). I am using the first reported cases of AIDS among homosexual men in Los Angeles, California to illustrate that disease was first associated with gay men and the gay lifestyle. The AIDS activist Cindy Patton argues how AIDS entered the “American Consciousness” as a disease associated with gay men. See Cindy Patton, *Sex and Germs: The Politics of Aids*. 1st ed. (Boston: South End Press, 1985), 22-25. For an analysis of the news media coverage of AIDS see James Kinsella, *Covering the Plague: AIDS and the American Media* (New Brunswick, Rutgers University Press, 1989). The women’s and gender scholar has also provided a detailed linguistic analysis of the public health and scientific literature regarding early discussions about AIDS in gay men; see Paula A Treichler, *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS* (Durham: Duke University Press, 1999), 11-98.

²² Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge*, Medicine and Society (Berkeley: University of California Press, 1996), 54; John-Manuel Andriote, *Victory Deferred: How AIDS Changed Gay Life in America* (Chicago: The University of Chicago Press, 1999), 47-121.

disease,” Epstein continued, “primarily because clinicians, epidemiologists, and reporters perceived it through that filter, but secondarily because gay communities were obligated to make it their own.”²³ This does not suggest that the gay community was comfortable with the gay disease frame—they were not. As scholar Dennis Altman argued in 1986, gays were “ambivalent about AIDS, claiming that it should not be seen as a ‘gay disease’ while tending to talk about it as if that’s all it is.”²⁴ The “gay disease” frame proved a powerful determinate in cultural perceptions of AIDS as reports of this new syndrome affected non-gay communities in the United States, which included early dismissals of children with AIDS within the medical and scientific communities.

This changed between 1983 and 1986 as physician-researchers in Newark and the Bronx (New York City) provided scientific explanations of pediatric AIDS, and as pediatric AIDS awareness increased among both scientists and the American public. For physicians and AIDS-care advocates in Newark during this period, the pediatric AIDS patient came to represent one of many unfortunate consequences of the epidemic among urban populations of color, and eventually became part of growing narrative in the United States that cast certain non-gay groups affected by AIDS, such as hemophiliacs, as “innocent victims” of the epidemic. More importantly, the purported unique circumstances that exacerbated the problem of AIDS among newborn children of color—primarily IV drug use and heterosexual transmission—helped AIDS advocates from Newark differentiate the HIV-infected child of color within this innocent victim discourse. Though they did not know it at the time, these advocates in Newark—

²³ Epstein, *Impure Science*, 54-55.

²⁴ Denis Altman, *AIDS in the Mind of America* (New York: Anchor Press, 1986), 39; 30-57.

particularly one vocal pediatrician, Dr. James Oleske—were laying the foundations for the family disease discourse that would emerge by the end of the 1980s. Through their early public health research and public advocacy efforts, the “gay disease” frame would not come to define the AIDS epidemic in Newark.

Between 1981 and 1982, AIDS was quickly associated with the gay community and gay lifestyle. As Gay Related Immune Disease (GRID) became Acquired Immunodeficiency Syndrome (AIDS)—because of the stigma attached to the former, and the fact that language of GRID did not accurately capture the various others diagnosed with the disease—the frame of AIDS as a “gay disease” took shape.²⁵ By 1982, there were signs that the disease was appearing in heterosexuals, both men and women, Haitians, hemophiliacs, recipients of blood transfusions, heroin users, and infants.²⁶ At a time when scientists and public health officials continued to search for evidence regarding how AIDS was transmitted, the appearance of AIDS in newborn children particularly baffled some physicians. In Newark, Dr. James Oleske, a practicing pediatrician and medical researcher, witnessed a young girl who “died of an unusual type of pneumonia, *Pneumocystis carinii* pneumonia.” He was unclear as to why the young girl was sick, but he knew that her father was an IV drug user who was also dying from

²⁵ Brandt, *No Magic Bullet*, 184. Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York: St. Martin’s Press, 1987), 121-171. Dennis Altman also argued that the GRID terminology, and the “fact that the first reported cases were exclusively among gay men was to affect the whole future conceptualization of AIDS,” as a gay disease; Altman, *AIDS in the Minds of America*, 33. With respect to the power of cultural frames, Steve Epstein posits that the “power of frames as organizers of experience is precisely that they work to exclude alternative ways of interpreting and experience;” Epstein, *Impure Science*, 50. See also Gerald Oppenheimer’s “In the Eye of the Storm: The Epidemiological Construction of AIDS” in *AIDS: The Burdens of History*.

²⁶ Brandt, *No Magic Bullet*, 183-184. Centers for Disease Control, “Unexplained Immunodeficiency and Opportunistic Infections in Infants” ---New York, New Jersey, California,” *Morbidity and Mortality Weekly Report (MMWR)* 31(49) (December 17, 1982), 665-667, <http://www.cdc.gov/mmwr/preview/mmwrhtml/00001208.htm> (accessed August 13, 2011).

AIDS.²⁷ In fact, Oleske recalled that he saw that “something was happening” as early as 1978, but he was unsure what the “disease” was they were witnessing.²⁸ Dr. Arye Rubinstein, who also witnessed similar pediatric AIDS cases among minority patients at Albert Einstein College of Medicine in the Bronx, New York, tried alerting the scientists and public health officials to what he saw. He was told, however, that “Gay pneumonia and gay cancer were diseases of homosexuals,” and James Curran at the Centers for Disease Control (CDC) told Rubenstein: “Ayre, what am I going to do? I’m convinced that this is pediatric AIDS, but no one in a sane mind will accept it. How do we bring it out to the public?”²⁹ Rubinstein persisted. He submitted his findings of 11 babies infected with AIDS to the *New England Journal of Medicine*, but the article was rejected on the grounds that the children “most certainly did not have AIDS, the homosexuals’ disease.”³⁰

²⁷ James Oleske, interviewed by Barbara S. Irwin and Robert B. Burnett, July 28, 1994, New Jersey AIDS Oral History Program, (hereafter cited UMDNJ Oral History Collection), University of Medicine and Dentistry of New Jersey, University Libraries, University Libraries Special Collections, Newark, New Jersey, 4-5.

²⁸ Oleske, oral history, 2-4. Reflecting on these early events, Oleske does not say for certain whether these early cases were linked to IV drug use, but he implies the risk factor is IV drug use, 2-4. Reflecting on these early events, Oleske does not say for certain whether these early cases were linked to IV drug use, but he implies the risk factor is IV drug use. Such claims were retrospectively corroborated by researchers and scholars in the 1990s, which provided evidence suggesting that IV drug users were transmitting the virus as early as the mid to late 1970s. See for example, Don C. Des Jarlais, Samuel R. Friedman, and Jo L. Sotheman, “The First City: HIV among Intravenous Drug Users in New York City,” in *AIDS: The Making of a Chronic Disease*, 280-281. See also Douglas Crimp, *Melancholia and Moralism: Essays on Aids and Queer Politics* (Cambridge, Mass.: MIT Press, 2002), 58-59.

²⁹ Ronald Bayer and Gerald M. Oppenheimer, *The AIDS Doctors: Voices From the Epidemic* (Oxford: Oxford University Press, 2000), 30-31.

³⁰ Shilts, *And the Band Played on*, 172.

This ambivalence towards pediatric AIDS changed, however, in the spring of 1983. In May of that year, Dr. Oleske and colleagues published findings in the *Journal of the American Medical Association (JAMA)* showing AIDS among children in Newark. Dr. Oleske's article, "Immune Deficiency Syndrome in Children," was the culmination of a study that followed "eight children with an otherwise unexplained immune deficiency syndrome and infections of the type found in adults with AIDS." These children moreover, were born "into families with recognized risk of AIDS" from the Newark area.³¹ Of the eight families, five were African American, two were Hispanic/Black, and one was Hispanic. In addition, all but two of the families had one parent, mother or father, with a history of IV drug use.³² Ultimately, Oleske and his colleagues argued that there was "evidence supporting the appearance of AIDS in children appears to be reasonably persuasive."³³ Though the article represented only one of the first studies providing evidence of the disease among children, there was no clear indication showing the virus's transmission pathway among children. Pondering the possible modes of transmission, Oleske and his colleagues concluded that, "children living in high-risk households are susceptible to AIDS and that sexual contact, drug abuse or exposure to blood products is not necessary for disease transmission."³⁴ With this conclusion, Oleske

³¹ James Oleske, et al. "Immune Deficiency Syndrome in Children," *Journal of the American Medical Association (JAMA)* Vol. 249, no. 17 (May 6, 1983), 2345. Arye Rubinstein, who also published an article in the same *JAMA* issue: Arye Rubinstein "Acquired immunodeficiency with reversed T4/T8 ratios in infants born to promiscuous and drug-addicted mothers," *Journal of the American Medical Association* Vol 249, no. 17 (May 6, 1983), 2350-6. See also Kinsella regarding news media coverage of pediatric AIDS; Kinsella, *Covering the Plague*, 106-107.

³² Oleske, "Immune Deficiency Syndrome in Children," 2348.

³³ *Ibid.*, 2349.

³⁴ *Ibid.*, 2345.

gained unexpected, and perhaps unwanted, national notoriety inside and outside the scientific medical community.

A *JAMA* press release indicated that Oleske's findings revealed the possibility that the children in the study acquired AIDS through casual contact in the household. Though the commentary in the press release created controversy, it also illuminated Oleske's work and the patients he was treating in Newark. In the press release, Anthony S. Fauci, from the National Institutes of Health (NIH), gave a rather dire prediction based on the article's conclusion. Fauci stated that "if routine contact, can spread the disease, AIDS takes on an entirely new dimension..."³⁵ Although the press release mentioned the possible transmission of AIDS from mother to fetus "in the mother's womb"—referring to Rubinstein's and Sonnabend's work—Randy Shilts argued in 1987 that the commentary added to the "hysteria" surrounding AIDS. The "report of routine household contact," Shilts posited, "lent scientific credibility to ungrounded fears; the social damage would linger for years."³⁶ Responding in 1994 to Shilt's analysis, Oleske felt that he was left with the "stigma" of being a "second-rate New Jersey physician who was spouting fear about casual spread of the disease, which was not true." Oleske also stated that Fauci's focus on the study's hypothesis that "close family contact somehow was related to the transmission," cast Oleske as "being a hysterical monger." Others, such as the journalist and scholar James Kinsella argued that Oleske's *JAMA* article was "wrongly interpreted."³⁷ Regardless of whether Oleske's article implied casual contact, or whether

³⁵ Shilts, *And the Band Played On*, 299.

³⁶ *Ibid.*, 301.

his conclusion was misread, his reputation as one of the preeminent pediatric AIDS physicians and researchers only grew after 1983.

Oleske's voice was heard beyond his profession as well. In the years following his 1983 article, Oleske would take on a number of roles as he continued to voice his concerns: heading AIDS advisory committees, providing expert testimony in front of congress, and becoming a prominent go-to for reporters, both locally and nationally, regarding AIDS-infected children. In this process, Oleske, helped illuminate the presences of children, women, men, and Newark in the nascent scientific, medical, and public conversations regarding AIDS among families of color.³⁸ This came at a time when the Newark had the fourth highest prevalence of AIDS in the country, especially among IV drug users. Moreover, the epidemiology and demographics of AIDS in Newark and New Jersey revealed how the incidence and prevalence of the disease seemed concentrated in urban communities of color. This concentration of the disease in Newark also illustrated how health care professionals, especially physicians, gained "expertise" for this newly emerging disease—many of whom surely did not intent on becoming

³⁷ Kinsella, *Covering the Plague*, 252. Kinsella also argued that in the rush to publish the findings, the news media "forgot to get the story right," 56.

³⁸ Draft of the "Red Book" report by the Advisory Committee to the New Jersey State Commissioner of Health, J. Richard Goldstein, M.D., August 1, 1985. There are no page numbers on the draft, but there is a list of the committee members—called the red book report in a letter to Dr. James Oleske from Commissioner Goldstein, James Oleske Private Collection (here after cited as Oleske Collection). The other 13 members of the committee was largely comprised of members working for the state or were associated with other AIDS-related organizations, such as N.J Lesbian and Gay Coalition, Funeral Directors Association, Hemophilia Association of New Jersey, Medical Society of New Jersey, N.J Association of Health Care Facilities, and Jersey Shore Addiction Services. This is not an inclusive list of all members.

AIDS-specific health care professionals.³⁹ Oleske was, of course, not the only concerned advocate for the problem of AIDS in cities like Newark, but his work provided some early attention and scientific legitimacy towards pediatric AIDS. In short, the continued vocalized concerns by Oleske and others brought state and national attention to the problem of AIDS among women and children in Newark.

Pediatric AIDS advocates like Oleske situated the infected inner city child of color within growing national discourse that cast certain individuals as “innocent victims” of the AIDS epidemic. By 1985, major news networks were “hungry,” Kinsella argued, for putting a “sympathetic face on the epidemic.” In doing so, the national news media followed Ryan White, a hemophiliac from Kokomo, Indiana who contracted AIDS from a tainted blood-clotting product (Factor VIII concentrate), and his family’s struggles with their community trying to get Ryan readmitted to school after he was not permitted to attend because of his malady.⁴⁰ In Northern New Jersey, *The Record* reported on cases

³⁹ Dr. Oleske and Dr. Patricia Kloser, for example, took on the role of “AIDS doctors.” See, for example, Dr. Oleske’s oral history; and Patricia Kloser’s oral history interviewed by Barbara S. Irwin, October 6, 1993 UMDNJ Oral History Collection. For how physicians became “AIDS doctors” see Bayer and Oppenheimer *The AIDS Doctors*. For some AIDS-related statistics in the Newark area, see Centers for Disease Control, *Acquired Immunodeficiency Syndrome (AIDS) Weekly Surveillance Report - United States, AIDS Activity, Center For Infectious Diseases*, December 31, 1984, <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/pdf/surveillance84.pdf>, (accessed August 15, 2011). For Newark-specific AIDS statistics, see Information from David Bynes, East Orange Health Officer, June 5, 1990, The Health Officers of Essex County have compiled data on the numbers of AIDS cases throughout the county, broken down by town, and other factors. Miscellaneous Brochures, Flyers, Handouts, etc., UMDNJ New Jersey AIDS Collection, University of Medicine and Dentistry of New Jersey, University Libraries, University Libraries Special Collections, Newark, New Jersey (hereafter cited UMDNJ AIDS Collection). Due to a planned reorganization of the UMDNJ New Jersey AIDS collection, folder-level citations are not included in this study. The CDC ranked Newark as the city with the fourth highest prevalence of AIDS in the nation. Of note, these statistics were based on the Standard Metropolitan Statistical Area (SMSA), rather than just the AIDS cases in the city. The Newark SMSA was made up of Essex, Morris, Sussex, and Union counties. This information is derived from, a Memorandum to Frances Dunston from Robert F. Hummel, April 2, 1990, Division of AIDS Prevention and Control, Manuscript Collection, Administrative Records, Department of Health, Division of AIDS Prevention and Control, Subject Files of Kenneth Black, Executive Assistant, 1983-1991, SHEA1001, New Jersey State Archives Box 1 Folder: Legislation (hereafter cited New Jersey State Archives).

⁴⁰ Kinsella, *Covering the Plague*, 185-193.

of pediatric AIDS, describing New Jersey having “disproportionately large share of the disease’s most defenseless victims: babies infected before birth.” Dr. Oleske also spoke of the children born with AIDS as “certainly” being innocent victims.⁴¹

Within this context, Dr. Oleske appeared before a Congressional hearing to provide expert testimony about HIV and AIDS among children. The hearing, held in 1986, and titled “Infants at Risk: Parental Addiction and Disease,” sought to address, according to George Miller (D-CA), “the severe health calamities which befall infants whose mothers abuse drugs, alcohol or tobacco, or who suffer from AIDS,”⁴² Here, Oleske’s testimony spoke of the growing number of pediatric AIDS cases both nationally, and in Newark. He stressed that AIDS did not just affect children. According to Oleske, the majority of women, who gave birth to HIV/AIDS-infected children, were IV drug users or had sexual contact with other high-risk male IV drug users, or men who were bisexuals. Oleske felt that, building on his experience in Newark, folks “should not give up” on educating drug users, particularly women, regardless of the difficulties inherent in reaching the drug-using population. He also expressed personal concerns that “nothing was being done for drug using women, and the child who develops AIDS...nothing.”⁴³ Others, such as the AIDS activist Cindy Patton, raised similar

⁴¹ Kathleen O’Brien, *The Record*, “Born into the defenseless world of AIDS,” March 4, 1985. According to the scholar David L. Kirp, many Americans held similar sentiments “Over and over again it is said,” Kirp argued, “that the sins of the parent (let alone an unknown blood donor) should not be visited up these children, that the disease is not their fault.” The quote comes from the following work: David L. Kirp and Steven Epstein, *Learning by Heart: AIDS and Schoolchildren in America’s Communities* (New Brunswick, Rutgers University Press, 1989), 15-16.

⁴² U.S. Congress. House. House *Placing Infants at Risk: Parental Addiction and Disease: Hearing before the Select Subcommittee on Children, Youth and Families*. 99th Cong. 2nd sess. May 21, 1986, 1.

⁴³ *Ibid.*, 21-23.

concerns a year earlier. For Patton, the incidence and prevalence of AIDS among poor inner city women and children of color did not factor in the cultural consciousness surrounding AIDS in the United States.⁴⁴ Nevertheless, Oleske dolefully mentioned how “sad” it was seeing children “born to a family that is fractured, has little ability to care for the child. Twenty-eight percent of our mothers are dying of AIDS themselves, and trying to take care of a child who is dying.” Pediatricians, Oleske stated, “and people taking care of children, have always been, or tried to be the spokesmen for these silent victims of society’s mishaps,” but he felt that these “spokesmen’s” plaintive calls were ignored.⁴⁵

He discussed the strain families experienced caring for these children because of the lack of resources necessary for AIDS-related care. Upset at what he saw as misguided federal fiscal priorities, Oleske opined that there were disparities in funding when it came to AIDS care in places like Newark. He felt that billions were being spent on military equipment, such as “nuclear aircraft carriers,” and that AIDS care received “one-fifth of one cent.” When pressed by Congresswoman Lindy Boggs (D-LA) about how much money is needed, Oleske replied, perhaps half sarcastically, “if you ask me to give a number, I will give you a number; yes, give us an aircraft carrier. Give us—\$20 billion dollars.”⁴⁶ However, calls for more AIDS-related funding to help those affected in Newark elicited a rejoinder by Congressman Dan Coats (R-IN). “It is a public perception, based on some reality, that the victims of AIDS are victims of their own choosing,” Coats argued. He believed that AIDS was “primarily the result of homosexuality, prostitution,

⁴⁴ Patton, *Sex and Germs*, 41-42.

⁴⁵ U.S. Congress. House, *Placing Infants at Risk*, 21-23.

⁴⁶ *Ibid.*, 72-86; quote on page 72 of hearing.

and drug use,” and that “treating the consequences of those acts” were not effective uses of “tax dollars”⁴⁷ Oleske, seemingly agitated by Coats response, underscored how the problems of inner city and lack of resources perpetuated Newark’s tragic AIDS narrative. “If you worked in Newark, and saw what we saw,” he lamented, “you would come down here...and get a little angry....you want people to listen. We want you to know about the problem...you guys write the checks, we just take care of the patients.”⁴⁸

Yet if he was a spokesperson for the community that he served, one does not get a sense of which community he represented. One could only surmise that the community in question is Newark’s people of color, which represented the majority of AIDS cases in 1986.⁴⁹ Though Oleske’s discussed the social ills and funding issues related to the persistence of AIDS among Newark families, the language of race was absent from his remarks. Oleske’s omission of categorizing his patients in terms of their racial status was perhaps a measured response. One can interpret his exclusion of the racial demographics of AIDS in Newark as an implicit attempt to avoid participating in conversations that involved racializing the disease. Caring for his sick patients was paramount. Describing his patient’s race thus seemed ancillary to the broader concerns of health and funding disparities related to the AIDS epidemic in Newark, which he attempted to highlight. Though it remains unclear why Oleske avoided such language, the Congressional hearing clearly revealed how Newark came to represent the problem of AIDS among impoverished urban communities. However, race and ethnicity would feature more

⁴⁷ U.S. Congress. House, *Placing Infants at Risk*, 84.

⁴⁸ *Ibid.*, 86.

⁴⁹ David Bynes, East Orange Health Officer, UMDNJ AIDS Collection.

prominently in this growing discourse surrounding AIDS in Newark over the next few years. Nevertheless, the Congressional hearing foreshadowed how the city eventually became a metaphor for the varied problems of poverty, IV drug use, sexuality and issues surrounding single motherhood, to name a few, that contributed to and exacerbated the AIDS epidemic in the Newark. For the time being, Newark's HIV-positive children helped garner some attention towards the problem of AIDS in the city.

But in Newark, the evolving conversations about the pediatric AIDS patient's innocent victimhood seemed more complicated. Descriptions of HIV infection among urban children of color placed the "parents" in a precarious and ambiguous position with respect to the HIV-infected child. In communities like Newark, the mother was portrayed either as an IV drug user, prostitute, or, like their HIV-infected baby, an innocent victim.⁵⁰ Meanwhile, the father remained tangentially associated with the infected mother and child, and often depicted as an IV drug-using (sexual) partner. Although descriptions of innocent victimhood vacillated, one aspect seemed static in Newark's emerging AIDS narrative: all parties were cast—explicitly or implicitly—as victims of social pathologies that exacerbated the epidemic in these communities. By the end of the 1980s, advocates for Newark, were not only molding the innocent victim script, they were attempting to create a new one. In this narrative, the "HIV-positive family" came to dominate the discourse surrounding AIDS among communities of color in cities like Newark.

⁵⁰ Patton, *Sex and Germs*, 41-42.

The Rise of the “Family Disease”

By the late 1980s, the family disease discourse surfaced within the context of the growing national attention regarding the problem of AIDS among communities of color. In 1987, *Time Magazine* published an article, “The Changing Face of AIDS,” which stated that the epidemic was “getting younger, darker, and more feminine.”⁵¹ The article pointed to the growing racial disparities in the epidemiology of the disease. The total reported cases of AIDS among people of color were less than half of all AIDS cases in the United States by 1986. However, both African American and Hispanics represented 25 percent of total cases, while only representing 18 percent of the U.S. population. These racial disparities were more pronounced among woman and children. During this time, scientists isolated how HIV was vertically transmitted from mother to child, and the majority of non-hemophiliac pediatric AIDS cases were children of color, most of who were perinatally infected. In addition, women of color represent nearly three-quarters of all female cases of AIDS. These disparities were present in Newark; yet there were no demographic shifts in the disease’s incidence and prevalence in the city.⁵² “It’s the same

⁵¹ For the heightened attention of AIDS in communities of color, see Cohen, Cathy J. *The Boundaries of Blackness*, 105; Daniel Fox, “The Politics of HIV Infection,” *AIDS: The Making of a Chronic Disease*, 125-143. Richard Stengel and Mary Cronin/New York and Steven Holmes/Washington, “The Changing Face of AIDS,” *Time Magazine*, August 17, 1987.

⁵² Centers for Disease Control, “Epidemiologic Notes and Reports Acquired Immunodeficiency Syndrome (AIDS) among Blacks and Hispanics -- United States,” *Morbidity and Mortality Weekly Report (MMWR)* / 35(42) (October 24, 1986), 655-8,663-6. <http://www.cdc.gov/mmwr/preview/mmwrhtml/00000810.htm> (accessed August 20, 2011). For Newark-specific AIDS statistics (1983-1990) I used a Report from David Bynes, UMDNJ AIDS Collection. For the isolation of vertical transmission of HIV, see for example, S Sprecher, et al. “Vertical Transmission of HIV in 15-week Fetus,” *The Lancet*, 2 (August 2, 1986), 288-9.

face of AIDS that I've always seen, from the beginning" of the epidemic, Dr. Anita Vaughn argued, "[intravenous drug users] and women"—people of color.⁵³

As cultural perceptions of the disease changed between 1987 and 1990, Newark, and the families affected by the HIV and AIDS, became a symbol of the epidemic among impoverished communities of color, which drew national attention. Though Newark was not the only city that drew this attention, it represented a particular modeled response to the disease. During this brief period, politicians, physicians, and AIDS-care professionals quickly recognized the political utility in casting AIDS as a disease that affected families of color, especially with new federal AIDS funding on the horizon.⁵⁴ Overt descriptions of HIV-positive families thus sought to capture the complex biological and social circumstances surrounding the disease in these communities. New Jersey health officials and AIDS advocates in Newark described the high rates of HIV-infection among women and children during this period as a “unique” AIDS-related phenomenon in the state. Such efforts also attempted to elucidate how intractable problems—such as poverty, IV drug use, and health disparities—resulted in, and exacerbated the epidemic among urban communities of color. In addition, the family disease discourse represented a subtle critique regarding the decades of urban neglect, mainstream perceptions of impoverished

⁵³ Bayer and Oppenheimer, *The AIDS Doctors*, 234; See Jacob Levenson's *The Secret Epidemic: The Story of AIDS in Black America* (New York: Pantheon Books, 2004), 50; Perrow and Guillen, *The AIDS Disaster*, 55-105. Though they are focused on the response to AIDS, they do talk about the recognition by state and federal officials—within and outside the realm of public health—HIV-AIDS among African Americans; Randy Shilts also mentions communities with a predominantly minority population, such as the Bronx; Shilts, *And the Band Played On*.

⁵⁴ Daniel Fox, “The Politics of HIV Infection: 1989-1990 as Years of Change,” *AIDS: The Making of a Chronic Disease*, 125-143; Epstein, *Impure Science*, 235-238.

urban communities of color, and, perhaps, notions about the “changing face of AIDS” itself.

In 1987, the New Jersey Department of Public Health provided a for-the-public report detailing what they felt was the state’s distinctive AIDS characteristics. The report, *AIDS in New Jersey: A Report from the Department of Health*, provided general information regarding broad HIV-AIDS statistics, projected AIDS cases over the next several years, and the state’s plan for addressing the epidemic in New Jersey, which included an emphasis on containment.⁵⁵ New Jersey state health officials argued that the AIDS epidemic in the state was unlike other parts of the country because, since the beginning of the epidemic, the disease was most prevalent among IV drug users, women, and children, rather than among homosexual men. According to the report, this was the “special character of Jersey’s people with AIDS.”⁵⁶

In many ways, the state seemed to take a utilitarian approach, thus focusing their efforts towards the group, or groups, they believed most vulnerable to HIV infection. While homosexual men were also mentioned in the report, women of childbearing age, children, and IV drug users became the state’s priority. The report illustrated this focus,

⁵⁵ New Jersey Department of Health, *AIDS in New Jersey: A Report from the Department of Health*. (Trenton: Department of Health, 1987), UMDNJ AIDS Collection. The report made clear any proactive attempt at mitigating the spread of AIDS in New Jersey would include addressing the problem of IV drug use. In fact, prior to the creation of the Division of AIDS Prevention and Control in the fall of 1988, New Jersey’s HIV/AIDS response fell under the purview of the Division of Narcotics and Drug Abuse Control (DNDAC). This is derived from “Organization Questions” regarding the formation of the Division of AIDS Prevention and Control, Manuscript Collection, Administrative Records, Department of Health, Division of AIDS Prevention and Control, Subject Files of Kenneth Black, Executive Assistant, 1983-1991, SHEA1001, New Jersey State Archives Box 1 Folder: Briefs, New Jersey State Archives.

⁵⁶ New Jersey Department of Health, *AIDS in New Jersey*, 6. The “special character of Jersey’s People with AIDS” came from a subtitle in the report, which emphasized “intravenous drug abusers,” in most areas of the United States, constituted “what is being called the ‘second wave’ of the epidemic.” In New Jersey, state health officials illustrated that the problem of IV drug use and AIDS was not new in the state.

and the purported unique epidemiology of AIDS, in a “case history” of a woman, “Gloria,” who was infected with the disease through her IV drug using male partner, “Juan.” Gloria, who died in 1986, also gave birth to a HIV-infected daughter, Maria, who died at the age of three in December that same year—Juan, who was 27-years-old, also died.⁵⁷ HIV-positive women, the report cited, were “a major source of AIDS cases among infants and children.”⁵⁸ Implied in such descriptions was how prevalent the disease was in New Jersey’s inner city communities of color. By the end of the decade, it was clear that the disease was disproportionately affecting these communities.⁵⁹ The state’s message seemed clear: AIDS was a disease of poor urban populations of color, especially women and their unborn children.

Federal officials were receiving a similar message from physicians in Newark. In 1988, The General Accounting Office (GAO), which was preparing to brief Congress about HIV-AIDS surveillance, asked Dr. Oleske for input regarding HIV-infection among women in Newark—and whether the city was considered a “high risk” area. Continuing his AIDS advocacy, Oleske underscored how the pernicious intersection of IV drug use and heterosexual sex place women of color at risk of infection. By 1988, Oleske stated, women were primarily infected through sex with their male partners, who were either IV drug users or bisexual—“or both.” He also continued to supply social criticism. Reflecting on his personal experience with patients, women “in the inner city,” he wrote, were tethered to male partners for economic security. Such partnerships, he

⁵⁷ New Jersey Department of Health, *AIDS in New Jersey*, 3.

⁵⁸ *Ibid.*, 1-14; quote on 9.

⁵⁹ David Bynes, East Orange Health Officer, UMDNJ AIDS Collection.

argued, resulted in “oppressive relationships,” where women, fearing violent reprisals or losing their partner for financial support, were unable to demand safe sex practices or to inquire about their partner’s behavior outside the home. This in turn, Oleske believed, exacerbated HIV infection among women, and potentially their unborn or newborn children.⁶⁰ This correspondence foreshadowed a national conversations regarding HIV infection among men, women, and children in Newark.

By 1989, AIDS was explicitly framed as affecting impoverished urban families of color in Newark. Wayne Duncan’s remarks that AIDS was a “disease of the family...in cities like Newark,” undoubtedly sought to construct, for a public audience, a specific type of AIDS awareness. His comments were a reflection of the growing scientific, cultural, and political recognition of the problem of AIDS among communities of color—a message, of course, Olekse and other advocates had professed since the early 1980s. Furthermore, Duncan’s remarks were a conscious effort to create a powerful shorthand that attempted to de-stigmatize mainstream perceptions of those infected with HIV and AIDS in urban communities of color. Simultaneously, this shorthand underscored how certain social ills, like IV drug use, became pernicious determinants of HIV infection in these communities. Yet a clear definition of the “family” seemingly remained absent in this AIDS awareness-raising effort.

Duncan’s statement appeared in a front-page *New York Times* article on February of 1989, which partially detailed the impact AIDS had on Newark families. Here,

⁶⁰ Letter, Dr. James Oleske to Eric M. Larson, Program Evaluation Methodology Division, United States Gernal Accounting Office, July 26, 1988, Oleske Collection. Larson’s inquest seemed to be part of information gathering related to a brief being prepared for Congress “on the issue of projections of HIV and AIDS cases and of issues pertaining to the surveillance system.” For an analysis of how poverty factored in the prevalence of HIV and AIDS among women, see, for example, Paul Farmer *Infections and Inequalities: The Modern Plagues*. (Berkeley: University of California Press, 1999), 127-149.

descriptions of single-mother and two-parent families affected and infected by the disease were juxtaposed in the article. For example, a young boy from Newark, whose entire family died from AIDS, hoped to contract the disease in order to “join his mother, father, sister and brother in heaven.” There were vague accounts of how single women were infected with HIV through their IV drug using partners, which led to the transmission of the virus their unborn child. Equally unclear were interpretations of the disease by Newark residents of color. Though Newarkers were aware of what they called the “virus,” and how the disease affected their community, we do not get a clear sense of whether they categorized AIDS as a “gay disease,” “family disease,” or one of IV drug users—or all of the above.⁶¹ Nevertheless, such conversations reflected how Newark became, in part, the national representative for describing the effects the AIDS epidemic had on urban communities of color. More importantly, AIDS advocates over the next few years would clearly delineate how Newark families, were victims of HIV-AIDS, persistent urban neglect, and intractable urban “problems” associated with disease’s prevalence in the city.

This was evident in the Congressional hearing, “Children and HIV Infection,” which was held in February of 1989. The hearing sought to address the problem of AIDS among inner city children, and families, of color. The Congressional committee assembled experts in pediatric AIDS care from Miami, Newark, Harlem, and the Bronx. The choice of these four areas was obvious for the Congressional Subcommittee chairman, Ted Wiess (D-NY). These “locations were at the center of the epidemic”

⁶¹ Lena Williams, “Inner city under siege.” It is difficult to discern whether Duncan’s comments—or the *New York Times* article for that matter—were the first overt attempts to cast AIDS as a family disease. What is clear, however, was that more overt description of the disease affecting families would appear in the press, Congressional record, and New Jersey’s response to AIDS in the next few years.

among children.⁶² The junior Congressman from New Jersey, Donald Payne, who was also part of the subcommittee, and was the first African American elected to represent New Jersey in Congress, supported Wiess' statement. "We recently learned an alarming statistic," Payne stated, "one out of every 22 babies at the University Hospital in Newark test positively for the AIDS antibodies."⁶³ The overall tone of the hearing underscored the relationship between life in a poor urban environment and the disproportionate amount of pediatric AIDS cases in the United States. The infected child was seen as "concentrated among the most vulnerable people in American society," where drugs, poverty, and "inadequate health care" were stated as some of the problems contributing to the existence of HIV and AIDS among children. Yet the child came to represent something more than an AIDS patient for the Congressional subcommittee. "When a child has AIDS," Weiss commented in his opening statement, "you are witnessing not only the possible destruction of an individual life, but also the life of the family."⁶⁴ For these individuals, IV drug use became the most pernicious vector for HIV infection among children and their families.

⁶² U.S Congress. House. *Children and HIV Infection: Hearing before the Human Resources and Intergovernmental Relations Subcommittee of the Committee on Government Operations*. 101st cong. 1st session. February 22 and 23, 1989, 2. The *Children and HIV Infection* hearing was split into two sessions, as was the Congressional hearings about AIDS in Newark and Detroit. In addition, the *Children and HIV Infection Hearing* was the second in the list of hearings held leading up to the passage of the Ryan White CARE Act. The first, according to Cathy Cohen, was in the summer of 1987, which was titled *Pediatric AIDS Hearing*, and was held in Harlem. For list of the hearings, see Cohen, *Boundaries of Blackness*, 314-317. For her discussion regarding elected African American Congressman present at the hearings, see 312-318.

⁶³ U.S Congress. House. *Children and HIV Infection*, 5; Raymond Hernandez, "Donald M. Payne, First Black Elected to Congress From New Jersey, Dies at 77," *The New York Times*, March 6, 2012.

⁶⁴ *Ibid.*, 2.

While Congressional leaders and health care professionals were compelled to discuss how this specific social ill was devastating families in the inner city, some AIDS-care experts wanted to make clear how single-mother families were particularly affected by AIDS and the urban environment in which they lived. Mary Boland, the Director of the AIDS Program at Newark's Children's Hospital, articulated how the mother-child family came to be infected by HIV-positive male partners. Moreover, Boland asserted, that in Newark most of the women were not "prostitutes" or "IV drug users," which her fellow panelist surely concurred. These HIV-infected women, Boland argued, were in "monogamous" relationships, and that many of them were "poor, single-parent working women in the inner city striving for a better life for themselves and their families."⁶⁵

In such discussions, however, the woman's marital status was not described as a social determinate of HIV infection, nor was the woman's status explicitly or implicitly deemed an unfortunate consequence of life in an impoverished urban environment. Instead, when higher insentience of HIV and AIDS among single mothers was purported, these women were described as over-burdened not only by AIDS but by poverty and neglect as well. Boland, for example, seemed less interested in how one came to be married or single. In such examples, advocates were thus claiming how the burden of AIDS was seen as something many families faced, regardless of whether this phenomenon occurred among single or two-parent households.⁶⁶ Yet Boland's comments

⁶⁵ U.S Congress. House. *Children and HIV Infection*, 32; 6-7; 46-54.

⁶⁶ This is informed by Rickie Soinger's analysis regarding women of color choosing to remain single during the post-World War II period. See Rickie Solinger, *Wake up Little Susie*. 2nd Routledge pbk. ed. (New York: Routledge, 2000), 78-85. Perrow and Guillen discuss how HIV and AIDS affected single mothers of color in New York, *The AIDS Disaster*, 89-105. Their analysis was derived from William J. Wilson's, *The Truly Disadvantaged*.

are also instructive in understanding the emerging family disease discourse in 1989. While Boland and others described the family in terms of a single or two-parent household, it is the HIV-positive single mother that seemed to represent the dominant description of families in Newark and New Jersey writ large—this was especially the case as the discourse evolved over the next few years. Although descriptions of the family varied, one depiction remained static: they were all families of color.

African American Congressional leaders sought to further contextualize the affects AIDS, and the problems of the inner city, had on urban families of color. Congressman Payne was present, again, at another Congressional hearings held in March of 1989, which focused on the AIDS epidemic in urban communities of color. Instead of solely focusing on HIV infection among children and their mothers, this hearing focused on the problem of AIDS in two cities. The "AIDS Epidemic in Newark and Detroit" hearing—a two-day hearing held in Newark and Detroit—focused broadly on the social and medical conditions associated with the disease in Newark. Payne emphasized, as he did a month earlier, that "drug abuse, the cause of so many other ills in our society, is heavily implicated in the AIDS epidemic." This particular social ill, and the seemingly lack of resources, were some of the issues that were underscored by Payne that resulted in the "terrible anguish" Newark families—and families in other urban communities of color—had to shoulder. In fact, by the late 1980s, other elected African American leaders, like John Conyers from Michigan and the Congressman Charles Rangel from New York, also emphasized how social determinates of HIV infection contributed to intractable AIDS problem in these communities.⁶⁷

⁶⁷ U.S. Congress. House. *The AIDS Epidemic in Newark and Detroit: Hearing before the Human Resources and Intergovernmental Relations Subcommittee of the Committee on Government Operations*.

The focus on families, particularly the “innocently infected” woman and children, represented a way for African American leaders to “own” the disease. In 1989, the scholar Harlon L. Dalton argued that African Americans were reluctant to discuss openly the AIDS epidemic because of the “myriad of social issues” that surrounded “the disease and [gave] it its meaning.”⁶⁸ Two such social issues include IV drug use and HIV infection among men of color who have sex with men. This reluctance to discuss AIDS openly showed signs of abating by the time of Dalton’s publication. According to the political scientist and African American studies scholar, Cathy Cohen, black leaders, beginning in 1987, recognized the political importance of addressing HIV-AIDS in their communities.⁶⁹ “Urged to respond to this burgeoning crisis,” Cohen argued, “indigenous black leaders sought out ways to distance themselves from the more stigmatized aspects of AIDS and the populations associated with it,” namely “children and the unsuspecting female sex partners of HIV infected men.”⁷⁰ Women and children infected with HIV seemed to gain most of the attention with in this political discourse.

101st cong. 1st sess. March 27 and April 24, 1989, 2-3; quotes from 3. For the presence of Payne and Conyers at the Congressional hearings, and how other elected black leaders used similar hearings to discuss social determinates of HIV infection see Cohen, *Boundaries of Blackness*, 323-325; 329-330.

⁶⁸ Harlon L. Dalton, “AIDS in Blackface” *Daedalus*, Vol. 118 No. 3 (Summer 1989), 213-217; quote on 205.

⁶⁹ Cohen, *Boundaries of Blackness*, 79-118.

⁷⁰ Cohen, *Boundaries of Blackness*, 105; 91-101. Cohen reminds us that elected black leaders, for example, were not the first to raise awareness of the disease in African American communities. During the early 1980s, active gay men of color attempted to inform their communities of the problem, which later partially became the province of elected African Americans leaders by the end of the decade. In Newark, there was no politically connected and vocal gay community. For Newark’s lack of a politically active gay community, see Eugenia Lee Hancock “AIDS is Just a Four Letter Word: An Ethnographic Study of Theodicy and the Social Construction of HIV/AIDS in Newark, New Jersey” (Ph.D diss., Drew University, 2002), 65. For AIDS activism among gay men of color, in communities of color, see Andriote, *Victory Deferred*.

Of course, not all women, or those infected with HIV, were treated equally. The injection drug using women or mother did not gain the same empathized attention, Cohen argued, and, the attention on “innocently” infected women and children shifted awareness away from HIV infection among gay black men and men of color who have sex with men. In short, the framing of both women and children and families as “innocent victims” of the AIDS epidemic seemed a political priority for some elected African American leaders. Their political calculus during this period, however, ignored gay men of color. In addition, either the IV drug user was described as vector of HIV infection, or their status was seen as an unfortunate consequence of benign urban neglect, worthy of recognition in further efforts to mitigate the spread of the virus.⁷¹

In this respect, the family disease discourse represented a veiled critique of both urban neglect and decades-old perceptions of inner city families of color. For elected African American leaders like Payne and Conyers, Newark and Detroit became the inner city frames of reference in the emerging discourse surrounding the AIDS epidemic in impoverished communities of color—much like New York and San Francisco became, within the cultural memory of Americans, sister cities of the AIDS epidemic among gay men. Nevertheless, efforts to highlight the problems of AIDS in Newark and Detroit seemed less about constructing an “us too” AIDS narrative. The efforts of Payne, and other like-minded elected African American leaders, were, perhaps, representative of post-World War II black health care advocacy and activism that attempted to draw attention to both specific radicalized health inequities, as well as the social and cultural determinates that facilitated and exacerbated these problems. The prevalence of HIV and

⁷¹ Cohen, *Boundaries of Blackness*, 324-325.

AIDS was thus deadly proof that the family was affected by “social pathologies,” rather than contributing to them.

Much of this new family disease discourse, as seen in these Congressional hearings, thus became an essential rhetorical component in the emerging politics surrounding AIDS-related federal funding. The Congressional hearings that focused on Newark, and other communities of color affected by the disease, were part of a number of AIDS-related hearings that factored in the passage the Ryan White Comprehensive AIDS Resource Act—or Ryan White CARE Act—in 1990. The infected mother and child of color—and the family—factored prominently in a portion of this legislative history.⁷² Here, elected black politicians, and other AIDS advocates in poor urban communities of color, joined the chorus of plaintive calls for “compassionate” care for those “innocently” affected by the disease that were central in the formation of the Ryan White CARE Act. In doing so, these political leaders, and others, secured the image of HIV-infected woman and child—especially the child—as innocent victims of the epidemic while simultaneously ensuring their communities were recipients of needed, and well deserved, resources in the care and prevention of AIDS.⁷³

⁷² For a brief history of the Ryan White Care Act see, Patricia D. Siplon, *Aids and the Policy Struggle in the United States* (Washington, DC: Georgetown University Press, 2002), 93-110.

⁷³ For the politics of race and Ryan White CARE Act, and the involvement of black elected Congressional Representatives, see Cohen, *Boundriess of Blackness*, 324-325; 293-337. Cohen also argued that by focusing on “innocent” women and children African American leaders further marginalized gay men of color and IV drug users in these communities, which she saw as problematic in constructing an open dialogue about AIDS among African American groups in the United States. For Cohen, “unlike children, women as a group were constructed not only as ‘innocent victims,’ but also as spreading the virus to the ‘real victims of the epidemic, children. Thus, in a political calculation whereby members were looking for issues with which they could win—those issues and groups whose negatives were low—certain women, those who injected drugs, found only qualified support from black officials,” 326. This was the case in the Congressional record leading up to the passage of the Ryan White ACT. But as Boland indicated in her Congressional testimony, certain AIDS experts—she was also an AIDS-care advocate—wanted to avoid blaming the victim. For the importance of “seeing” White as an innocent victim and how it factored in the politics of the Ryan White CARE Act, see *Stephen Pemberton, The Bleeding Disease:*

As the AIDS epidemic entered its second decade, the family disease discourse provided national visibility for a group of Americans that were largely ignored within cultural and political discussions regarding AIDS before the late 1980s. For some advocates, discussions of HIV infection among families clearly illustrated how the conditions of the inner city had exacerbated the problem of AIDS among urban communities of color. Newark, both the place and the AIDS advocates in the city, factored in this phenomenon. It was perhaps no surprise that the family disease narrative would become central in New Jersey's, and Newark's, AIDS prevention and care agendas over the next few years. However, as state health officials New Jersey incorporated the family disease frame, particular problems would emerge. For some, the HIV-positive child came to dominate the family disease discourse. Women's health AIDS advocates, for example, questioned the child-centered focus that permeated the family disease AIDS agenda in New Jersey, thus revealing a potential weakness in the political utility of the family disease discourse.

Problems with Ownership: The Emerging Pitfalls of the Family-Focused AIDS Agenda

The family disease discourse met immediate, albeit subtle critiques. As the discourse gained political utility, women's health advocates in New Jersey simultaneously began addressing what they saw as potential problems in a statewide

Hemophilia and the Unintended Consequences of Medical Progress, (Baltimore: Johns Hopkins Press, 2011), 263.

AIDS policy agenda that took a child-centered, family-focused approach. Between 1989 and 1991, the family disease narrative became the central theme that guided the public health and AIDS-care response to the disease in New Jersey. During this period, the family disease discourse would reach its zenith. The benefits of the family disease approach became clear in Newark. By this time, the city had established a women AIDS clinic and a national pediatric AIDS resource center was housed at Children's Hospital, for example. In addition, Dr. Oleske, Mary Boland, and their colleagues at Children's hospital, became the recipients of international attention and European philanthropy. While focusing on protecting—and caring—for families with HIV and AIDS provided some clear benefits, it also began to show a few substantial flaws. For women's AIDS advocates, this new family disease focus had the potential of cultivating a negative and highly stigmatized public perception of HIV-positive women as vectors of HIV infection among children. Though these advocates were of course concerned about HIV-positive children, they also wanted to ensure that HIV prevention efforts in New Jersey equally addressed the protection of women and children from the disease. More importantly, the adoption of the family disease discourse by New Jersey health care policy officials further underscores how this new cultural framing of AIDS became primarily associated with families of color.

In September of 1989, the Pediatric Advisory Committee, in conjunction with the New Jersey Department of Health, published a report, *Generations in Jeopardy: Responding to HIV Infection in Children, Women, and Adolescents in New Jersey*. The report provided recommendations to the New Jersey's Department of health for addressing the gaps in HIV-AIDS services, prevention, and HIV and AIDS-related

services for women, children and adolescents. The publication of the Committee's report sought to address the social, biomedical, public health, and health care delivery they believed were essential in reducing HIV infection among New Jersey families.⁷⁴ The committee also provided a brief glimpse of the family or families they sought to protect. Quoting the Association for the Care of Children's Health's Family Meeting of Pediatrics (1988), the Committee pointed out that many of the families are "single or foster parents, extended family members, and friends. While different from the traditional nuclear family, these families fill all the roles traditionally associated with family."⁷⁵ Though the report was a broad-based attempt to address and frame the issue of HIV-infection as a matter of importance for all families, such descriptions of the family revealed, if nothing else, the shifting public health policy imperative in protecting the urban family of color—both the "traditional" and nontraditional." In this approach, the HIV-positive child of color took precedence. The cover of the report further suggested this subtle message. Adorning the front page was an illustration of the state of New Jersey. Within the borders of this illustration was the face of an African American child.⁷⁶ The committee, and the New Jersey Department of Health, made clear which New Jersey generations, and families, were in jeopardy of HIV infection.

⁷⁴ Report from the New Jersey Pediatric AIDS Advisory Committee, Mary Boland, R.N., M.S.N., Chairman, *Generations in Jeopardy: Responding to HIV in Children, Women and Adolescents in New Jersey*, UMDNJ AIDS Collection (Pediatric AIDS Advisory Committee, 1989).

⁷⁵ Ibid., 12.

⁷⁶ New Jersey Pediatric AIDS Advisory Committee, *Generations in Jeopardy: Responding to HIV in Children*, Front Cover.

As New Jersey public health officials, politicians, and advocacy groups planned an organized statewide response to the disease, Newark's pediatric HIV-AIDS professionals gained international attention. In 1989, a Swiss countess, Albina du Boisrouvary, visited New York City searching for an institution to house an international training center for health care workers who cared for and treated children with HIV-AIDS. Countess du Boisrouvary represented the Francois-Xavier Bangound Foundation (FXB Foundation)—an organization she cofounded in 1989 to honor her son who died three years earlier during a helicopter accident in Africa—was a philanthropic organization that focused on “children in distress.” According to Dr. Oleske and UMDNJ, the countess, while in New York saw, by “chance,” a made for television movie, “The Littlest Victims,” which was based on Oleske's experience with pediatric AIDS patients. Oleske was not entirely pleased with the movie. Perhaps showing his modesty—or his displeasure with the outcome of the film—Oleske felt “embarrassed” that the film would make him a “laughingstock.” But the movie, according to Oleske, had an unintended, albeit beneficial, consequence: it brought the countess to his door. This “chance meeting” certainly paid off for Oleske and UMDNJ. The FXB Foundation gave \$1.2 million for an endowed chair, which Oleske was the first to hold, and a \$1.05 million donation for the creation of an international training center.⁷⁷ By the 1990s, the FXB-funded Center at run

⁷⁷ UMDNJ press release, “Chance Meeting Pays Off: European Foundation Funds First International Program to Train Health-Care Workers in Pediatric AIDS; Dr. James Oleske to Hold Endowed Chair,” October 3, 1990, UMDNJ AIDS Collection; see also Oleske, oral history. For Oleske's statements about his portrayal in the film see, Oleske, oral history, 37.

Mary Boland and housed at Children's Hospital, would eventually train physicians from places like "South Africa, Cuba...and parts of the former Soviet Union."⁷⁸

The same year the Swiss countess visited Newark, a statewide women's AIDS advocacy groups, The New Jersey Women's and AIDS Network's (NJWAN), emerged in New Jersey. The stated purpose of NJWAN was to provide advocacy and activist voice for women with HIV and AIDS. The NJWAN sought to empower and educate women, regarding HIV prevention and care, which was "culturally competent..."gender-specific...and class conscious."⁷⁹ Though the group wanted to raise AIDS awareness with all women in the state, their cultural and class focus and sensitivity arguably spoke to those women most affected by the disease in New Jersey: poor women of color. The NJWAN did not end with advocacy and AIDS awareness. The group also operated as policy advocates. The NJWAN's efforts to include women's health priorities, with respect to public health policy discussions surrounding AIDS, were seen in the Pediatric Advisory Committee's *Generations in Jeopardy Report*.⁸⁰

A gender-conscious voice was present in these AIDS policy recommendations. Women's health advocates sought to ensure that New Jersey health care officials did not

⁷⁸ Joseph F. Sullivan, "For children of AIDS, new hope in Newark," *The New York Times*, July 11, 1993.

⁷⁹ New Jersey Women's AIDS Network Statement of Philosophy, 2nd Annual Symposium, "Confronting the Crisis: The Power of Our Voices," September 1990. UMDNJ AIDS Collection. The quote is from an Oral History with the organization's Executive Director Marion Branzaf, Interviewed by Janet Koch, February 14, 1994, UMDNJ Oral History Collection, 3. On page 4 of the transcript, Branzaf mentions that the organization was the only statewide women's AIDS advocacy group in the country.

⁸⁰ New Jersey Women's AIDS Network. Membership Information. 2nd Annual Symposium, "Confronting the Crisis: The Power of Our Voices," September 1990, UMDNJ AIDS Collection. The NJWAN was represented in the report by Rikki Jacobs, who was one of the 49 members that made up the Pediatric AIDS Advisory Committee.

relegated women to a "causal" role within public health and health care conversations. Culturally sensitive and gender-specific language in the report reflected this phenomenon, especially when it came to HIV prevention efforts among inner city women of color. The report indicated that HIV prevention efforts should focus on “*all* women...regardless of their reproductive capacity.” Warnings were raised regarding public health efforts that “narrowly” focused on “childbearing women,” ran the risk of creating a perception of women “as potential vectors of infection to infants.” Women’s health advocates stressed how inadequate access to health care, poverty, and unemployment, continued to complicate the prevalence of HIV and AIDS among women. In addition, women-specific recommendations emphasized empowering women to refuse unsafe sex with their male partners, and for IV drug counseling.⁸¹

The gender-specific language in New Jersey’s AIDS policy discussions thus revealed the influence of women’s health advocates in the state, and the openness of state health officials towards such perspectives. Within a year of their formation, NJWAN was present in the AIDS policy discourse. Of course, policy makers, public health officials, and physicians were undoubtedly concerned about HIV infection of women in the state. However, the emergence, and relatively quick reception of women’s health advocacy concerns, revealed an unintended consequence of the family disease frame: the intense focus on HIV infected children may have overshadowed other “family members”

⁸¹ New Jersey Pediatric AIDS Advisory Committee, *Generations in Jeopardy*, 21. For women as vectors for disease see, Brandt, *No Magic Bullet*.

affected by the disease. For Women health advocates, the protection of the child and mother were equal in the family focus approach to AIDS in New Jersey.

These perspectives emerged within the context of increased national attention regarding women with HIV and AIDS. By the late 1980s and early 1990s, for example, cities like Newark and Chicago saw the establishment of AIDS clinics for the treatment and care of women and children with the disease. In Newark, Dr. Patricia Kloser, who helped create the Women's AIDS Clinic at University Hospital, argued that male partners “innocently” infected her female patients. Kloser also highlighted the fact that most of her patients, who were poor women of color, were not “junkies,” and that they tended to die quicker than men who had the disease. Kloser comments mirrored similar concerns among other women's health advocates—and her comments echoed those made by Mary Boland that same year.⁸² Nevertheless, during this period, ACT UP's Women's Caucus's AIDS advocacy and activism was gaining momentum.⁸³ According to the feminist scholar Paula Trichler, these women sought to elucidate the problem of AIDS among women, that had been relatively absent in the biomedical , public health, and popular

⁸² Gena Corea, *The Invisible Epidemic : The Story of Women and Aids*. 1st ed. (New York: HarperCollins, 1992), 76-198. For the Chicago Women’s AIDS Project’s opening of their clinic, see, for example, Corea, *The Invisible Epidemic*, 156. For Kloser’s comments see, UMDNJ press release. “AIDS Specialist Concentrates on Women,” UMDNJ AIDS Collection, articles, January to December, 1990. For Newark Women’s AIDS Clinic see Kloser, Oral History, 1-6. Kloser was commenting on the high percentage of women with HIV-AIDS in 1993, when the oral history was conducted. The percentage of patients who are African American at the time of interview was 91 percent.

⁸³ Corea, *The Invisible Epidemic*, 123-197. See also Marion, Banzhaf and ACT UP (Organization). *Women, Aids, and Activism: New York Women and AIDS Book Group*. (Boston, MA: South End Press, 1990).

media discourse in the early 1980s, as well as address the "problematic conceptions surrounding woman and AIDS" that were becoming part of the public consciousness.⁸⁴

In 1990, African American women in Newark also became active in promoting AIDS awareness and advocacy. The mission of African American Women United Confronting AIDS (AAWUCA) was not much different from the NJWAN's. The group promoted "strategies for changing current risk behaviors associated with the transmission of HIV in Essex County and the State of New Jersey," as well as to promote legislation which insures equal rights for all women regardless of race, creed, color or ethnic group." In addition, AAWUCA sought to ensure women of color and their families received the information needed in treating the affects of the disease, as well as harm reduction practices, such as safe sex and avoiding "dirty needles." Though AAWUCA indicated they promoted culturally and gender competent legislation, they seemed less directly involved in policy decision making, and did the NJWAN.⁸⁵

Both groups did not seem to have divergent views on how best to serve women of color at risk of HIV infection. However, the perception of NJWAN as part of New Jersey's health care policy establishment may have spurred the community-level support AAWUCA sought to provide. What is more, aiding "families" affected by the HIV and AIDS was not a pronounced public health or policy imperative for AAWUCA. For the members of this group, who presumably lived in Newark before the AIDS epidemic

⁸⁴ Treichler, *How to Have Theory in an Epidemic*, 42-98; for public perceptions of women and HIV infection, 235-277; quote 236.

⁸⁵ African-American Women United Confronting AIDS, Mission Statement, "Telling It Like It Is: Straight, No Chaser," Conference, A Tribute to Rosemarie Johnson, April 13, 1996. The group's mission statement, and other information about the group, was part of a small private collection of papers provided to me by one of AAWUCA's former members, Gwen Davis.

became entrenched in the city, helping families affected by AIDS was a mission they undoubtedly carried out for almost a decade.

Within this context, pediatric AIDS advocates in Newark began explicitly addressing AIDS as a family disease in their efforts to establish a more compressive AIDS-care and prevention agenda in 1990. For example, the Children's Hospital's AIDS Program (CHAP) established a National Pediatric HIV Resource Center (NPHRC). In a grant proposal for the establishment of this center, The CHAP staff argued that the "epidemic of HIV in children is a family disease, rooted in the larger epidemic of HIV infection and intertwined with intravenous drug use."⁸⁶ More importantly, this represents a key moment in the evolution of the family disease discourse. Though AIDS advocates in Newark described, through the mid-1980s, how the disease affected families, the explicit description and framing of AIDS as a family disease did not become part of their AIDS-care and prevention agenda until this point. This explicit mentioning of the family disease among Newark AIDS professionals further suggests how these advocates were essentially claiming ownership of discourse they helped engender.

This same year, New Jersey State officials began developing a response to the disease that also centered, in part, on the care and prevention of HIV and AIDS among mothers and their children. Here, the mother and child came to dominate descriptions of the family. In his first year as New Jersey governor, Jim Florio (1990-1994) hired Dr.

⁸⁶ Children's Hospital AIDS Program, Grant application to the Bureau of Maternal and Child Health Resource Development, May 1990, UMDNJ AIDS Collection. Information regarding the NPHRC is derived from: Brochure for the National Pediatric HIV Resource Center, Operations Advisory Committee Information Packet, December 5, 1990, UMDNJ AIDS Collection. This same year, Oleske, along with eight others, went to the Soviet Union city Elista to help children with HIV and AIDS. One of the eight-member party, Terrence Zealand, directed the AIDS Resource Foundation, which ran "homes for children with AIDS," commented that "since the Iron Curtain is now down, it is a nice gesture on our part to provide good will internationally...and we are proud that is happening from Newark, N.J. This information is derived from Angela Stewart, "Jersey pediatric AIDS experts fly to soviet city stricken by epidemic," *The Star Ledger*, June 30, 1990.

Frances Dunston as the New Jersey Commissioner of Health. Dunston, an African American woman, and an experienced pediatrician, had experience dealing with pediatric AIDS while the Director of Virginia's Office of Family Health Services, Virginia's Assistant State Health Commissioner, and Director of Richmond, Virginia's Public Health Department.⁸⁷ Florio, who publicly expressed concern about HIV and AIDS among women and children, directed Dunston to develop a comprehensive plan for addressing the disease in the Garden State. Dunston publicly declared, "We haven't done enough, particularly for women and children." Recalling her experience in Richmond, where she cared for HIV-AIDS positive children, she lamented about disease's devastating effect on families, and that any purposed approach in dealing with HIV in New Jersey would not just care for "children or woman," as individual patients, but Dunston stated, "you have to see them as part of a family."⁸⁸

The culmination of the Florio-Dunston HIV-AIDS public health agenda resulted in a comprehensive plan to address the disease in New Jersey. In January of 1991, the New Jersey Department of Health published their plan: *New Jersey: A State Organized to Fight AIDS*—or simply the New Jersey AIDS Plan. The report was a voluminous series of recommendations to Governor Florio regarding what policy actions New Jersey should take regarding all HIV and AIDS-related issues—it was clear women and children of color were a primary focus. The state's "HIV epidemic," the report argued, "wears the

⁸⁷ Dr. Frances Dunston, Oral History, Interviewed by Gerry Albarelli, October 27, 1994, UMDNJ Oral History Collection; Donna Leusner, "Washington State, Virginia Officials Tabbed for Human Services, Health," *Star-Ledger*, February 23, 1990; Richard S. Remington and Donna Leusner, "Nominees, for 3 agencies clear legislative hurdle," *Star-Ledger*, March 13, 1990, quote is from this article.

⁸⁸ Bob Groves, "She's mapping a state battle plan for AIDS," *The Record*, November 30, 1990.

face of a woman or an infant more often than it does elsewhere in the country,” and that women of “childbearing age” were the fastest growing segment of the HIV-AIDS population. For these public health officials, HIV and AIDS was increasingly becoming “a *family disease*” in New Jersey.⁸⁹ By the early 1990s, HIV and AIDS still disproportionately affected urban women and children of color in New Jersey.⁹⁰ This intense focus, however, left an impression that inner city families, particularly women and children, were most susceptible to HIV infection.

In this respect, stories of hemophiliac families affected by HIV and AIDS stood in stark contrast to the narrative of urban families of color affected by the disease. In her book *Cry Bloody Murder* (1997), Elaine De Prince, who lived in New Jersey, told a sorrowful tale of how her family dealt with her adopted hemophiliac sons diagnosed with HIV and AIDS.⁹¹ Her story reflected thousands of families who were caring for hemophiliac children and spouses infected and dying from the disease by the late 1980s and early 1990s. In some cases, women, as was seen among inner city families, were infected through sexual contact with their husbands and sexual partners.⁹² Yet the presence of hemophiliac families, at least in the context of the New Jersey AIDS Plan,

⁸⁹ New Jersey Department of Health, *New Jersey: A State Organizes to Fight AIDS: Recommendations of State Commissioner of Health Frances Dunston to Governor Jim Florio* (Trenton: Department of Health, 1991), quote on 3, UMDNJ AIDS Collection (Hereafter cited The New Jersey AIDS Plan). Here, the report references the *Generations in Jeopardy* report published two years earlier.

⁹⁰ For demographic disparities in New Jersey and Newark area see, David Bynes, East Orange Health Officer, UMDNJ AIDS Collection.

⁹¹ Elaine De Prince, *Cry Bloody Murder: A Tale of Tainted Blood*, (New York: Random House, 1997).

⁹² Pemberton, *The Bleeding Disease*, 272-273.

remained, along with other “non-minority families,” on the periphery.⁹³ This exclusion underscored how the real and imagined perceptions of certain “urban pathologies,” which led to and exacerbated the problem of AIDS among families of color, came to define this unique cultural frame.

The HIV-positive woman and child played a central role in New Jersey’s burgeoning response to AIDS the early 1990s. Of course, AIDS was not deemed solely as a problem facing women and children. The emphasis on protecting and caring for this specific group perhaps spoke to the epidemiology of the disease in Newark and New Jersey. Undoubtedly, racialized and gendered disparities in HIV infection among inner city populations clearly factored in New Jersey’s family-focused approach, which also came to define the AIDS epidemic in the state. Yet this approach brought with it unforeseen consequences as well. The use of the family disease narrative in these efforts further reveals how this farming of AIDS was myopically convinced to discuss and describe HIV-positive families of color—specifically children and women. Nevertheless, this script became for New Jersey AIDS-advocates, as it did for others beyond the borders of the state, an important narrative to communicate the both the intractability of AIDS among urban populations of color, as well as the particular urban problems associated with the disease. In this respect, the family disease narrative proved useful in discussing how IV drug use—who were often described as men—became an intractable vector for HIV infection among families, but the discourse simultaneously seemed to obscure how to best mitigate this problem. During the early and mid-1990s, new AIDS drugs showed promise in reducing vertical transmission of HIV from mother to child, but

⁹³ The New Jersey AIDS Plan, 44.

reducing HIV infection among IV drug users—and thus the family—became politically complicated. The family disease frame would quickly lose its political capital.

The Birth of a Chronic Disease and the Death of the Family Disease: AZT, Needle Exchange, and the Politics of Prevention

By the late 1980s and early 1990s, pharmacotherapies showed signs of mitigating death rates among people with HIV and AIDS. In 1989, after four years of drug trials, azidothymidine (AZT) proved effective in reducing the chance that patients could die from the disease. Such effective pharmaceutical treatments bolstered notions that HIV had the potential of becoming “chronic manageable illness.”⁹⁴ Two years later, the AIDS Clinical Trial Group (ACTG) began an AZT drug trial, 076, which studied the effects of the drug on reducing the vertical transmission of HIV from mother to child—and UMDNJ in Newark became one of the trial sites. The UMDNJ medical community was enthusiastic in taking part in the trial. The medical school also took the opportunity to underscore their years of expertise in treating women and children with HIV and AIDS. Dr. Edward Connor, who directed the AIDS Clinical Trial Unit at the UMDNJ, and was associate professor of pediatrics, believed that AZT, if proven effective, could drastically reduce the number of pediatric cases of AIDS in Newark and the U.S. According to Connor, the number of pediatric AIDS cases was “growing rapidly” by 1991, especially “in urban centers like Newark.” He continued stating, “These babies often live only between six and 38 months. We still don’t know how to stem the viral transmission—

⁹⁴ Epstein, *Impure Science*, 237.

AZT may be the answer.”⁹⁵ For many, AZT represented hope in reducing HIV infection among children. For others, the drug, while seen as a promising advent in HIV care and treatment, was only part of a broader prevention agenda. If AZT was seen as the predominate method of protecting children from HIV, then needle exchange was seen, by some, as the harm reduction method that could reduce HIV infection for the entire family.

Between 1992 and 1997, the family disease frame lost its political utility. During this period, the advent of new AIDS drugs—AZT and later Highly Active Antiretroviral Therapy (HAART)—marked the end of the family disease discourse.⁹⁶ These drugs helped prevent the mother-to-child transmission of HIV. Since the family disease discourse had a strong child-centered focus, the introduction of effective pharmacotherapies essentially made any calls for protecting the child irrelevant. Also during these years, needle exchange advocates argued that access to clean needles could reduce HIV infection among families of color in Newark and New Jersey writ large. Since the beginning of the epidemic, public health professionals, physicians, AIDS advocates, and politicians argued how intractable urban social ills, specifically IV drug use, exacerbated the problem of HIV and AIDS among women and children. Now, AIDS advocates in the state were forcing top political and public health officials to confront the problem IV drug use, as it related to HIV infection among urban families of color. Of course, proponents of needle exchange did not believe this approach was a panacea for

⁹⁵ UMDNJ Press release, “At UMDNJ-New Jersey Medical School, AIDS Clinical Trials Unit-to Test Whether AZT Can Prevent Transmission of AIDS Virus from Mother to Fetus,” UMDNJ AIDS Collection, articles, January to December, 1991.

⁹⁶ For a brief policy history and discussion about new AIDS drugs, see Siplon, *Aids and the Policy Struggle in the United States*, 19-41.

preventing HIV infection among women and children—or families. Instead, they felt needle exchange should become part of a comprehensive harm reduction agenda that included safe sex education, drug treatment programs, and AZT to name a few. But these plaintive calls for needle exchange, as a way to protect the family, were politically unsustainable. Many of these advocates met stiff political opposition by some politicians and state public health officials. The struggles of needle exchange advocates thus revealed that the political utility of the family disease discourse had its limits, especially with respect to helping the “non-innocent victims” of the AIDS epidemic. In short, the family disease framing of AIDS ceased to have the same cultural resonance and political purchase once treatments effectively transformed AIDS into a chronic, manageable disease.

The family disease discourse continued to factor in HIV prevention conversation prior to the scientifically proven effectiveness of AZT in preventing vertical transmission of the virus. In 1992, the national HIV and AIDS Education and Training Centers (AETC) held their second annual meeting in Newark. The “AIDS as a Family Disease” conference brought together HIV-AIDS care professionals from inside and beyond the medical profession, which also included biomedical and public health researchers. Here, descriptions of AIDS as a family disease continued to stress how the disease had affected communities of color. Mathilde Krim, Founding Co-Chair and Chair of the Board of Directors for the American Foundation for AIDS Research, stated that HIV and AIDS had “literally” become a “disease of families.” She defined this phenomenon arguing that “given the modes of transmission, cases of AIDS are not isolated but are clustered in certain groups and families”—that is, if “the baby is infected, the mother is; and if she is,

her sexual partner probably is...” In describing HIV infection among populations of color, Krim, and others at the conference, were following a familiar script. But many of the speakers at the conference, sought to build on the family disease narrative.⁹⁷

Unlike earlier public conversations regarding HIV and AIDS among families of color, the AETC conference seemingly attempted to expand the family disease discourse to include all families, especially “non-traditional” ones. Marc L. Rivo, Director of the Division of Medicine Bureau of the Health Professions at the Health Resources and Services Administration (HSRA), stated how he believed HIV and AIDS was “a condition that affects all of us,” which includes “traditional and non-traditional families.”⁹⁸ Other speakers, such as a Cheryl Griffin-Miller, a nurse from UMDNJ-University Hospital’s Discrete AIDS Unit, expressed her experience with HIV and AIDS among families in Newark. Through her work with HIV-positive families she understood that family was not necessarily defined in terms of “blood” relations. In addition, Thomas J. Webster, an AIDS Specialist from Cicatelli Inc., saw gay family units as part of the family disease discourse.⁹⁹

As the conference attendees attempted to reframe the discourse regarding HIV and AIDS among families, the professionals gathered in Newark also spoke of promising advances in both medicine and harm reduction techniques. Edith Springer, a social worker and Supervising Program Development Specialist for the New Jersey

⁹⁷ Proceedings of the Second Annual Meeting of the AIDS Education and Training Centers, “AIDS as a Family Disease,” December 12-14, 1992, 11-13; quote on 13, UMDNJ AIDS Collection.

⁹⁸ Ibid., 4.

⁹⁹ Ibid., 33-35; quote on 29.

AETC/NIMH (National Institutes for Mental Health), promoted needle exchange as a benefit in reducing HIV infection among families. Springer contextualized her comments about needle exchange within a broader discussion regarding harm reduction. Springer saw needle exchange, therefore, as one of the more prudent methods in reducing the chances drug users had in acquiring HIV-AIDS. According to Springer, “harm reduction says that, first of all, HIV prevention takes priority over drug treatment and drug prevention because HIV is a much greater threat to the individual, family, the community...”¹⁰⁰ In addition, the promise of pharmacotherapies, which were transforming the disease into a chronic condition, were also topic at the conference.¹⁰¹

The perceived promise in needle exchange and pharmacotherapies as both harm-reduction and treatment techniques briefly occupied discussions at the conference. The appearance of both methods of treatment provided a glimpse into an emerging discourse regarding how health care and public health professionals perceived harm reduction and HIV-AIDS care in the early 1990s. More importantly, the AETC meeting sought to incorporate the family disease narrative in their efforts to raise HIV awareness and prevention strategies for the communities these AIDS-care professionals served. However, this phenomenon was short lived. Efforts to broaden the family disease narrative to included discussion about HIV prevention for all families in the United States came at a time of new drug trials, questions about the side effects related to these

¹⁰⁰ Proceedings of the Second Annual Meeting, “AIDS as a Family Disease,” 70; 63-73.

¹⁰¹ Ibid., 11-13. Also, others, for example James Oleske, talked of the promise AZT showed in prolonging the lives of HIV-positive children, 41-49.

medications, and the politically contentious debates surrounding calls for needle exchange in states like New Jersey.

The nascent 076 AZT trial raised concerns for women's AIDS advocates in the 1991 and 1992. The NJWAN, for example, wanted to raise awareness among women with HIV about the potential delirious health effects of the drug. The coordinator for the NJWAN, Marian Banzhaf, argued that there was insufficient data regarding the side effects AZT had on women and unborn children. In addition, Banzhaf felt that the drug trial was "only about the fetuses," and not about "women."¹⁰² Here, Banzhaf echoed similar sentiments held by ACT UP/New York Women's Caucus—she was a member of ACT UP/New York in the late 1980s—that saw the trial as "prioritizing the fetus over adult women in clinical trial research."¹⁰³

These concerns were voiced at a forum in Newark in 1991. Defending the trial, Dr. Edward Connor stated that there was little interest at the national level in drug-related research on women, and that the 076 trial represented a "back door" in conducting such research. However, Marcia Abramson, a medical ethicist from Robert Wood Johnson Medical School in New Brunswick, New Jersey, argued that "the public sees babies with AIDS as the 'innocent victims of their mother's folly,' and the focus of the study perpetuates that notion by treating women as 'mere vector[s] for transmission to the fetus.'" Stephanie Harris-Kuiper, of the African American Women United Against AIDS, (formally AAWUCA) voiced her group's concerns that the minority women were

¹⁰² Joan Whitlow, "UMDNJ tests AZT in pregnant women to protect fetus from AIDS," *The Star-Ledger*, March 16, 1991.

¹⁰³ Epstein, *Impure Science*, 291; For Banzhaf's involvement with ACT UP/New York. See Banzhaf, Oral History, UMDNJ Oral History Collection.

targeted for the trial. Referencing the Tuskegee Syphilis study, Harris Kuiper felt that studies “focused solely on minority population” did not “benefit” people of color in the United States.¹⁰⁴ The perceived gender and racial biases seen in the study were clearly unsettling for these women’s health advocates.

While the results of the AZT trial were still uncertain, The NJWAN, championed needle exchange. In 1992, Lisa Berlin, one of the writers for the group, argued in the NJWAN’s newsletter that needle exchange programs supported women’s health, with respect to the prevention of HIV infection. Though not dismissing the usefulness of drug treatment programs, the NJWAN saw needle exchange efforts as an imperative in protecting the health of women in New Jersey. The NJWAN argued that, “in order to combat the spread of HIV through a Needle Exchange Program, New Jersey must respond to the fact that it has the highest rate of women with AIDS by creating drug programs that are sensitive to the concerns of women.” Moreover, they saw needle exchange as not only discouraging the use of “dirty needles” but also promoting safe sex by distributing “condoms, dental dams and information.”¹⁰⁵ The group’s promotion of needle exchange reflected their move towards a harm reduction strategy that was explicitly professed as protecting women. Implied, however, was the protection of the father and the child as well. The NJWAN’s promotion of needle exchange emerged within a growing advocacy discourse linking the availability of clean needles with the protection of New Jersey families of color.

¹⁰⁴ Joan Whitlow, “High proportion of black women in AZT trial raises eyebrows,” *The Star-Ledger*, March 19, 1991.

¹⁰⁵ Lisa Berlin, *NJWAN News* Vol. 2 no.3 Summer 1992; see also, *NJWAN News* Vol. 2, No.1 Winter 1992, UMDNJ AIDS Collection.

By the end of 1992, the links between needle exchange advocacy and the protection of New Jersey families began to coalesce. The Governor's AIDS Council on AIDS published a report titled, *Confronting the AIDS Pandemic: Principles and Priorities for the Second Decade*, which made policy recommendation to Governor Florio for the implementation of a statewide needle exchange program. According to the report, "AIDS threatens not just individuals, but whole families" in New Jersey, and that "while HIV/AIDS affects all segments of our society, poor and minority communities have been hardest hit by the epidemic." Further emphasizing their point, the report's contributors referenced the National Commission on AIDS stating that IV drug using black men, in "some of our inner cities," were "less likely to reach the age of 65 than are men in Bangladesh."¹⁰⁶ Within the context of racial, class, and gender disparities, the AIDS council pressed for a needle exchange program to protect all those affected by IV drug-transmitted HIV-AIDS. "Short of drug treatment," the Council called for "immediate action to make clean needles legally available."¹⁰⁷

The Council was not the first group to press Governor Florio about the creation of needle exchange programs. In 1991, the 40 member HIV/AIDS Community Advisory Committee recommended a state-sanctioned needle exchange program as a part of the New Jersey's larger HIV prevention efforts. For the committee, "the distribution of needles and syringes to the drug-using population is a health issue, not a political one..."

¹⁰⁶ Governor's Advisory Council on AIDS, *Confronting the AIDS Pandemic: Principles and Priorities for the Second Decade*, A Publication of the Governor's Advisory Council on AIDS (Trenton: on AIDS, 1992), 2.

¹⁰⁷ Ibid., 45.

¹⁰⁸ Health Commissioner Dunston and Florio were opposed. “It is the position of the Department of Health,” Dunston stated, “that the evidence currently available does not warrant introduction of a needle/syringe exchange program.” For her, safe sex, and “responsible behavior,” was essential in HIV prevention measures.¹⁰⁹ Such political opposition towards needle exchange was not uncommon in the early 1990s. For Florio, needle exchange seemed politically out of the question. The politics of needle exchanged may have swayed Dunston’s decision, as did her personal and professional views. Nevertheless, needle exchange proponents were also found beyond these specific AIDS-advocacy organizations and councils.

Physicians in New Jersey also began accepting needle exchange as a prevention option. In 1993, the Medical Society of New Jersey, the “largest physicians group” in the state, supported a “trial” needle exchange program. The Commissioner of Health, Bruce Siegel, who supported needle exchange programs, also endorsed the move for a trial program. Siegel commented on the legislative obstacles in having a needle exchange program in New Jersey. Yet as the reports of needle exchange circulated in the press, it was not removed from the family disease discourse. The comments by Siegel and the Medical society were juxtaposed with comments about the epidemiology of HIV and AIDS in New Jersey, which, according to one news article, continued to link the high rate of IV drugs and the infection of women and children. “The reason for New Jersey’s high percentage of infected women and children,” the article continued, included “drug use

¹⁰⁸ The New Jersey AIDS Plan, A-1.

¹⁰⁹ The New Jersey AIDS Plan, 86. For Florio’s public claims opposing needle exchange, see, for example, David Blomquist, “AIDS report says no to needle exchanges,” *The Record*, February 6, 1991. For Dunston’s position on needle exchange, see Dunston, oral history, UMDNJ Oral History Collection.

among women, the spread of AIDS from drug users to female sex partners, and the prenatal transmission of AIDS” from mother to child.¹¹⁰

Moreover, New Jersey legislators touted needle exchange as one way to protect families from HIV infection. A bill introduced in July of 1993 by state Senator Wynona Lipman (D-Essex) sought the legal establishment of a needle exchange program in the state. Lipman, who was also a member of the Governor’s Advisory Council on AIDS, stated that “The thing that worries me so is that 60 percent of the children with AIDS are born to women who contract it either from injection drugs or have a partner who uses drugs.”¹¹¹ However, other Newark-area politicians saw the proposed bill as endorsing illicit drug use.

Senator Ronald Rice (D-Essex), for instance, was “adamantly opposed” to Lipman’s bill. For Rice—who was also councilman in Newark—felt that access to clean needles encouraged “the use of drugs...” which he further believed support both local drug dealers and the transnational drug trade.¹¹² However, Lipman’s bill had political support in Newark. Less than a month later, George Branch, a Central Ward Councilman, insisted that his fellow Newark council members “give it [needle exchange] a try” in the city. Yet Rice stood his ground calling Lipman’s proposal “a dumb bill and a dumb law.” Rice’s stance echoed similar language used in needle exchange debates in New York City

¹¹⁰ Joan Whitlow, “Medical Society backs pilot needle exchange: Doctors endorse measure to stem AIDS transmission among addicts,” *The Star-Ledger*, July 28, 1993.

¹¹¹ Joan Whitlow, “Legislature to weigh needle-giveaway program: Pilot plan for drug users backed by Governor’s council on AIDs,” *The Star-Ledger*, August 15, 1993.

¹¹² Steven Walker, “Rice remains critical of clean needles bill,” *The Star Ledger*, September 28, 1993

during the late 1980s and early 1990s. According to Cohen, the “outcry over needle exchange” among black officials “seemed to engage in a calculus of human worth, where the lives of ‘innocent’ children and ‘regular, law-abiding community folk’ were designated as more important and worth saving than the lives of black injection drug users.”¹¹³

As debates over needle exchange discussed the moral and utilitarian merits of such preventive practices, the 076 trial results were made public in 1994. The study showed a drastic reduction of the vertical transmission from mother to child. For example, “more than quarter of the babies born to women who received a placebo became HIV positive, but only eight percent of the babies whose mothers received AZT became infected with the virus.”¹¹⁴ After the results of the AZT trial became public, the New Jersey “medical community and state government” sought to have pregnant women tested.¹¹⁵ New Jersey’s newly elected Governor, Christine Whitman, and the acting Commissioner of Health, Len Fishman, commented a press conference held in Newark that the AZT study gave hope for pregnant women. “Our job now,” Fishman stated, “is to get the message out to all women and medical providers...we must not stop until voluntary testing is an integral part of parental care in our state.”¹¹⁶ The urgency to

¹¹³ Cohen, *Boundaries of Blackness*, 334.

¹¹⁴ Epstein, *Impure Science*, 312; Centers for Disease Control, “Zidovudine for the Prevention of HIV Transmission from Mother to Infant,” *Journal of the American Medical Association* 271 (25 May 1994), 1567-1570

¹¹⁵ “State backs AIDS drug for HIV pregnant women,” *The Times*, April 6, 1994. No author was listed. The article was found in the UMDNJ AIDS Collection, Articles, January to December, 1994.

¹¹⁶ Caryl R. Lucas, “Whitman urges HIV tests for pregnant women,” *Star-Ledger*, April 6, 1994

prevent further mother-to-child transmission was expressed by some physicians in New Jersey. Dr. Lawrence Frankel, Chairman of the Medical Society of New Jersey and pediatrician commented that “anyone who has visited a pediatric AIDS ward is filled with a sense of anguish knowing full well that these tiny infants will probably not live until their fifth birthday. We must build upon the results of the AZT study to help protect these innocent lives...”¹¹⁷

In the wake of the findings, The NJWAN continued their efforts to educate women about the benefits and side effects of AZT. According to NJWAN, “women are hopeful, since they do not want to pass HIV on to their infants. Physicians are ready to start prescribing. Health departments are considering issuing policies....once again, infants and children are the focus and women’s concerns are not being addressed.”¹¹⁸ The concerns of NJWAN, however, were not wholly anti-AZT. “We want women fully informed,” Maria Banzhaf stated, “it’s not an easy decision to take a drug during pregnancy.” Commenting on the toxicity of the drug, Banzhaf conveyed the perceived potential side effects inherent in taking the drug. Moreover, three quarters of HIV-positive women “did not transmit the disease to their unborn babies,” Banzhaf stated, and that she did not want women to be “forced” in taking the drug. However, Banzhaf did feel that AZT provided “hope,” which was difficult to come by in the “AIDS crisis.”¹¹⁹

¹¹⁷ Joan Whitlow, “State doctors advocate AIDS tests in push for treatment in pregnancy,” *The Star-Ledger*, April 19, 1994.

¹¹⁸ *NJWAN News*, Spring 1994, UMDNJ AIDS Collection.

¹¹⁹ “State backs AIDS drug for HIV pregnant women,” *The Times*.

For HIV and AIDS advocates such as NJWAN, informing women regarding AZT treatments was not to dissuade women from protecting their unborn children. The organization recognized the benefits in taking AZT while pregnant. True to their mission, the group thus sought comprehensive health education for women, whether they were pregnant or not. The circumspection in the group's message further underscored notions raised by HIV and AIDS advocates for an equitable approach in protecting the women and unborn child.

The effectiveness of AZT in reducing vertical transmission also allayed some of the anxiety for HIV-positive women who were pregnant or who planned to be pregnant. For Patricia Kloser, the results of the study were exciting—in fact, one of Dr. Kloser's patients was enrolled in the AZT study. Informed by her experience with female patients in Newark, Kloser speculated how “a lot of women, for religious and other reasons, have no choice but to carry” their child to term. In addition, Kloser pondered how some women might carry a sense of “guilt” for giving birth “to a [HIV] positive baby,” and how labor intensive this process was—which could further “compromised” the woman's health. She envisioned women entering her clinic asking: “Does this mean I can get pregnant?” Kloser, aware that AZT was not a panacea for vertical transmission, said she would inform her patients that the drug only reduced the chance of transmitting the disease to their unborn child, and that the woman would have to “carefully weigh” their choices. Yet Kloser saw AZT as a way to lift the “fear and trepidation” involved in initiating “a pregnancy” for those women whose “life dream is to have a baby.”¹²⁰ In this

¹²⁰ Mary Jo Patterson, “Study launched in Newark finds drug limits AIDS transmission to unborn,” *The Star-Ledger*, February 22, 1994.

respect, the emergence of AZT was arguably seen as a potential family planning option in the HIV and AIDS era of the mid-1990s.

From 1994 through 1995, the attention paid towards HIV-positive women seemed to remain part of the protection discourse. In the wake of the results of 076 trial, segments of the medical community urged for HIV testing among pregnant women. The Medical Society of New Jersey, for example, told “obstetricians and family doctors” to “encourage” their pregnant patients to be tested for the disease. However, in 1994, the NJWAN argued that doctors should not solely focus on pregnant women. Instead, the group wanted doctors to take an active role in ensuring that all “sexually active” men and women were tested. Dr. Frankel, who chaired the Medical Society, agreed that all should be tested, but stated that pregnant women represented a group that physicians could “actually do something to reduce and suppress the transmission of the disease.”¹²¹ The following year, the New Jersey legislature passed a bill (A-1669) which had doctors “present women with the option of being tested and their right to refuse the test” for HIV. Counseling was offered to those women found positive, and fines were levied for anyone who violated the “bill’s confidentiality provision.”¹²² By 1995, the efficacy of AZT reducing transmission of HIV began to influence policy decisions as well. This same year saw a high prevalence of HIV and AIDS infection among women of color in Newark.¹²³ The NJWAN seemed to approve of the legislature’s adherence to voluntary testing over

¹²¹ Whitlow, “State doctors advocate AIDS tests in push for treatment in pregnancy,” *The Star-Ledger*.

¹²² Donna Leusner, “Bill nears law to inform moms-to-be about AIDS,” *The Star-Ledger*, May 26, 1995.

¹²³ Maryann Spoto “Study: women harder hit by AIDS in Newark than in other regions,” *The Star-Ledger*, August 17, 1995.

monitory testing—which became law in July of 1995.¹²⁴ In addition, the group emphasized that testing should be a priority “regardless of risk,” and that “prior to pregnancy, women need to be tested in a supportive, stress-free environment.”¹²⁵ With a law in place geared towards protecting unborn children, HIV and AIDS advocates continued to push for legislation for needle exchange programs.

By 1996, the needle exchange discourse continued to frame the protection of the family. The New Jersey Medical Society’s journal *New Jersey Medicine: Health Care in the Garden State*,¹ for example, took part in the discussion of needle exchange and the family. In a “Point, Counter Point” piece titled, “Do you Support a Government-Sanctioned Needle Exchange Program?” Jim McGarry, in opposition to needle exchange, and Dawn Day, in support, both posed different views on the effects IV drug use-related had on families. For McGarry, needle exchange would promote continued drug use, which has “doomed thousands of children and other non-addicts to a slow painful death from AIDS”—the “non-addicts” were presumably women. Conversely, Day saw opposition to needle exchange as dangerous. Arguing for the “best medical care,” for families, she felt health care professionals should not be put in the position of saying, “sorry, we cannot give your family member life-saving medical care because it would send the wrong message.”¹²⁶ In addition, groups such as the NJWAN continued to support needle exchange legislation. Addressing their readers in 1996, the organization

¹²⁴ *NJWAN News* Vol. 5 No. 3 December, 1995, UMDNJ AIDS Collection.

¹²⁵ *NJWAN News* Winter, 1995, UMDNJ AIDS Collection.

¹²⁶ Jim McGarry and Dawn Day, “Do You Support a Government-Sanctioned Needle-ExchangeProgram?” *New Jersey Medicine: Health Care in the Garden State*, August 1996, UMDNJ AIDS Collection.

ran a piece in their newsletter titled, “Needle Exchange: Reducing Risk, Promoting Health.” The NJWAN support Lipman’s bill, while bemoaning Governor Whitman’s stiff opposition towards establishing a needle exchange program in New Jersey.¹²⁷ In Newark, Mayor Sharpe James supported Whitman’s anti-needle exchange stance. Echoing Senator Rice’s views on needle exchange, James saw such programs as “an unattractive solution” that only “condones drug abuse.”¹²⁸

As the 1990s drew to a close, pharmacotherapies clearly showed signs of preventing perinatal transmission and prolonging the lives of those infected with HIV. The use of AZT, combined with Public Health Service (PHS) guidelines for the recommendation of voluntary HIV testing of pregnant women, resulted, in part, in a substantial decline of mother-to-child infection between 1994 and 1996.¹²⁹ In addition, the CDC indicated that “516 children were diagnosed with AIDS in 1996,” which was a 43 percent decline from 905 cases reported four years earlier.¹³⁰ The use of the HAART therapy also proved more than effective AZT group of in prolonging the life of those with the virus. There were benefits and burdens associated with this new drug “cocktail.” The drugs’ efficacy was tied to strict patient compliance that required a daily regimen of the

¹²⁷ *NJWAN News*, Fall 1996, UMDNJ AIDS Collection. Elizabeth Moore, “Experts’ needle exchange stand rejected by state health chief,” *The Star-Ledger*, January, 25, 1996.

¹²⁸ Gale Scott and George Jordan, “AIDS council delays vote on needle exchange,” *The Star-Ledger*, March 7, 1996.

¹²⁹ ML Lindegren, et al. “Trends in Perinatal Transmission of HIV/AIDS in the United States,” *Journal of the American Medical Association* Vol 282, No. 6 (August 11, 1999):531-538. <http://jama.ama-assn.org/content/282/6/531.full.pdf+html> (accessed September 1, 2011).

¹³⁰ Associated Press, “Fewer moms passing AIDS to their babies,” *The Star-Ledger*, November 21, 1997.

HAART therapy, and there was a high price tag for the drugs. But for those with HIV, any of the burdens associated with taking the medications were arguably outweighed by the rewards.¹³¹

As AIDS was being transformed from a deadly disease to a manageable one, women continued a push for legal access to clean needles. In 1997, “100 mothers, grandmothers and foster mothers participated in a ‘Mothers March’” in Trenton to push for needle exchange. Marching towards the Statehouse, the crowd chanted “Clean needles save lives...How many more have to die before we change the law?” The report of the march revealed how inseparable conversations regarding HIV-AIDS among families were from the politics of needle exchange. One woman at the rally, Flettie LaCoste Spruill, a resident of East Orange, New Jersey, lost “four sons, two stepsons and a godson,” to what she referred to as “the virus,” while a two of her living children had contracted the disease.¹³² That same year, New Jersey Senator Lipman continued her legislative push for needle exchange, while folks like Diana McCague faced prosecution for distributing clean needles to IV drug users in New Jersey.¹³³ Little did the members of the “Mothers March,” Sen. Lipman, or McCague realize that it would take just under a

¹³¹ Siplon, *Aids and the Policy Struggle in the United States*, 32-41.

¹³² Donna Leusner, “Mothers who lost kids to AIDS cry out for clean-needle effort,” *The Star-Ledger* October 22, 1997.

¹³³ Kit R. Roane, “Unresolved HIV debate: should addicts get free needles?” *New York Times* April 27, 1997.

decade for New Jersey legislators to pass the state's first legalized needle exchange program.¹³⁴

As the politics of prevention continued, Newark's United Hospital, along with Children's Hospital, went bankrupt. In February of 1997, Dr. Oleske, along with his colleagues and staff at Children's Hospital's FXB-funded international pediatric AIDS training center, went to University Hospital.¹³⁵ They left behind a facility that factored prominently in the treatment and care of many children who were infected and died from AIDS. In an effort to remember the children and family members who died, members of Children's Hospital planted flowers, shrubs, and other various florae in memory of those who passed. A *Star-Ledger* headline perhaps best captured the unwanted abandonment of both the memorial garden and the hospital: "Bloom of hope wilts with hospital's demise."¹³⁶ Dr. Oleske and his colleagues undoubtedly continued to care for and treat children with HIV and AIDS, regardless of the facility they occupied. Yet the memorial garden established at Children's Hospital was a stark reminder of the toll the disease had on the citizens of Newark and New Jersey. The "demise" of the hospital, and the garden, was also perhaps a reminder of how the confluence of new AIDS drugs, combined with economic and political forces, and the political divisiveness surrounding needle exchange, reconfigured the medical, social, and cultural priorities, and challenges, in the

¹³⁴Susan K Livio, "N.J legalizes needle exchanges - Corzine hails 'historic day for public health' as law ends stalemate in AIDS battle," *The Star-Ledger*, December 20, 2006.

¹³⁵ Gale Scott, "Bloom of hope wilts with hospital demise," *The Star-Ledger* February 22, 1997.

¹³⁶ Gale Scott, "University Hospital takes over United Pediatric AIDS Program," *Star-Ledger* February 25, 1997.

era of “chronic disease management” of HIV-AIDS in Newark. The family disease script was no longer relevant.

Conclusion: The Family (Disease) Legacy

The creation of the family disease frame was not a trite exercise in establishing a counter narrative within broader discussions about AIDS in the United States. This narrative was an attempt to illuminate the affects HIV and AIDS had on urban populations of color. In this respect, many of the framers of the family disease responded to the perceived cultural dominance of the “gay disease” narrative in American during the 1980s and 1990s. Consequently, the numerous AIDS advocates, medical AIDS-professionals, politicians, and policy-makers helped generate a response to the disease and other AIDS-related issues, which clearly mitigated the spread of HIV among children of color. Such efforts extended beyond the elucidation of epidemiological and demographic differences as well. The use of the family disease language sought to clearly delineated how the HIV-positive family was a victim of both the epidemic and stubborn social ills that were seen as associated with the disease’s prevalence among minority women, men, and children in cities like Newark. Yet the family disease narrative arguably had potentially deleterious, albeit unintentional, consequences as well. Efforts to expand the family disease frame to “traditional” and “nontraditional” families failed to shed its close ties to race. Moreover, the family disease discourse, and those who found it politically and socially useful, did not comprehensively articulating how such social ills became so intractable. The family disease frame thus made ambiguous the inner city

family's relationship to the existence and perpetuity of the "urban pathologies" associated with the intractability of HIV and AIDS.

In addition, the varied descriptions of the family within this discourse may have unintentionally reinforced racial and gendered stereotypes. Much of the family disease discourse centered on the mother-child family-unit. While this may have been a demographic reality, such descriptions resulted in a less than clear understanding of the father's role in the discourse. The description of "male sexual partners" echoed stereotypes of African American men as engaging in "reckless" sexual behavior, or as "baby factories."¹³⁷ The vague descriptions of the father also implied culturally insensitive notions of "absentee fatherhood." It is also unclear how other men, particularly men of color who have sex with men, factored in framing AIDS as a family disease.

Finally, the emphasis on women and children may have perpetuated the invisibility of men on the "Down Low,"—or men who secretly have sex with men— as well as gay men of color in cities like Newark. This last unintended consequence of the family disease narrative has undoubtedly complicated HIV-AIDS prevention campaigns among populations of color. Men of color who have sex with men were relatively framed out of the family disease discourse. The marginalization of these men is nothing new, however. As Cathy Cohen reminds us, men who have sex with men were continually marginalized within the larger AIDS discourse that emerged in the late 1980s among African American

¹³⁷ Cathy Cohen, "Punks, Bulldaggers, and Welfare Queens: The Radical Potential of Queer Politics" in *Black Queer Studies: A Critical Anthology*, eds. E Patrick Johnson and Mae G. Henderson (Durham, NC: Duke University Press, 2005), 40-41. Here, Cohen is explicitly reacting to post-Moynihan Report social science descriptions of the family that often reinforce racial stereotypes, 40-41.

leaders.¹³⁸ The absences of these men from the family disease narrative thus demonstrates the possibly negative public health consequences that can result from any AIDS discourse that ignores open discussions about sexuality and HIV prevention among men of color who have sex with men.¹³⁹

However, the intended promise of the family disease frame, and what it illustrates about the AIDS epidemic, might transcend any of its shortcomings. Notions of the “family” are socially, culturally, and politically malleable, which are undoubtedly more inclusive. In this respect, “AIDS as a family disease” stands in stark contrast to the exclusivity inherent in the various other cultural framings of AIDS we have witnessed since 1981. What is more, the family disease discourse, faults and promises aside, recalls the tragic nature of the AIDS epidemic, which, according to the historian Allan Brandt, is often lost in the “complex web of social and scientific questions surrounding AIDS.” Although disease “tells us much about the nature of our society,” Brandt continued, “it also reveals the nature of illness, suffering, and death and dying.”¹⁴⁰

This was Cynthia Givens’ story. She only knew a life with AIDS. She never knew her “biological” mother or father, though she was surely cared for, and loved, by her

¹³⁸ Cathy Cohen makes a larger argument in *The Boundaries of Blackness* about the marginalization of gay black men within the changing politics of AIDS. Here, Cohen posits that, unlike children and certain women, gay men were not included in conversations of innocent victimhood. For an excellent analysis of the “Down Low,” see Russell K. Robinson’s “Racing the Closet,” *Sanford Law Review* Vol 61:1463 (April 2009), 1463-1533.

¹³⁹ For increased racial disparities among men who have sex with men (MSM) see Prejean, Joseph, et al. “Estimated HIV Incidence in the United States, 2006–2009.” *PLoS ONE* 6(8): (2011), e17502. <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0017502>. (accessed October 1, 2011).

¹⁴⁰ Brandt, *No Magic Bullet*, 203.

adopted stepmother, Jean Givens. Nevertheless, the story of Cynthia's biological mother, whose name remains anonymous, illustrated her struggles with drug addiction. Forced to survive, Cynthia's mother turned to prostitution. She also gave birth to three more HIV-positive children—also orphaned at the hospital. Cynthia's stepmother perhaps best summed up these tragic circumstances. "The hardest thing was not to judge the mother," Givens stated, "but I decided it wasn't my place. That's best left to God...My concern is the children"¹⁴¹ This is Newark's tragic AIDS legacy; a legacy the city has yet to escape. Stories of children with HIV and AIDS certainly highlighted the unforeseen consequences of urban neglect, which of course affected their parents as well. However, such stories failed to include a comprehensive and culturally sensitive account of *all* those in urban communities of color affected by both the AIDS epidemic and the "problems" of the inner city. Had AIDS been explicitly recognized as a family disease from the beginning, the tragedy that befell Cynthia's family, and the countless other Newark families affected by the disease, would have undoubtedly engendered empathy through their visibility. Instead, many of these stories and people remain either invisible or perceived as enmeshed within a tangle of social and biological pathologies — a truly tragic tale.

¹⁴¹ Judy Peet, "Kids with AIDS:" Jersey struggles with a 'deadly legacy,' *Star-Ledger*, December 20, 1987.

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